

**Doctoral Thesis** 

Submitted in partial fulfilment of the Lancaster University Doctorate in Clinical Psychology

Fathers' experiences of perinatal loss

Doctorate in Clinical Psychology

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# **Word Count**

Section	Main text	Appendices, References, Figures and Tables	Total
Abstract	289	0	289
Literature Review	7998	5515	13,513
Empirical Paper	7999	11,314	19,313
Critical Appraisal	3953	1183	5136
Ethics Section	5322	6700	12,022
Total	25,561	24,712	50,273

### Fathers' experiences of perinatal loss

### Abstract

This thesis is split into three sections comprising a systematic review and thematic synthesis of literature, an empirical study, and a critical appraisal of the thesis overall. The systematic review involved a thematic synthesis of 20 studies investigating experiences of perinatal loss, with the research question focusing the analysis on fathers' experiences of support following miscarriage, stillbirth, and infant death. The review yielded three themes of this experience: (1) Gendered expectations and experiences of loss, (2) 'if I talk about it, it upsets her even more': conflict between supporting and needing support, and (3) Male experiences of support and service provision. The findings from the review are presented as a conceptualisation of the experience, highlighting the cyclical nature of barriers to support for fathers. The empirical study aimed to investigate fathers' relational experiences of stillbirth through a lens of continuing bonds and the use of objects. Interpretative Phenomenological Analysis was conducted on data from semi-structured interviews with 6 fathers who had experienced stillbirth from 20 weeks of gestation onwards. Analysis revealed five themes: (1) 'his baby didn't die the mum's baby died': loss and continued bonds in a mother-mediated dynamic, (2) 'its connected to your baby but it's not connected to you and your baby together': objects as manifestations of relational and meaningful memories, (3) 'their death does not erase their existence': exerting existence and continued connection to others, (4) 'to replace the fact that she isn't physically here': a continued bond through physical presence, (5) 'over time the relationship shifts too': evolving expressions of love and fatherhood. The findings of both papers along with their strengths, limitations and pertinent clinical implications are presented in the critical appraisal along with the authors reflections on the completion of this thesis.

# Declaration

This thesis comprises research conducted between December 2020 and May 2022 for the Doctorate in Clinical Psychology Programme at the Division of Health Research, Lancaster University. The work presented in this thesis is my own, except where due reference is made. This thesis has not been submitted for the award of any higher degree elsewhere.

Name: Amy Burgess

Date: 25<sup>th</sup> May 2022

### Acknowledgments

First and most importantly, I want to thank the fathers who took part in my study. I am incredibly grateful for your time, openness, passion and enthusiasm for sharing your stories with me. I sincerely hope that the findings resonate with you and represent the meaning of the experiences you shared with me. I would also like to thank all of the children you lost through stillbirth, who had and continue to have clear and profound impact on your lives. I am hopeful that they will continue to have impact through the stories you shared with me, that through this thesis will be shared further, changing the way we view fatherhood and bereavement.

I would also like to thank my research tutor, Craig, for all his support throughout this study as well as my field supervisor, Anna who instigated the idea for researching experiences of receiving objects following perinatal bereavement.

Finally, I'd like to thank my family and friends for supporting me throughout the process of writing my thesis and completing the doctorate for the past 3 years. Particularly, I'd like to thank Vince for being there for me through every peak and trough of the experience, I couldn't have done it without you.

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## Section One: Systematic Literature Review

Fathers' experiences of formal and informal support following perinatal loss: a systematic review and thematic synthesis of qualitative literature.

Word count (Excluding references, tables and appendices): 7781

Abstract: 217 words

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#### Abstract

There has been a recent increase in research on fathers' experiences of perinatal loss indicating the impact of loss on fathers' wellbeing and experiences of grief. The present systematic review aimed to thematically synthesise findings specific to fathers' experiences of support following perinatal loss, including miscarriage, stillbirth, and infant death up to age one to inform effective support for bereaved fathers. The 20 studies included covered a range of perinatal loss types and methodologies. Where studies comprised interview data from both mothers and fathers, data for fathers was extracted prior to analysis. Thematic synthesis yielded three themes of fathers' experiences of support: (1) Gendered expectations and experiences of loss, (2) 'if I talk about it, it upsets her even more': conflict between supporting and needing support, and (3) Male experiences of support and service provision. The findings from the review are presented as a conceptualisation of the experience, highlighting the cyclical nature of barriers to support for fathers. Clinical implications of the findings are explored with importance placed on offering regular support for fathers that is maintained despite initial low engagement, supporting a shift in societal expectations for the expression of emotion in fathers, and encouragement for services to take an innovative approach to designing support offerings for fathers that are in line with their support needs.

Keywords: perinatal loss, support, fathers, thematic synthesis

### Introduction

Perinatal bereavement is widely defined as death occurring during pregnancy, birth or up to 1 year of life (Nguyen & Wilcox, 2005). Perinatal death can be further defined by type however, definitions are inconsistent, with eight different definitions for "foetal death" in the United States alone (Nguyen & Wilcox, 2005). Infant death is however, consistently defined as death from birth up until 1 year of life (Nguyen & Wilcox, 2005), estimated to account for 40% of all deaths in children under the age of 5 globally (Vogel et al., 2014). Stillbirth has a wide array of definitions which focus on a gestational age as a 'cut-off', ranging between 16 and 28 weeks (Nguyen & Wilcox, 2005), with an estimated 2.6 million stillbirths annually worldwide (Vogel et al., 2014). The definition of miscarriage is a loss that occurs any time from conception up until the 'cut-off' for stillbirth. Miscarriage is the most common form of perinatal loss with an estimated 23 million miscarriages every year globally (Lancet, 2021).

There is substantial evidence for the impact of perinatal loss on mothers' wellbeing. Reviews of the literature indicate increased anxiety, depression and negative wellbeing following stillbirth (Campbell-Jackson, & Horsch, 2014) and miscarriage (Farren et al., 2018). Research has also indicated high scores on measures of difficulties coping, despair and grief, with scores for despair increasing in the 3 months following loss (Köneş & Yıldız, 2021). Furthermore, studies investigating the impact of infant death have outlined high scores on measures of anxiety and depression (Goldstein et al., 2018), with scores significantly higher than non-bereaved parents (Wall-Wieler, Roos, & Bolton, 2018). Equivalent research for fathers tends to report a 'lesser' psychological impact than that of the mothers, with lower rates of post-traumatic stress, anxiety and depression following perinatal loss of all types (Christiansen, 2017; Farren et al., 2018; Jones et al., 2019). This group of research is limited however, by its use of mental health outcome measures normed predominantly on women and samples comprising significantly more women than men (Lewis & Azar, 2015). Crucially, research that focusses on measures of grief, has outlined that bereaved fathers experience considerable levels of grief across all loss types, with scores meeting the threshold to be considered a "high level" of grief (Obst et al., 2021). Importantly this suggests that men do experience the psychological impact of perinatal loss, despite this not being captured by mental health measures. It is also important to consider the wealth of qualitative research that indicates the intense emotion and personal difficulty men experience following perinatal loss (Nguyen, Temple-Smith, & Bilardi, 2019). A recent meta-synthesis of such research argued that the effects and experiences of perinatal loss for fathers are equal to that of mothers (Aydin & Kabukcuoğlu, 2020). In this way qualitative research offers a different perspective on the impact of perinatal loss on fathers in a way that quantitative research cannot, by exploring the personal meaning and impact of loss.

Despite the commonality of perinatal loss and the clearly documented psychological impact of this, sensitive and appropriate support is lacking. International research on the provision of perinatal bereavement support is limited and focused on mothers (Shakespeare et al., 2019). Differences in the provision of interventions for bereaved parents were found between professionals in Spain and the United States; for instance, some offered keepsakes and emotional support where others focussed on supporting funeral planning (Steen, 2015), suggesting an inconsistency in care internationally. Consequently, Shakespeare et al. (2020) conducted a study to develop a global consensus from professionals on a set of core principles in delivering effective bereavement care, specifically for stillbirth. This study concluded that reducing stigma, offering emotional support and acknowledging the grief experience of parents were important aspects of good practice. Research on fathers'

satisfaction with support provided is limited, however in thinking about bereavement support broadly men tend to rate the quality of bereavement care significantly lower than women (Office for National Statistics, 2016). Importantly, a recent review of the literature of father's experiences of loss, found that men frequently report feeling overlooked as grieving fathers within women-centred bereavement care (Obst et al., 2020).

The provision of formal interventions for the psychological impact of perinatal grief has been investigated, with a recent meta-analysis suggesting the effectiveness of a range of group-based, family and individual interventions for anxiety and depression following perinatal loss (Shaohua, & Shorey, 2021). However, only one study in this review included fathers leaving an unclear picture of the usefulness of formal intervention for this group. Importantly, parents' interactions with healthcare professionals can significantly impact their experience of loss (Gold, 2007, Lang et al, 2011), highlighting that support comprises not only formal intervention, but informal interaction. For fathers, a recent study suggested that a perceived lack of social recognition for their distress compounds their experience of grief (Obst et al., 2020). Consequently, it becomes important to explore fathers' experiences of support, to evaluate its impact on fathers' grief and inform effective support for fathers facing perinatal breavement.

Given the limitations in quantitative research that suggests fathers' experience lesser distress than mothers, it is important to utilise qualitative methodologies to allow fathers to express their lived experiences of loss and subsequent support. The qualitative research investigating fathers' experiences of perinatal loss broadly is gaining traction with recent reviews of such literature published (Aydin & Kabukcuoğlu, 2020; Jones et al., 2019; Nguyen, Temple-Smith, & Bilardi., 2019; Obst et al., 2020; Williams et al., 2020). Such reviews often contain findings pertaining to experiences of support, however to date, as far as

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the author is aware, there has been no systematic review focused on fathers' experiences of support following perinatal loss.

Given the incidence of perinatal loss, the psychological impact and experiences of fathers, and lack of research focusing on fathers, it is important to strengthen the evidence base and literature that informs support offered. Systematic reviews and thematic synthesis bring together findings from primary research that answer a particular research question (Thomas & Harden, 2008). The present systematic review aims to synthesise findings from primary research to explore how fathers experience support following perinatal loss. Given the similarities in experience across perinatal loss types, and the wide variance in definitions for different loss types in the literature, "perinatal loss" is defined as the death of a baby at any point from conception up until one year post birth.

### Method

### **Search Strategy**

Given the dearth of research explicitly aiming to investigate fathers' experiences of support following perinatal loss, a broad search strategy was devised to capture papers that may include relevant data. Therefore, the search strategy aimed to yield papers pertaining to fathers' experiences of perinatal loss broadly, where papers with insufficient data to contribute towards the aims of the review were excluded during the screening process.

Search tools are applied in systematic literature reviews as an organising framework to appraise and select terms determined by the main concepts within the research question (Methley et al., 2014). In the present study, the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research Type) tool was adopted to devise the search strategy given its focus on qualitative or mixed method studies (Cooke, Smith & Booth, 2012). Search terms were devised to represent each of the concepts identified (Appendix B). These free text search terms were applied in combination with database specific subject headings, in individual searches for each database (CINHAL, PsycINFO, Academic Search Ultimate, Medline Complete). The search strategy was refined through consultation with university librarians, who suggested including databases such as Medline, to capture studies aimed at hospital staff. It was also suggested that key studies containing highly relevant data be identified through an informal web search and located in any results of formal systematic searches to ensure relevant papers were being captured. This process identified papers including the term 'parent' in place of father not yielded in the formal search, resulting in their addition to the search strategy.

# **Inclusion and Exclusion**

Studies were included in the review if they were peer reviewed indicating a high level of methodological quality. Studies were included if they were empirical studies with qualitative data from fathers who had experienced the death of their baby anytime from conception to the age of 1 that were available in English language. This definition of perinatal loss was used to capture studies on miscarriage, stillbirth and infant loss despite variance in definitions across studies.

For studies that included a sample of fathers who had experienced the death of children either side of this age, studies were included only when data for babies that died below the age of 1 was extractable. Studies were assessed to determine whether they contained sufficient data to contribute to answering the research question. Those studies deemed to contain sufficient data contained 3 or more paragraphs of findings relating to experiences of support with at least two sentences of quotes or specific findings for fathers that were extractable from that of findings on mothers.

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Studies comprising interviews with parents who identified as men or fathers but were not the partner or ex-partner of the parent carrying the pregnancy, for instance transexual men carrying pregnancy, were also excluded. This is due to the phenomenon of study being the experiences of fathers, who typically occupy the role of partner to the person carrying the baby.

### **Search Results**

A summary of the screening process following PRISMA guidelines (Moher et al., 2009) is presented in Figure 1. The final search took place in December 2021 and yielded an initial 5198 results with Zotero software used to facilitate the screening process. 351 papers were sought for retrieval following title and abstract screening, however 19 were excluded due to being unavailable in English and 9 were requested through inter library loan but were unavailable for retrieval. There was not enough information in the title and abstracts of these papers to assess eligibility thoroughly. Through the application of inclusion and exclusion criteria 303 papers were excluded, leaving a final set of 20 papers to be included in the review. Reference lists of these 20 papers were screened, however no further relevant papers were yielded.

## **Quality and Characteristics of Selected Studies**

The studies included were conducted in a range of countries, with various aims and methodologies as shown in Table 2. The quality of these studies was assessed using the Critical Appraisal Skills Programme (CASP) tool which is a widely used and recommended tool (Noyes et al., 2018). To quantify the CASP findings a rating scale was adopted that has previously been used in meta-synthesis (Duggleby et al., 2010). A weak score (1) was given where there was little to no evidence of the quality criterion being met, a moderate score (2) was given where there was evidence for the quality criterion, but this was not fully explored,

and a strong score (3) was given where there was clear and elaborate evidence that the quality criterion had been met. A summary of CASP scores for each paper is presented in Appendix C. Such scores allowed the findings of the included studies to be appraised in lieu of the robustness of the research, however scores were not used to exclude studies from this review. Importantly, scores obtained in this way reflect ordinal rankings rather than interval measures of features that can be discerned from reading a publication of a study rather than necessarily being absent in the production of the study. Therefore, in considering the relative contribution that studies made to the analysis, those CASP items that were judged to be most indicative of quality were given particular attention. For instance, findings from two studies (Puddifoot & Johnson, 1997; Samuelsson, Rådestad & Segesten, 2001) were balanced with findings from others since both studies received a weak score for rigour of analysis or data collection

A second researcher rated a sample of the studies using to ensure inter-rater reliability of CASP ratings. Although there was some small variance in the ratings for individual standards in some papers, the overall CASP ratings were the same for each paper between raters.

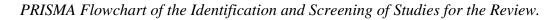
## Analysis

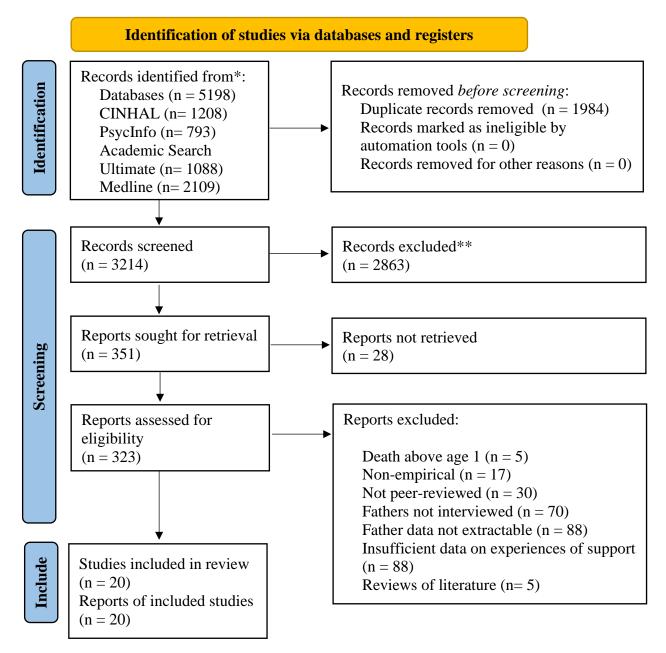
Given the variance in the methodologies of the yielded studies with greater descriptive than phenomenological approaches, findings from the included studies were analysed using Thomas and Harden (2008)'s approach to thematic synthesis. This approach was chosen as an alternative to meta-synthesis, since it was designed to synthesize descriptive findings pertaining to participant experiences and perspectives (Thomas & Harden, 2008).

In line with Thomas and Harden's (2008) approach, all text included under the results section of each paper was extracted and analysed. For each paper, the data was analysed individually with initial codes created by the researcher to capture the data relevant to the

research question. For instance, "others invalidate pain of loss due to gender", which captures the finding from Chavez et al (2019), that fathers conveyed distress when others suggested the loss did not matter because they were a father not a mother. Codes were split into small groups outlining themes of the findings from each paper. An extract of this analysis is presented in Appendix D. This process was repeated for each of the 20 studies individually. Themes across studies were then collated into smaller groups with similarities or relationships between them, resulting in a final set of overall themes. An example of this process for theme two is presented in Appendix E.

# Figure 1





# Table 2

# The Characteristics of the 20 Studies Included in this Systematic Review

Author (Year)	Research question	Methodology	Participants	Location
	To explore fathers' experiences of pregnancy after a prior	Unstructured interviews.	4 fathers. Range from 12-20	
Armstrong (2001)	perinatal loss.	Phenomenological	weeks gestation for loss not	United States
	permaan 1055.	analysis.	specified for each participant.	
	To explore fathers' experiences of support following	Semi-structured	10 fathers. Neonatal death	
Azeez et al (2021)	neonatal death, including availability and perceived	interviews. Thematic	from 30 minutes to 27 days of	Australia
12002 et al (2021)	adequacy of support, barriers, and facilitators to support and desired support	analysis.	age.	Tustiana
		anarysis.	age.	
Bonnette & Broom	To explore how fathers engage with their unborn and	Semi-structured	12 fathers. Stillbirth (not	
(2011)	stillborn child and the legitimacy of male grief	interviews. Interpretative	defined).	
(2011) Stillborn child and (	sumborn ennu and the regitimacy of male grief	analysis.	defined).	
Cacciatore,	To avaluate fathers' experiences of stillbirth and	Opling survey Content	131 fathers. Stillbirth (defined	
Erlandsson &	To evaluate fathers' experiences of stillbirth and	Online survey. Content	as 22 weeks gestation	Sweden
Radestad (2013)	psychosocial care	analysis.	onwards).	

Chavez et al (2019)	To understand the lived experience of 31 male participants whose partners had miscarried a child	Analysis of existing online data with passive phenomenological methodology.	31 fathers. Miscarriage (not defined).	Unknown. Anonymous online data
Edwards et al (2009)	To document experiences of Māori fathers and their grieving around the SIDS death of their own infant, to investigate the reported perception that this grieving is dysfunctional and to use traditionally accepted Māori forms of grieving as a context against which to consider what these young men report	Interviews. Thematic discourse analysis.	9 fathers. Infant death (not defined).	New Zealand (Māori population)
Fernández-Sola et al (2020)	To explore describe and understand the impact of perinatal death on parents' social and family life	Interviews. Inductive analysis.	Mothers and 8 fathers. Of the fathers 6 stillbirths, 2 infant deaths at 3 and 6 days.	Spain

	To describe the fathers' perceptions of the preventability of				
Hughes & Page-	the loss, their closeness to the foetus prenatally and their	Interviews and written	51 fathers. Loss from 28 weeks		
	experiences with significant others during the grieving	questionnaire. Content	gestation to end of 'neonatal	United States	
Lieberman (1989)	period and to describe the nature, intensity and duration of	analysis.	period' (not defined).		
	the bereavement experience				
Kavanaugh, Trier & Korzec (2004)	To examine parents' descriptions of the ways family and friends supported them after they had experienced a perinatal loss	Secondary analysis of data pertaining to experiences of support,	mothers and 9 fathers.		
		from two broader		United States	
		phenomenological	Infant death.		
		studies. Analysis guided			
		by Knafl and Webster			
		(1988).			

		Observation of	14 fathers. 15 stillbirths, 8	
	Aims to describe the experiences of men whose partner had	pregnancy loss support	miscarriages. (5 men had	Northern
McCreight (2004)	experienced pregnancy loss'	groups and in-depth	experienced a mixture of	Ireland
	experienced pregnancy loss	interviews. Content	stillbirths, miscarriages and	netand
		analysis.	infant deaths).	
Millor Tomple	To address the cap in Australian literature by exploring	Semi-structured		
Miller, Temple-	To address the gap in Australian literature by exploring	interviews. 'general	10 fathers. Miscarriage (up to	A
	ith & Bilardi     miscarriage from a male partner perspective and men's	inductive approach' to	20 weeks gestation).	Australia
(2019) needs for additional support'	analysis.			
Murphy (1998)	Aims to add to the understanding of early miscarriage by discussing the experience from a male perspective'	Unstructured interviews. Phenomenological	5 fathers. Early miscarriage (up to 16 weeks gestation).	United Kingdom
	discussing the experience from a male perspective	analysis.	to to weeks gestation).	Kingdom
	To explore Australian men's experiences of both formal	Semi-structured	8 fathers. 7 stillbirths and 2	
Obst & Due (2019)	and informal supports received following a female partner's	interviews. Thematic	miscarriages.	Australia
	pregnancy loss	analysis.	nnscarrages.	

### 1-16

Mothers and 11 fathers.

O'Leary, Warland &	Addresses bereaved parents' perceptions of their parents'	Interviews. Thematic	Miscarriage, Stillbirth and	Australia and
Parker (2011)	(grandparents) reactions to perinatal loss.	analysis.	Infant death (loss in pregnancy	United States
			up to 8 weeks of life).	
O'Leary & Thorwick	To present information about the fathers' perspective			
·	during the experience of a pregnancy following perinatal	Interviews.	10 fathers. Loss type unclear.	United States
(2006)	loss			
Dahán Farawagan G	To understood and describe the meaning of noningtal death	Semi-structured	15 fath and All stillbirth from	
Pabón, Fergusson &	To understand and describe the meaning of perinatal death	interviews.	15 fathers. All stillbirth from	Colombia
Palacios (2019)	in sample of fathers	Phenomenological.	22-38 weeks gestation.	
Duddifaat & Johnson	To explore phenomenological aspects of miscarriage by	Semi-structured	20 fathers. Miscarriage	United
Puddifoot & Johnson	reference to the actual experience of a small sample of men	Interviews. Content	(defined as loss prior to 24	
(1997)	during and after their partners' miscarriage	analysis.	weeks).	Kingdom
Samuelsson,		Interviews.	11 feeth and for the bacteria and	
Rådestad & Segesten	To describe how fathers experienced losing a child because of intrauterine death	Phenomenological	11 fathers. Stillbirth between weeks 29 and 42 gestation.	Sweden
(2001)		analysis.		

		Semi-structured		
Wagner et al (2018)	To examine fathers' lived experience of miscarriage and	interviews. Descriptive	11 fathers. Miscarriage prior to	United States
wagner et al (2010)	describes themes essential to that experience	phenomenological	24 weeks gestation.	
		analysis.		
			Mothers, Fathers and	
White, Walker &Examines social support between grandparents and theirRichards (2008)adult children in the aftermath of infant death'	Exemple as sight our part hot ways area descents and their	Interviewe Crowndod	Grandparents. 9 fathers.	
	Interviews. Grounded	Stillbirth (undefined) and	United States	
	aduit children in the altermath of infant death	theory.	Infant death (from 2 days to 7	
			months old).	

#### Results

Thematic synthesis yielded the following three themes: (1) gendered experiences and expectations of loss and support, (2) conflict between supporting and needing support, (3) male experiences of support and service provision.

### Theme 1: Gendered experiences and expectations of loss and support

Present in 14 of the reviewed studies, and representing research on miscarriage, stillbirth and infant death, this theme captures gendered experiences of grief and its influence on seeking and receiving support. Fathers across these studies discussed how their perception of prevailing societal narratives around masculinity resulted in perceived expectations for the expression, or suppression of emotion (Armstrong, 2001; Fernández-Sola et al., 2020; Miller et al., 2019; Puddifoot & Johnson, 1997; Chavez et al., 2019; Wagner et al., 2018). Such expectations for the fathers' management of emotions were also seen in their descriptions of interactions with family as well as professionals. As one father described: "a female physician met me with the attitude that the loss was not as sorrowful for me as for my wife" (Cacciatore et al., 2013, p. 668). Fathers conveyed a sense that a lack of acknowledgement for their loss impacted how they saw themselves: "There was just no-one there to acknowledge that it happened to me as well. . .one day I saw myself as a dad, the other day I was not a dad anymore" (Miller et al., 2019, p. 6). This lack of acknowledgement left fathers stifled in their expression of grief interrupting opportunities to seek support: "a few times I could have spoken to people about things, but I wasn't asked so I never said anything" (O'Leary & Thorwick, 2006, p. 81).

In studies investigating miscarriage and infant death specifically, it also seems the lack of support offered to fathers directly, coupled with support aimed towards the mother (Azeez et al., 2021; Edwards et al., 2009; Miller et al., 2019) reinforced this expectation to fathers: "I thought to myself that they cared more about her, so it looks like I need to cope alone" (Edwards et al., 2009, p. 145). Fathers became reluctant to share their feelings: "I was a little bit closed off as well, but they would more often talk to her about what was going on" (Azeez et al., 2021, p. 4). Across loss types, the fathers seemed to internalise narratives of masculinity, feeling "embarrassed" of their feelings, reluctant to share them for fear of judgement (Chavez et al., 2019; Edwards et al., 2009; McCreight, 2004; Puddifoot & Johnson, 1997). The fathers show clear suppression of their emotions, "I cried a little when I first found out, but sucked it up because men don't cry, or at least that's what I was raised to believe" (Chavez et al., 2019, p. 672). In this way the fathers in the studies seemed to experience intense but hidden emotions surrounding the loss of their baby:

You're always fighting those emotions really, but when you lose your baby, it sort of confuses you, you want to tell some-one how you feel but yet you think 'I'm a man, I shouldn't be feeling like this'. (McCreight, 2004, p.342)

The ways in which the fathers in the studies suppressed their emotions and hid emotional expression from others, might suggest to others that these men are unaffected by the loss of their baby. This is expressed by one father who reports: "support is what I definitely need no matter how I act outwardly" (Chavez et al., 2019, p. 670).

This suppression of emotion was 'broken' for some fathers in Bonnette and Broom (2011)'s study, where fathers who had experienced stillbirth stated that male friends asking directly how they were coping helped them to recognise and express their own support needs:

He was the first thing to make me aware of, you know, 'it's alright for everyone patting Amber on the back and giving her a hug to see how she's coping but how are you going Patrick? How are you personally going?' He was the first person to bring it to the attention of maybe I'm struggling a little bit. (Bonette & Broom, 2012, p. 260) Importantly, there were fathers across studies of all loss types who seemed to value support which facilitated connection with other bereaved fathers (Azeez et al., 2021; O'Leary et al., 2011; Wagner et al., 2018). Group support helped fathers through normalising their experiences: "it's nice to talk to other dads too, that went through it, and you see their point of view and you know what, I'm not alone" (O'Leary et al., 2011, p. 82). Fathers in this study also seemed to value support from those with similar experiences as this made it easier to communicate their feelings: "to share stuff with people who are coming from the same place, so when that happens you can skip a whole load of jumble, trying to explain about a feeling" (O'Leary et al., 2011, p. 82). In this way some fathers were able to overcome notions of masculinity to share their experiences in group settings.

However, a common finding across studies of all loss types, indicated barriers to group support rooted in masculine ideas of the management of emotion (Miller et al., 2019; Obst & Due, 2019; O'Leary et al., 2011; Wagner et al., 2018). The fathers seemed to find the idea of attending a support group difficult, as this conflicted with a traditional masculine image: "I can't see a bunch of 300-pound burly men sitting in a room bawling" (O'Leary et al., 2011, p. 82). Another father in this study conveyed what they perceived as a static trait in men that they considered a barrier to formal support: "guys are not the type to let their feelings show, they're not going to sit there and tell you how they feel, that's just the way they are" (O'Leary et al., 2011, p. 82). This creates a discomfort with group support:

Seeing people sitting in a circle can be a little bit confronting because it then makes you feel like you're going to have to stand up and talk to people about something that's incredibly personal and I don't know that that's something that men are particularly good at. (Obst & Due, 2019, p. 3) For others who did attend group support, the balance between men and women in attendance served as a barrier to continued engagement with this support, "We did try one, (mother) and I together . . .but we actually felt that we were wasting their time because I was the only bloke there" (Miller et al., 2019, p. 15).

Importantly findings in the included studies suggested that male support needs differ from that of mothers, as one father described:

I was just, I almost distracted myself by focussing on some of the medical and technical things that happened, and I think I was affected emotionally, in a more slow and over a longer period of time, so I think it's the different kind of support. (Azeez et al., 2021, p. 5)

In some studies fathers described alternative forms of support that they felt were aligned to the support needs of fathers specifically including one to one support to mitigate discomfort in sharing feelings in a group (O'Leary et al., 2011). Another father suggested a less formal approach to support to engage fathers:

I think personally the way to reach out to men and make them connect with (support) is to frame the proposition completely differently, and not make it about support... tap into what they're probably thinking about themselves and that's about supporting other people and through that you actually support them. (Obst & Due, 2019, p. 4)

In summary this theme presents fathers' experiences of support following miscarriage, stillbirth and infant death which are characterised by societal expectations of masculinity and men's management of emotions. This in turn influences fathers' expectations for managing their grief, often incongruent with support on offer which is aimed at and better attended by mothers. The interactions men experience with family and healthcare professionals, further reinforces this message to fathers, who begin to suppress their emotions and learn to cope alone. In turn, fathers reported that their support needs may appear hidden to others, and this coupled with low engagement in support offered may add to a societal narrative of fathers experiencing 'lesser' emotions than mothers, impacting the level of support offered and again reinforcing a message to fathers that they are less in need of support.

### Theme 2: Conflict between supporting and needing support

The perceived role of a father to be a supporter to the mother of the baby was a strong finding throughout seven of the included studies with findings from participants experiencing miscarriage, stillbirth, and infant death (Bonette & Broom, 2012; Hughes & Page-Lieberman J, 1989; McCreight, 2004; Murphy, 1998; O'Leary et al., 2011; Puddifoot & Johnson, 1997; Samuelsson et al., 2001). The fathers expressed a need to "be strong" and meet the needs of the mother, (Bonette & Broom, 2012; Hughes & Page-Lieberman, 1989; Murphy, 1998; O'Leary et al., 2011; Samuelsson et al., 2001).

There were mixed findings across studies as to fathers' perceptions of a hierarchy of distress of the mother and the fathers. In one study of fathers who experienced stillbirth and infant death, fathers seemed to place the mothers support needs as more important than the fathers, "my wife wanted support, I felt the mother needed more support" (Hughes & Page-Lieberman, 1989, p. 549). However, for others the strength of the father-infant relationship and the subsequent equality of distress and support needs was emphasised: "You can't say it was worse for Melissa because it was in her stomach; it is not. Obviously, the baby was in there but the bond and therefore the loss is just as much" (Bonnette & Broom, 2011, p. 255).

Irrespective of any perceived hierarchy of distress, fathers across studies expressed the presence of distress at the loss of their baby (Bonette & Broom, 2012; Hughes & Page-Lieberman J, 1989; McCreight, 2004; Murphy, 1998; O'Leary et al., 2011; Puddifoot & Johnson, 1997; Samuelsson et al., 2001, p. 127). The fathers seemed to suppress their own distress to maintain a 'strong' exterior and support their partners. For instance, one father who had experienced stillbirth stated: "She felt a greater need to talk about it, while I was actually very reticent. Didn't want to be sad and make her even sadder" (Samuelsson et al., 2001, p. 127). For some fathers, this suppression of emotion was upheld around others and emotion was consequently expressed only at times when fathers were alone: "I was just in tears and just felt like.... It was like while you've got people here, like Anna and Zoe and you've got to be strong for them and stuff like that, but they were gone and I was here on my own" (Bonette & Broom, 2012, p. 258).

The 'supporter' role was also encouraged in fathers, sometimes explicitly by family members: "I had a bit of a weep and mum snapped at me and said that I was being selfish and had to pull myself together before I upset (baby's mother)" (Puddifoot & Johnson, 1997, p. 839). Some fathers feared for how, as a couple, they would cope if both were expressing intense emotion: "I could lose it for a minute and not feel that I'm going to cause her to lose it even more. I felt like if I was with her and I lost it we would never recover" (Bonnette & Broom, 2011, p. 258).

Importantly this perceived role and expectation as a supporter seemed to mask fathers' own support needs through this suppression of emotion across all loss types (Bonette & Broom, 2012; Hughes & Page-Lieberman J, 1989; McCreight, 2004; Murphy, 1998; O'Leary & Thorwick, 2006; Puddifoot & Johnson, 1997; Samuelsson et al., 2001). The effort to support their partner for one father who had experienced stillbirth, seemed to suggest to others that he was coping: "you're having to function for someone else and so because you're doing the best to function for them, a lot of people are thinking that you are doing okay and they're missing it" (Bonnette & Broom, 2011, p. 259). This suggests a link with theme 1, in that the perceived expectations and manifestation of fathers' supporting the mother of the baby, conveys a message to others that fathers are coping well, despite their incongruent internal grief experience.

### Theme 3: Male experiences of support and service provision

This theme was contributed to by 19 of the included studies representing experiences of miscarriage, stillbirth and infant death. The theme brings together fathers' experiences of the initial provision of support as well as perceptions of support received.

The first step in providing support is the recognition and acknowledgement of support need, without this the provision of support may seem unnecessary to the provider. Findings from the reviewed studies portrayed common strong findings that the fathers felt ignored and unacknowledged in their experiences of all loss types, both by professionals and their own social networks (Azeez et al., 2021; Cacciatore et al., 2013; Chavez et al., 2019; McCreight, 2004; Miller et al., 2019; O'Leary et al., 2011; Puddifoot & Johnson, 1997; Samuelsson et al., 2001; Wagner et al., 2018). In one study exploring experiences of miscarriage, this treatment resulted in fathers that feel "the hospital treats me as luggage that the wife brings" (Chavez et al., 2019, p. 670). In studies with samples comprising all loss types, the fathers yearned for acknowledgement through supportive relationships with hospital staff: "If even one of the hospital staff had said, 'Connor, I'm sorry, you know you're a dad and you feel pain as well', it would have helped" (McCreight, 2004, p. 339).

This neglect of fathers support needs can also be seen as a consequence of low male engagement with support offered. One father who had experienced infant death, describes a coffee morning that was cancelled due to poor sign-up:

They had like a fathers' group... there was supposed to be like a coffee thing that I was going to go to but then they cancelled it because there was only two people that

said yes, and they just like I don't know, don't know if it's a cultural thing or a masculinity thing. (Azeez et al., 2021, p. 5)

It is important to consider that the fathers who were reluctant to engage in this support may well have been experiencing underlying emotions in need of such support but felt unable to access this due to gendered expectations of how they should manage these emotions, as explored in theme one.

Fathers' support needs were also neglected through a clear channelling of support towards the mothers in studies investigating all loss types (Azeez et al., 2021; Fernández-Sola et al., 2020; Miller et al., 2019; O'Leary et al., 2011; Puddifoot & Johnson, 1997; Samuelsson et al., 2001; Chavez et al., 2019). As one father experiencing stillbirth described: "she was given more attention, when it came to explaining things, when it came to telling things, most of the time it was more towards her... I was invisible to many people, however I was also having a hard time" (Fernández-Sola et al., 2020, p. 7). This is also seen for fathers experiencing miscarriage, with staff conveying the message they care only about the mother: "The hospital. . .they always treat the mum... she's gone through it... that's all we care about, you're just the dad" (Miller et al., 2019, p. 10). Furthermore, for both miscarriage and stillbirth, there was a tendency for others to use the father to find out how the mother is doing (Bonnette & Broom, 2011; Wagner et al., 2018), as one father conveys:

Look, it's not only Melissa who lost a child, I've lost a child as well, I'm not the telephone operator to tell you the news about how Mellissa is doing, ask me how I'm doing I've lost my child and I couldn't do anything for it. (Bonette & Broom, 2012, p. 260)

Importantly, there were examples of support in which fathers did not feel ignored or 'less than' the mothers. For instance, in a study exploring experiences of stillbirth one father conveyed: "the midwife who had the greatest responsibility for taking care of us saw me as a father and talked just as much with me (as my wife) and about being a father of a son" (Cacciatore et al., 2013, p. 6). Another father in this study valued that "they invited me in as father and also thought about me, they took the time to think only of me" (Cacciatore et al., 2013, p. 4). In this way, professionals seemed to play an important role in opening up avenues of support, whereby attending to fathers' experiences of loss is perceived as an invitation to be thought about.

This theme also encompasses fathers' conveyed sense of practical and informational support being valued and appreciated alongside the emotional recognition and validation, a finding present in studies of all loss types (Edwards et al., 2009; Puddifoot & Johnson, 1997; Wagner et al., 2018; White et al., 2008). For instance, one father greatly valued the pastor's practical support in arranging the funeral: "the most practical help came from our associate pastor who... made the calls around to various funeral homes to find out prices for caskets and cremation" (Wagner et al., 2018, p. 197). In another study, for a father who was incarcerated, prison staff offering practical solutions to facilitate his attending of funeral rituals was also greatly valued: "the wardens were trying to get me out for parole and the I had to go to the tangi, they change my security so I could go" (Edwards et al., 2009, p. 141). In both cases the practical support is strongly linked to the funeral rituals, and in this way perhaps the practical support was highly valued due to its indirect influence on the fathers' capacity to attend to this more emotional and meaningful element of grief.

Importantly, where fathers did receive support through interactions with either family, friends, or healthcare staff, many experienced a sense of this support lacking in empathy (Azeez et al., 2021; Cacciatore et al., 2013; Pabón et al., 2019; McCreight, 2004; Miller et al., 2019; Murphy, 1998; Wagner et al., 2018; White et al., 2008). For some fathers experiencing infant death, this was experienced through a lack of direct contact: "all of the support we

were given was basically booklets and things like that with information... but no direct contact" (Azeez et al., 2021, p. 4). For others experiencing miscarriage or stillbirth there was a clear experience by which supporting professionals displayed a seeming lack of emotion or a cold, clinical approach to the fathers (Cacciatore et al., 2013; Miller et al., 2019; Murphy, 1998; Puddifoot & Johnson, 1997). In this way the experience of miscarriage or stillbirth may present with a unique, unempathetic reaction from others. For instance, one father who had experienced stillbirth conveyed: "the reception we got when we were confronted by the delivery and the staff said that he was dead, a physician showing no feelings, who just left us alone in the room" (Cacciatore et al., 2013, p. 5). For other fathers experiencing stillbirth, the delivery of the words was lacking in emotion: "he's just reading a script... it's not heartfelt" (White et al., 2008, p. 202). In a study of experiences of miscarriage, fathers expressed value in professionals "actually wanting an answer" when exploring feelings (Wagner et al., 2018, p. 197). In this way the authenticity of support, is of great value to fathers. Indeed, the fathers in studies representing all loss types, who did receive such support conveyed the value of these experiences of warm, human, and emotive contact with professionals and their social networks (Hughes & Page-Lieberman, 1989; McCreight, 2004; O'Leary et al., 2011).

In summary this theme encompasses fathers' varied experiences with support surrounding a central experience of distress and support needs going unacknowledged either through invalidating interactions with family or staff or through a lack of support offered. The theme also highlights the benefits of practical support as well we authentic, empathic emotional support.

### Discussion

This systematic review aimed to synthesise the existing literature to investigate how fathers experience support following perinatal loss. Following a systematic search of the literature, 20 studies were included in the review. Thematic synthesis of the findings from these studies revealed three themes: (1) Gendered expectations and experiences of loss, (2) Conflict between supporting and needing support, (3) Male experiences of support and service provision. The themes will be explored below and presented as a novel, emerging conceptualisation of fathers' experiences of support following perinatal loss, with clinical implications suggested.

The fathers across the reviewed studies shared a strong sense of an underlying need for support that was shrouded by their experiences of masculinity and their resulting outward presentation. The fathers experienced clear shame that prevented them from expressing their emotions and fear for what others would think of them if they were to express feelings.

These notions of masculinity and their impact on the expression of emotion are well documented in the men's mental health literature (Harris, Kruger & Scott, 2022; Reeser & Gottzén, 2018; River & Flood, 2021). Factors such as identification with traditional masculinity and feeling emasculated have been found to predict men's dropout from therapy (Seidler et al., 2021). It has also been theorised that man engage in behaviours that present themselves as strong as a social practice to demonstrate masculinity (Courtenay, 2000). In this way it is possible that the behavioural response to loss of suppressing emotions and supporting the mother is one that displays fathers' masculinity in a way that showing emotion and seeking support would not. Importantly, there is an evidenced disparity between the rates of men's experiences of distress compared to their rates of engagement in support services. A recent study found that over 60% in a sample of men reporting symptoms of major depression, had experienced suicidal ideation in the 2 weeks prior but only 8% were currently accessing professional mental health support, with likelihood of help-seeking associated with reluctance to disclose mood-related symptoms (Rice et al., 2020). In considering fatherhood, although progress has been made to acknowledge the vulnerability of men in the perinatal period, men's experiences of perinatal mental health difficulties are thought to be

underrepresented in the research and are not well detected since assessment methods focus on the experiences of women (Baldoni & Giannotti, 2020).

Research investigating help seeking in men who have experienced perinatal loss is limited, with the context of masculinity a relatively new consideration. In a recent review, it was suggested that fathers' experiences of societal gendered expectations impacted their expression of emotion in the context of early pregnancy loss (Karali et al., 2021). The findings of the present review contribute to this emerging evidence base through considering this experience of masculinity across perinatal loss broadly, with specific link between masculine ways of managing emotion and accessing support.

Fathers across studies also experienced judgement and rejection of their feelings from family members and staff, who either negatively judged the presence of their emotion or suggested they should control it to support the mother of the baby. Importantly, though some fathers found the role as a supporter to their partner was supportive to them, others found this role to be a barrier to accessing support for themselves. This invalidating response to fathers' grief experience is important to consider as a reinforcer to fathers' social practices to display their masculinity (Courtenay, 2000). Furthermore, such experiences can be understood as a 'disenfranchised grief', an experience of loss in which a person's social surroundings perceive the loss as negligible (Sawicka, 2017). In a recent systematic review of fathers' grief following perinatal loss, authors coined the term 'double-disenfranchisement', to reflect fathers' experiences of the disenfranchisement of a perinatal loss, compounded by a lack of recognition as a father and the subsequent further disenfranchisement this brings (Obst et al., 2020).

Finally, fathers conveyed mixed experiences in the targeting of support, with some experiencing this aimed entirely at the mother, others feeling they were treated equally and

others reflecting on the absence of support entirely. Importantly, where support was aimed at the mother alone, fathers seemed to perceive this as a message that their support needs were less important or that they should not be struggling as it is the mother who requires support, not themselves. Such experiences further compound the 'double disenfranchisement' fathers face (Obst et al., 2020). The fathers in the reviewed studies also conveyed a sense of difficulty in engaging with more traditional support on offer such as support groups. The complexity of engaging 'hard-to-reach' groups has gained attention in research, with suggestions that the labelling of a group as 'hard-to-reach' negates the complexities in which this group feels unable to access services (Boag-Munroe & Evangelou, 2012).

In considering fathers' engagement in perinatal support more broadly there is a need for services to look inwards and develop staff confidence and competence in understanding and engaging fathers and adopting innovative approaches to engaging fathers with support (Tehan & McDonald, 2010). It is important to acknowledge that some fathers across studies found support groups helpful and valued being able to talk about their feelings and experiences with others. It is also important to consider the suggestion that inviting fathers to support others is an indirect way of engaging them in activities that also support their own wellbeing, without a need to focus on expressing their feelings. It has been recommended in the mental health literature that male-centred mental health campaigns and approaches to support may help men seek and engage with support (Seidler et al., 2018).

Furthermore, believing that support can help and knowing how and where to access help have been found to be strong facilitators for men seeking mental health support (Seidler et al., 2020). In this way the present review adds an important novel understanding to fathers' engagement in support following perinatal loss. This includes an understanding that an unequal provision of support with focus on mothers may give fathers the message they need to cope alone, reducing their engagement with any father focussed support offered.

Furthermore, it is suggested that indirect approaches to support may assist in engaging fathers, as opposed to offerings such as support groups involving a formal, direct, group-based expression of the fathers' feelings and experiences.

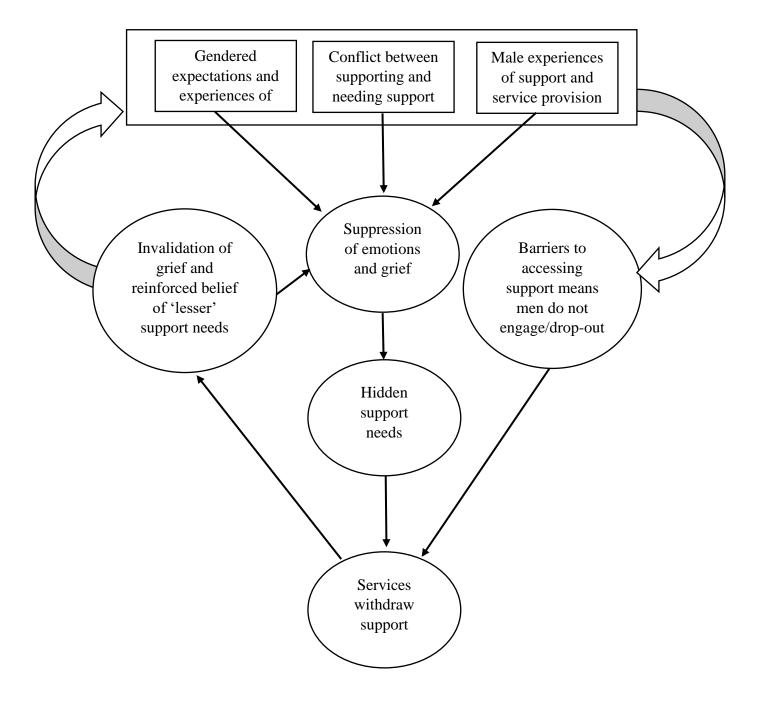
Considering the three themes of findings outlined in this review, a conceptualisation of fathers' experiences of support following loss was created indicating a vicious cycle in which fathers' difficulties with support are reinforced and maintained, as seen in Figure 2. In this cycle, notions of masculinity, an expectation to take on the 'supporter role' and an experience of support aimed towards mothers leads to fathers suppressing their grief and emotions resulting in hidden, underlying support needs. Such experiences also seem to influence fathers' decisions around accessing or engaging with support and as such may lead to low take-up in support offered. From the perspective of service providers, this low take-up can be seen as a lack of interest in the support or a 'lesser' need.

In the findings from Azeez et al (2021), this perception of a lesser need resulted in support groups being cancelled. Where services do react in such a way, this fuels the cycle whereby fathers feel their needs go unacknowledged and internalise this as a message that their needs are less important, reinforcing notions of masculinity and further contributing to fathers' potential non-engagement with support. This action from services also clearly contributes to fathers' experiences in which support for fathers is not available, with support on offer aimed only towards mothers. As such, the present review adds a novel conceptualisation of fathers' experiences of support following perinatal loss, in which a cycle of 'non-engagement' is maintained and reinforces notions of masculinity and a hierarchy in which mothers needs are better recognised and addressed through support provision.

# Figure 2

Conceptualisation of Findings of the Present Systematic Review Exploring Fathers'

Experiences of Formal and Informal Support Following Perinatal Loss



#### **Clinical Implications**

The findings from this review offer important implications for clinical practice and service provision. There are multiple 'exits' to the cycle presented as a conceptualisation of the review findings. Firstly, ensuring services exist that offer regular and formal support to fathers who have experienced perinatal loss in a way that is equitable to the offer existent for mothers. Aiming support at fathers as well as mothers will support a message for fathers that their support needs do exist and are as important as for the mother. Furthermore, professionals should avoid assumptions about fathers' role within the family and explore these roles with fathers to understand the systemic positioning of them within the family and the possible impact this is having on the father's ability to attend to his own support needs. Importantly such exploration may indicate that the father requires support to fulfil the role of supporter to his family, should this be something he is looking for.

Finally, a societal shift in expectations for fathers and men more broadly in how to express and manage their emotions is important in challenging the notion that fathers are less effected and have a lesser support need than mothers. This challenging of societal narratives may also serve to mitigate difficulties fathers have in expressing their emotions. For instance, public health campaigns in which men are encouraged to express emotion perhaps with fathers sharing their experiences of perinatal loss, may serve to normalise this experience for men. Importantly, professionals who are in contact with fathers who have experienced perinatal loss have an opportunity to explore fathers' wellbeing, taking the responsibility away from the father to disclose their difficult feelings given the findings that indicate the multifaceted barriers to this.

The above clinical implications are aimed at reducing the barriers men may face in accessing support following perinatal bereavement. However, it is also important to

acknowledge the importance of services maintaining their offers of support to fathers regardless of levels of engagement and to explore the complexity of non-engagement in place of positioning fathers as a 'hard-to-reach' group or a group with lesser support needs. Furthermore, it is important for services to innovate in their approach to engaging fathers with support and in the format of support offered. Traditional offers of support such as support groups or individual therapy may work for some fathers, but the findings of the present review suggest that less direct and more informal avenues of support may engage those fathers for whom expressing feelings in traditional formats is difficult. For instance, football teams have been created (SANDS, 2011) and walking groups organised (Strong Men, n.d), where fathers can connect with other bereaved fathers and talk about their grief only when they feel comfortable to. It would prove useful for services to collaboratively innovate avenues of support with bereaved fathers, to understand and offer support congruent with their needs, rather than relying on existing support incongruent with fathers' gendered experiences of grief.

#### **Limitations and Further Research**

The present review took an approach that synthesised findings pertaining to fathers' experiences of support, predominantly taken from studies that explored fathers' experiences of perinatal loss more broadly. Although this approach did allow for an in-depth and meaningful exploration of the experiences of support, the limited existence of literature exploring fathers' experiences of support specifically is important to consider. It is possible that through focussing on a broader research question, the studies included in this review may have comprised a limited exploration of experiences of support both in the collection of data and questions asked in interviews as well as in the presentation of findings to the reader. Further research should investigate more specifically fathers' experiences of support both broadly but also with reference to specific methods of supporting fathers, to investigate their

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effectiveness. Furthermore, research investigating fathers' experiences of support where fathers have either disengaged or not engaged to begin with may offer insights into the complexities of this non-engagement, offering developments to the presented conceptualisation of this experience (Figure 2).

Finally, to yield sufficient evidence to address the aim of this review, studies investigating experiences of support across miscarriage, stillbirth and infant death were sought. The inclusion of these three distinct loss types gave strength in the appraisal of similarities and differences across these experiences. Indeed, the findings of the review indicate a high level of commonalities across these experiences. The most notable difference in these experiences is seen in reports of cold and unempathetic responses from healthcare staff and social networks for fathers experiencing miscarriage and stillbirth, but not infant death. This may suggest a unique experience of miscarriage and stillbirth in which the response from others' is perceived as unauthentic and void of emotion. However, it is important to consider the relative number of studies contributing to these findings with the review, with only two studies investigating infant death specifically. In this way the findings of this review are likely bias towards the experiences of miscarriage and stillbirth and findings on differences between these loss types should be taken with caution.

Variance in definition of loss types across the reviewed studies limited the comparisons made due to a lack of clear distinction. Future principal studies should define loss types clearly and consistently and aim to avoid combining miscarriage, stillbirth and infant death or when doing so should make clear reflections on the nuances of experience across loss types.

#### References

- Armstrong, D. (2001). Exploring fathers' experiences of pregnancy after a prior perinatal loss. MCN: The American Journal of Maternal/Child Nursing, 26(3), 147–153. <u>https://doi.org/10.1097/00005721-200105000-00012</u>
- Aydin, R., & Kabukcuoğlu, K. (2020). Fathers' Experiences of Perinatal Loss: A Sample Meta-Synthesis Study. *Journal of Family Issues*, 42(9), 2083-2110. https://doi.org/10.1177/0192513X20966002
- Azeez, S., Obst, K. L., Oxlad, M., Due, C., & Middleton, P. (2021). Australian fathers' experiences of support following neonatal death: A need for better access to diverse support options. *Journal of Perinatology*, 1–8. <u>https://doi.org/10.1038/s41372-021-01210-7</u>
- Baldoni, F., & Giannotti, M. (2020). Perinatal distress in fathers: toward a gender-based screening of paternal perinatal depressive and affective disorders. *Frontiers in Psychology*, 11, 1892. https://doi.org/10.3389/fpsyg.2020.01892
- Boag-Munroe, G., & Evangelou, M. (2012). From hard to reach to how to reach: A systematic review of the literature on hard-to-reach families. *Research Papers in Education*, 27(2), 209-239. https://doi.org/10.1080/02671522.2010.509515
- Bonnette, S., & Broom, A. (2011). On grief, fathering and the male role in men's accounts of stillbirth. *Journal of Sociology*, 48(3), 248–265. https://doi.org/10.1177/1440783311413485
- Cacciatore, J., Erlandsson, K., & Rådestad, I. (2013). Fatherhood and suffering: A qualitative exploration of Swedish men's experiences of care after the death of a baby.
   *International Journal of Nursing Studies*, 50(5), 664–670. cin20.
   https://doi.org/10.1016/j.ijnurstu.2012.10.014

- Campbell-Jackson, L., & Horsch, A. (2014). The psychological impact of stillbirth on women: A systematic review. *Illness, Crisis & Loss*, 22(3), 237-256. https://doi.org/10.2190/IL.22.3.d
- Chavez, M. S., Handley, V., Lucero Jones, R., Eddy, B., & Poll, V. (2019). Men's
  Experiences of Miscarriage: A Passive Phenomenological Analysis of Online Data. *Journal of Loss & Trauma*, 24(7), 664–677. cin20.
  https://doi.org/10.1080/23802359.2019.1611230
- Christiansen, D. M. (2017). Posttraumatic stress disorder in parents following infant death: A systematic review. *Clinical psychology review*, 51, 60-74. https://doi.org/10.1016/j.cpr.2016.10.007
- Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO: the SPIDER tool for qualitative evidence synthesis. *Qualitative health research*, 22(10), 1435-1443. https://doi.org/10.1177/1049732312452938
- Courtenay, W. H. (2000). Constructions of masculinity and their influence on men's wellbeing: a theory of gender and health. *Social science & medicine*, 50(10), 1385-1401. https://doi.org/10.1016/S0277-9536(99)00390-1
- Duggleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C., & Williams, A. (2010).
  Metasynthesis of the hope experience of family caregivers of persons with chronic illness. *Qualitative Health Research*, 20(2), 148-158.
  https://doi.org/10.1177/1049732309358329
- Edwards, S., McCreanor, T., Ormsby, M., Tuwhangai, N., & Tipene-Leach, D. (2009). Maori men and the grief of SIDS. *Death Studies*, *33*(2), 130–152. https://doi.org/10.1080/07481180802602774

- Farren, J., Mitchell-Jones, N., Verbakel, J. Y., Timmerman, D., Jalmbrant, M., & Bourne, T. (2018). The psychological impact of early pregnancy loss. *Human Reproduction Update*, 24(6), 731-749. https://doi.org/10.1093/humupd/dmy025
- Fernández-Sola, C., Camacho-Ávila, M., Hernández-Padilla, J. M., Fernández-Medina, I. M., Jiménez-López, F. R., Hernández-Sánchez, E., Conesa-Ferrer, M. B., & Granero-Molina, J. (2020). Impact of Perinatal Death on the Social and Family Context of the Parents. *International Journal of Environmental Research and Public Health*, 17(10). mdc. <u>https://doi.org/10.3390/ijerph17103421</u>
- Gold, K. J. (2007). Navigating care after a baby dies: a systematic review of parent experiences with health providers. *Journal of Perinatology*, 27(4), 230-237. https://doi.org/10.1038/sj.jp.7211676
- Goldstein, R., Lederman, R., Lichtenthal, W., Morris, S., Human, M., Elliott, A., Tobacco,
  D., Angal, J., Odendaal, H., Kinney, C., Holly, G., & Prigerson, H. (2018). The grief of mothers after the sudden unexpected death of their infants. *Pediatrics*, 141(5). https://doi.org/10.1542/peds.2017-3651
- Harris, J., Kruger, A. C., & Scott, E. (2022). "Sometimes I wish I was a girl,'cause they do shit like cry": An exploration into Black boys' thinking about emotions. *Urban Education*, 57(2), 224-250. https://doi.org/10.1177/0042085920933327
- Hughes, C. B., & Page-Lieberman, J. (1989). Fathers experiencing a perinatal loss. *Death Studies*, *13*(6), 537–556. <u>https://doi.org/10.1080/07481188908252331</u>
- Jones, K., Robb, M., Murphy, S., & Davies, A. (2019). New understandings of fathers' experiences of grief and loss following stillbirth and neonatal death: a scoping review. *Midwifery*, 79 (102531). https://doi.org/10.1016/j.midw.2019.102531

Karali, H. F., Farhad, E. S., Zaigham, M. T., Wen, P. Y., Parveena, S., & Siong, T. J. (2021). partners' expected response, coping mechanisms, social and health institutions expectations after early pregnancy loss: A systematic review. *International Journal of Clinical Obstetrics and Gynaecology*.

https://doi.org/10.33545/gynae.2021.v5.i6a.1053

- Kavanaugh, K., Trier, D., & Korzec, M. (2004). Social support following perinatal loss. *Journal of Family Nursing*, 10(1), 70–92. <u>https://doi.org/10.1177/1074840703260905</u>
- Köneş, M. Ö., & Yıldız, H. (2021). The level of grief in women with pregnancy loss: a prospective evaluation of the first three months of perinatal loss. *Journal of Psychosomatic Obstetrics & Gynecology*, 42(4), 346-355.
  https://doi.org/10.1080/0167482X.2020.1759543
- Lancet, T. (2021). Miscarriage: worldwide reform of care is needed. *Lancet (London, England)*, S0140-6736. https://doi.org/10.1016/S0140-6736(21)00954-5
- Lang, A., Fleiszer, A. R., Duhamel, F., Sword, W., Gilbert, K. R., & Corsini-Munt, S. (2011). Perinatal loss and parental grief: The challenge of ambiguity and disenfranchised grief. *OMEGA-Journal of Death and Dying*, 63(2), 183-196. https://doi.org/10.2190/OM.63.2.e
- Lewis, J., & Azar, R. (2015). Depressive symptoms in men post-miscarriage. Journal of Men's Health, 11(5). https://doi.org/10.31083/jomh.v11i5.12

McCreight, B. S. (2004). A grief ignored: Narratives of pregnancy loss from a male perspective. Sociology of Health & Illness, 26(3), 326–350. <u>https://doi.org/10.1111/j.1467-</u>9566.2004.00393.x

- Methley, A. M., Campbell, S., Chew-Graham, C., McNally, R., & Cheraghi-Sohi, S. (2014).
  PICO, PICOS and SPIDER: a comparison study of specificity and sensitivity in three search tools for qualitative systematic reviews. *BMC health services research*, 14(1), 1-10. https://doi.org/10.1186/s12913-014-0579-0
- Miller, E. J., Temple-Smith, M. J., & Bilardi, J. E. (2019). There was just no-one there to acknowledge that it happened to me as well': A qualitative study of male partner's experience of miscarriage. *PLoS ONE*, *14*(5). https://doi.org/10.1371/journal.pone.0217395
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of internal medicine*, 151(4), 264-269. <u>https://doi.org/10.7326/0003-4819-151-</u>4-200908180-00135
- Murphy, F. A. (1998). The experience of early miscarriage from a male perspective. *Journal of Clinical Nursing (Wiley-Blackwell)*, 7(4), 325–332. cin20. https://doi.org/10.1046/j.1365-2702.1998.00153.x
- Nguyen, V., Temple-Smith, M., & Bilardi, J. (2019). Men's lived experiences of perinatal loss: A review of the literature. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 59(6), 757-766. https://doi.org/10.1111/ajo.13041
- Nguyen, R. H. N., & Wilcox, A. J. (2005). Terms in reproductive and perinatal epidemiology: 2. Perinatal terms. *Journal of Epidemiology & Community Health*, 59(12), 1019-1021. http://dx.doi.org/10.1136/jech.2004.023465
- Noyes, J., Booth, A., Flemming, K., Garside, R., Harden, A., Lewin, S., Pantoja, T., Hannes,
   K., Cargo, M., & Thomas, J. (2018). Cochrane Qualitative and Implementation
   Methods Group guidance series—paper 3: methods for assessing methodological

limitations, data extraction and synthesis, and confidence in synthesized qualitative findings. *Journal of clinical epidemiology*, 97, 49-58. https://doi.org/10.1016/j.jclinepi.2017.06.020

- Obst, K. L., & Due, C. (2019). Australian men's experiences of support following pregnancy loss: A qualitative study. *Midwifery*, 70, 1–6. cin20. https://doi.org/10.1016/j.midw.2018.11.013
- Obst, K. L., Due, C., Oxlad, M., & Middleton, P. (2020). Men's grief following pregnancy loss and neonatal loss: a systematic review and emerging theoretical model. *BMC pregnancy and childbirth*, 20(1), 1-17. https://doi.org/10.1186/s12884-019-2677-9
- Obst, K. L., Oxlad, M., Due, C., & Middleton, P. (2021). Factors contributing to men's grief following pregnancy loss and neonatal death: further development of an emerging model in an Australian sample. *BMC Pregnancy and Childbirth*, 21(1), 1-16. https://doi.org/10.1186/s12884-020-03514-6
- Office for National Statistics. (2016). National Survey of Bereaved People (VOICES): England, 2015.

https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthca resystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015

- O'Leary, J., & Thorwick, C. (2006). Fathers' perspectives during pregnancy, postperinatal loss. Journal of Obstetric, Gynecologic, & Neonatal Nursing: Clinical Scholarship for the Care of Women, Childbearing Families, & Newborns, 35(1), 78–86. https://doi.org/10.1111/j.1552-6909.2006.00017.x
- O'Leary, J., Warland, J., & Parker, L. (2011). Bereaved parents' perception of the grandparents' reactions to perinatal loss and the pregnancy that follows. *Journal of Family Nursing*, *17*(3), 330–356. <u>https://doi.org/10.1177/1074840711414908</u>

- Pabón, L. del M. L., Fergusson, M. E., & Palacios, A. M. (2019). Experience of perinatal death from the father's perspective. *Nursing Research*, 68(5), E1–E9. https://doi.org/10.1097/NNR.00000000000369
- Puddifoot, J. E., & Johnson, M. P. (1997). The legitimacy of grieving: The partner's experience at miscarriage. *Social Science & Medicine*, 45(6), 837–845. <u>https://doi.org/10.1016/S0277-</u>9536(96)00424-8
- Reeser, T. W., & Gottzén, L. (2018). Masculinity and affect: New possibilities, new agendas. *Norma*, 13(3-4), 145-157. https://doi.org/10.1080/18902138.2018.1528722
- Rice, S. M., Oliffe, J. L., Kealy, D., Seidler, Z. E., & Ogrodniczuk, J. S. (2020). Men's helpseeking for depression: Attitudinal and structural barriers in symptomatic men. *Journal of Primary Care & Community Health*, 11, 2150132720921686. https://doi.org/10.1177/2150132720921686
- River, J., & Flood, M. (2021). Masculinities, emotions and men's suicide. Sociology of Health & Illness, 43(4), 910-927. https://doi.org/10.1111/1467-9566.13257
- Samuelsson, M., Rådestad, I., & Segesten, K. (2001). A waste of life: Fathers' experience of losing a child before birth. *Birth: Issues in Perinatal Care*, 28(2), 124–130. https://doi.org/10.1046/j.1523-536X.2001.00124.x
- SANDS (2021, October 12). Sands United FC. SANDS. https://www.sands.org.uk/getinvolved/sands-united-fc
- Sawicka, M. (2017). Searching for a narrative of loss: interactional ordering of ambiguous grief. *Symbolic Interaction*, 40(2), 229-246. https://doi.org/10.1002/symb.270

- Seidler, Z. E., Rice, S. M., River, J., Oliffe, J. L., & Dhillon, H. M. (2018). Men's mental health services: The case for a masculinities model. *The Journal of Men's Studies*, 26(1), 92-104. https://doi.org/10.1177/1060826517729406
- Seidler, Z. E., Rice, S. M., Kealy, D., Oliffe, J. L., & Ogrodniczuk, J. S. (2020). Getting them through the door: A survey of men's facilitators for seeking mental health treatment. *International Journal of Mental Health and Addiction*, 18(5), 1346-1351.
   <a href="https://doi.org/10.1007/s11469-019-00147-5">https://doi.org/10.1007/s11469-019-00147-5</a>
- Seidler, Z. E., Wilson, M. J., Kealy, D., Oliffe, J. L., Ogrodniczuk, J. S., & Rice, S. M. (2021). Men's dropout from mental health services: Results from a survey of Australian men across the lifespan. *American journal of men's health*, 15(3), 15579883211014776. https://doi.org/10.1177/15579883211014776
- Shakespeare, C., Merriel, A., Bakhbakhi, D., Baneszova, R., Barnard, K., Lynch, M., Storey, C., Blencowe, H., Boyle, F., Flenady, V., Gold, K., Horey, D., Mills, T., & Siassakos, D. (2019). Parents' and healthcare professionals' experiences of care after stillbirth in low-and middle-income countries: a systematic review and meta-summary. *BJOG: An International Journal of Obstetrics & Gynaecology*, 126(1), 12-21. https://doi.org/10.1111/1471-0528.15430
- Shakespeare, C., Merriel, A., Bakhbakhi, D., Blencowe, H., Boyle, F. M., Flenady, V., Gold, K., Horey, D., Lynch, M., Mills, T. A., Murphy, M. M., Storey, C., Toolan, M., & Siassakos, D. (2020). The RESPECT Study for consensus on global bereavement care after stillbirth. *International Journal of Gynecology & Obstetrics*, 149(2), 137-147. https://doi.org/10.1002/ijgo.13110
- Shaohua, L., & Shorey, S. (2021). Psychosocial interventions on psychological outcomes of parents with perinatal loss: A systematic review and meta-analysis.

International Journal of Nursing Studies, 117, 103871. https://doi.org/10.1016/j.ijnurstu.2021.103871

Steen, S. E. (2015). Perinatal death: bereavement interventions used by US and Spanish nurses and midwives. *International journal of palliative nursing*, 21(2), 79-86. https://doi.org/10.12968/ijpn.2015.21.2.79

Strong Men (n.d). Weekenders. https://www.strongmen.org.uk/services/weekenders/

Tehan, B., & McDonald, M. (2010). Engaging fathers in child and family services.
Communities and *Families clearing House Australia*.
https://www.fatherhood.gov/sites/default/files/resource\_files/e000002050.pdf

- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology*, 8(1), 1-10. https://doi.org/10.1186/1471-2288-8-45
- Vogel, J. P., Souza, J. P., Mori, R., Morisaki, N., Lumbiganon, P., Laopaiboon, M., Ortiz-Panozo. E., Hernandez, H., Perez-Cuevas, R., Roy, M., Mittal, S., Cecatti, J. G., Tuncalp, O., & Gulmezoglu, A. M. (2014). Maternal complications and perinatal mortality: findings of the World Health Organization Multicountry Survey on Maternal and Newborn Health. *BJOG: An International Journal of Obstetrics & Gynaecology*, 121, 76-88. https://doi.org/10.1111/1471-0528.12633
- Wagner, N. J., Vaughn, C. T., & Tuazon, V. E. (2018). Fathers' lived experiences of miscarriage. *The Family Journal*, 26(2), 193–199. https://doi.org/10.1177/1066480718770154
- Wall-Wieler, E., Roos, L. L., & Bolton, J. (2018). Duration of maternal mental health-related outcomes after an infant's death: A retrospective matched cohort study using linkable

administrative data. *Depression and Anxiety*, 35(4), 305-312. https://doi.org/10.1002/da.22729

- White, D. L., Walker, A. J., & Richards, L. N. (2008). Intergenerational family support following infant death. *International Journal of Aging & Human Development*, 67(3), 187–208. <u>https://doi.org/10.2190/AG.67.3.a</u>
- Williams, H. M., Topping, A., Coomarasamy, A., & Jones, L. L. (2020). Men and miscarriage: a systematic review and thematic synthesis. *Qualitative health research*, 30(1), 133-145. https://doi.org/10.1177/1049732319870270

#### Appendix A

#### **Omega Journal of Death and Dying Instructions to Authors**

#### **Instructions for Authors**

Manuscripts can be submitted in APA style to https://mc.manuscriptcentral.com/omega.

Please refer to the latest Publication Manual of the American Psychological Association. A synopsis of this manual is available from the American Psychological Association. http://apa.org/

*Originality* Authors should note that only original articles are accepted for publication. Submission of a manuscript represents certification on the part of the author(s) that neither the article submitted, nor a version of it has been published, or is being considered for publication elsewhere.

*Format* Prepare manuscripts according to the latest Publication Manual of the American Psychological Association. A synopsis of this manual is available from the American Psychological Association. <u>http://apa.org</u>

*Manuscripts* Manuscript must be word processed, double-spaced, with wide margins. Paginate consecutively starting with the title page, which should be uploaded as a separate file. The organization of the paper should be indicated by appropriate headings and subheadings. Please be sure to remove all self-identifying information from the manuscript file before submitting. Author information should only be included on the title page.

*Style* Technical terms specific to a particular discipline should be defined. Write for clear comprehension by readers from a broad spectrum of scholarly and professional backgrounds. Avoid acronyms and footnoting, except for acknowledgments.

*Permissions* Authors are responsible for all statements made in their manuscript and for obtaining from copyright owners to reprint or adapt a table or figures, or to reprint a quotation of 500 words or more. Authors should write to original author(s) and publisher to request nonexclusive world rights in all languages to use the material in the article and in future editions. Provide copies of all permission and credit lines obtained at the time of manuscript submission.

#### **Manuscript Submission Guidelines:**

Manuscript must be word processed using Word or Open Office Writer, double-spaced, with wide margins. Paginate consecutively, starting with the title page.

Title Pages should be uploaded as a separate file and include the follow as is applicable:

• Full article title

- Acknowledgements/credits
- Each author's complete name and institutional affiliation(s)
- Grant numbers and/or funding information
- Corresponding author (name, address, phone/fax, e-mail)
- Up to five keywords as it should appear if it were to be published.

Abstracts of 100 to 150 words are required to introduce each article.

Most articles are between 5000-7500 words and while we accept long pieces that mandates additional evaluation because of space limitations.

Manuscripts should be saved in a Word .doc or .docx file type. The organization of the paper should be indicated by appropriate headings and subheadings.

Please be sure to remove all self-identifying information from the manuscript file before submitting.

When possible, all illustrations, figures, and tables are placed within the text at the appropriate points, rather than at the end. If this is not possible:

Figures should be referenced in text and appear in numerical sequence starting with Figure 1. Line art must be original "drawings" in black ink proportionate to our page size. Indicate top and bottom of figure where confusion may exist. Labeling should be 8 point type. Clearly identify all figures. Large figures should be drawn on separate pages and their placement within the text indicated by inserting:

#### \*Insert Figure 1 here\*

Tables must be cited in text in numerical sequence starting with Table 1. Each table must have a descriptive title. Any footnotes to tables are indicated by superior lower case letters. Large tables should be typed on separate pages and their approximate placement indicated within text by inserting:

\*Insert Table 1 here\*

# Appendix B

# **Search Terms**

# Table B1

Search Strategy and Search Terms for Each Database (free text search terms and subject headings were used together to search each

database individually before combining results across databases)

Search term type	Sample search terms: 'fathers'	Phenomenon of interest		Method of analysis search terms: 'qualitative'
type		search terms: 'perinatal		
		loss'		
Free text	Father* OR dad* AND OR paternal OR	(perinatal OR peri-natal	AND	experience* OR qualitative OR interview* OR
	male OR men OR man OR	OR "peri natal" OR baby		perception* OR attitude* OR view* OR
	"partner*" OR parent*	OR pregnancy OR		perspective*
		neonate OR fetus OR		
		foetus) N3 (loss OR death		
		OR bereave* OR die*) OR		

		miscar* OR stilb* OR	
		stillb*	
Subject headings (CINHAL)	MH "Parents" OR MH	MH "Infant Death" OR	MH "Phenomenological Research" OR MH
. ,	"Adolescent Parents" OR MH	MH "Sudden Infant	"Grounded Theory" OR MH "Naturalistic Inquiry"
	"Biological Parents" OR MH	Death" OR MH "Perinatal	OR MH "Ethnonursing Research" OR MH
	"Expectant Parents" OR MH	Death"	"Ethnological Research" OR MH "Ethnographic
	"Adolescent Fathers" OR MH "Expectant Fathers" OR MH "Fathers"		Research" OR MH "Qualitative Studies"
Subject headings (Psychinfo)	DE "Human Males" OR DE	DE "Sudden Infant Death"	DE "Focus Group" OR DE "Grounded Theory" OR
	"Parents" OR DE "Adolescent	OR DE "Spontaneous	DE "Interpretative Phenomenological Analysis"
	Fathers" OR DE "Single Fathers"	Abortion"	OR DE "Narrative Analysis" OR DE "Semi-
	OR DE "Expectant		Structured Interview" OR DE "Thematic Analysis"
	Fathers"		OR DE "Interviews" OR DE "Mixed Methods

Research" OR DE "Phenomenology" OR DE

"Qualitative Measures"

Subject headings (Accademic	DE "MEN" OR DE "PARENTS" OR	DE "STILLBIRTH" AND DE	DE "CONVERSATION analysis" OR DE "FOCUS
Search Ultimate)	DE	"FETAL death" OR DE	groups" OR DE "META-synthesis" OR DE
	"BIRTHFATHERS"		
	OR DE	"PERINATAL death" OR	"PHENOMENOGRAPHY" OR DE "ETHNOLOGY" OR
	"EXPECTANT		
	fathers" OR DE	DE "MISCARRIAGE" OR	DE "INTERVIEWING" AND DE "SEMI-structured
	"GAY fathers"		
	OR DE	DE "THERAPEUTIC	interviews" OR DE "TELEPHONE interviewing" OR
	"HETEROSEXUAL		
	fathers" OR DE	abortion"	DE "QUALITATIVE research
	"LGBTQ fathers"		
	OR DE		
	"MENTALLY III		
	fathers" OR DE		
	"MIDDLE-aged		
	fathers" OR DE		
	"SINGLE fathers"		
	OR DE "STAY-at-		
	home fathers"		
	OR DE "TEENAGE		
	fathers" OR DE		
	"WORKING		
	fathers") OR (DE		
	"FATHER-child		
	relationship"))		

	OR (DE "FATHERHOOD"		
Subject headings (Medline	MH "Fathers" OR MH "Single	MH "Perinatal Death" OR	MH "Qualitative Research" OR MH "Grounded
Complete)	Parent" OR MH "Parents"	MH "Fetal Death" OR MH	Theory"
		"Stillbirth" OR MH "Fetal	
		Resorption" OR MH	
		"Embryo Loss" OR MH	
		"Abortion, Septic" OR MH	
		"Abortion, Missed" OR	
		MH "Abortion,	
		Incomplete" OR MH	
		"Abortion, Spontaneous"	
		OR MH "Infant Death" OR	
		MH "Sudden Infant	
		Death"	

# Appendix C

# Critical Appraisal Skills Programme (CASP) Ratings Per Item for Each of the Included Studies (Noyes et al., 2018)

# Table C1

Table Displaying CASP Ratings for Each of the Included Studies

	Design appropriate to address` aims of research?	Recruitment strategy appropriate to aims of research?	Data collected in a way that addressed research issue?	Relationship between researcher and participants considered?	Ethical issues taken into consideration?	Data analysis sufficiently rigorous?	Clear statement of findings?	How valuable is the research?	
Author (Year)	Ξ.	6.	з.	4	у.	6.	7.	×.	Total Score
Armstrong (2001)	3	2	2	1	3	3	2	3	19/24
Azeez et al (2021)	3	2	3	3	3	3	3	3	23/24
Bonnette & Broom (2011)	3	3	3	2	3	2	3	2	21/24
Cacciatore, Erlandsson & Radestad (2013)	2	3	2	1	3	3	3	2	19/24
Chavez et al (2019)	2	2	2	3	3	2	3	3	20/24

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Edwards et al (2009)	2	2	3	2	2	2	3	2	18/24
Fernández-Sola et al (2020)	3	3	3	1	3	3	3	2	21/24
Hughes & Page-Lieberman (1989)	2	2	3	1	1	2	2	3	16/24
Kavanaugh, Trier & Korzec (2004)	3	3	3	1	2	2	3	3	20/24
McCreight (2004)	3	3	3	1	2	2	2	2	19/24
Miller, Temple-Smith & Bilardi (2019)	3	3	2	3	3	2	3	3	22/24
Murphy (1998)	3	2	3	1	2	3	3	3	20/24
Obst & Due (2019)	3	3	3	1	3	3	3	3	22/24
O'Leary, Warland & Parker (2011)	3	2	3	1	1	3	3	2	18/24
O'Leary & Thorwick (2006)	3	2	2	1	3	3	3	2	19/24
Pabón, Fergusson & Palacios (2019)	3	3	3	1	3	3	3	2	21/24
Puddifoot & Johnson (1997)	2	3	3	1	2	1	2	1	15/24
Samuelsson, Rådestad & Segesten (2001)	2	2	1	1	2	1	3	2	14/24
Wagner et al (2018)	3	2	3	1	1	2	3	3	18/24
White, Walker & Richards (2008)	3	3	2	1	1	3	3	3	19/24

# Appendix D Extract of Thematic Synthesis of Azeez et al (2021)

1-55

# Table D1

Table Displaying Extract of Thematic Synthesis Completed for Azeez et al (2021), Including Theme Title, Initial Codes and Illustrative Participant Quotes

Theme title	Codes	Participant quotes
Fathers feel	• Received pamphlets on support- only 1 received father-specific	"were included and basically put at the same level" (him and his
overlooked in	information	wife)
support	• Hospital review meeting focussed on mums	
surrounding	• Support focussed on mums	"there was a review session with the hospital as well, there was a
perinatal loss	• Focus on mother extended from physical to emotional support	definite focus on [my wife] rather than myself as the dad that may
	• Mothers, not fathers, specifically asked about feelings	have also been because I was a little bit closed off as well, but they
	• Inadequate info on male-specific support	would more often talk to her about what was going on and uh sort of
	• For one dad- mum and dad put 'at the same level'	like what feelings were happening for her rather than specifically
	• Fathers being overlooked	approaching me about them"
	• No facilities to accommodate dads at hospital	
	• Clear focus on the mother	

#### SYSTEMATIC REVIEW

• Dad not offered a place to sleep in hospital

Gendered	• Manage fear of emotion expression by focussing on practical tasks
experiences	• Support where don't have to worry about getting upset
of emotion	• Non-engage in support group for fear of expressing emotions
impacting	• Challenging to balance supporting partner and own support needs
support	• Fathers 'closed off' impacting support offered
offered	• Lack of male engagement limits subsequent service provision
	• Masculinity impacting engagement when offered= stuff then not
	offered because of low take up
	• Need for support to express emotions "otherwise it can overtake"
	• Masculinity preventing seeking help

• Formal support more likely to engage if accessed previously

"I was a little bit closed off as well, but they would more often talk to her about what was going on"

"I didn't go, I think there's probably two parts to it, one I was you I know, it was a lot to deal with and that was just another thing I didn't want to have to deal with, but there also is a lot of fear in that too, I'm going to have to go in there and address everything that I'm feeling, I'm better off just staying focussed on the task at hand"

"they had like a fathers group thing but the take up on that, like there was supposed to be like a coffee thing that I was going to go to but then they cancelled it because there was only two people that said yes, and they just like I don't know, don't know if it's a cultural thing or a masculinity thing that you know..."

#### SYSTEMATIC REVIEW

Experience of	• 'Different kind of support'' needed for mums and dads	"it affected my wife straight away and its obviously because she had
grief	• Need for other dads in group to normalise feelings	that physical connection with him um being in her and going
impacted by	• Hard when only dad in group ''because dads have different	through the birth whereas I was just, I almost distracted myself by
gender:	connections''	focussing on some of the medical and technical things that
differing	• Desire to connect with another dad to make sense of experience	happened and I think I was affected emotionally, in a more slow
support needs	• Want support distinguishable from mothers support	and over a longer period of time, so I think it's the different kind of
and a need	• Desire for male specific support	support.''
for gender-		
specific		"when you're the only dad and its full of you know eight or nine
support?		mums its hard because mum and dads have different connections"

# Appendix E Example Process of How Each Study Contributed to Final Review Theme 2

## Table E1

Table Displaying How Each Study Contributed to Final Review Theme 2, Including Initial Coding and Participant Quotes

Theme title	Study	Codes	Participant quotes
ʻif I talk about it, it	Hughes & Page-	Suppression of fathers feelings	'my wife wanted support, I felt the mother needed
upsets her even more':	Lieberman (1989)	and perceived hierarchy of	more support'
conflict between		support needs	
supporting and needing	McCreight, 2004	Being the supporter experienced	'I had to let her cry on me and then I would get into
support		as barrier to seeking support	the car and
			drive up into the hills and cry to myself.'
			'it took me a while to talk to Jane [partner]
			about losing the baby because I didn't think I could
			be seen to be breaking

		down crying in front of her, I mean I had to be
		strong for her'
Murphy (1998)	Being strong for partner means	'I always had to be strong, so I always put my fear
	no need to grieve or share my	to the back of my mind'
	feelings	
O'Leary & Thorwick,	Fathers as 'supporters': barrier	'I don't know what to do sometimes, I don't tell her
2006)	to sharing feelings	how I feel, every morning at 4am I'm awake, I
		don't tell her that I've been up, feel as though I
		can't, I try to support her, if I let her know that I'm
		worried then she'll think 'what are you talking
		about'
Puddifoot & Johnson	'if I talk about it, it upsets her	'mum said I should keep telling her I love her and
(1997)	even more': seeking support	stuff to make her feel better, I do all that, but no,
	seen as harming mother	and if you talk it will upset her more so its best just
		to forget it'

		'I had a bit of a weep and mum snapped at me and
		said that I was being selfish and had to pull myself
		together before I upset (susan- baby's mother)'
Samuelsson, Rådestad &	'didn't want to be sad and make	'we both wanted to protect each other and be
Segesten (2001)	her sadder': a gendered view of	careful not to hurt one another. She felt a greater
	emotion	need to talk about it, while I was actually very
		reticent. Didn't want to be sad and make her even
		sadder'
Bonnette & Broom	• Being away from the mother	'I think it was because she [wife] wasn't there and I
(2011)	allows expression of	could lose it for a minute and not feel that I'm
	emotion	going to cause her to lose it even more. I felt like if
	• Crying in front of mother,	I was with her and I lost it we would never recover.
	would lose it and never	
	recover	'So anyway I came home and I was mega-low,
		because Zoe wasn't here; Anna was not doing well,
		she was in hospital; mum and dad weren't here and

•	Being strong for others by	I was just in tears and just felt like It was like
	hiding feelings until alone	while you've got people here, like Anna and Zoe
		and you've got to be strong for them and stuff like
		that, but they were gone and I was here on my own
		'

## **Section Two: Empirical Paper**

# Fathers' relational experiences of stillbirth: Pre-natal attachment, loss and continuing bonds through use of objects

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**EMPIRICAL PAPER** 

#### Abstract

This study aimed to investigate fathers' lived experiences of stillbirth through the lens of continuing bonds, and use of objects. Semi-structured interviews were conducted with six fathers, who had experienced stillbirth from 20 weeks gestation. Interpretative phenomenological analysis of interview data revealed five themes: (1) loss and continued bonds in a mother-mediated dynamic, (2) objects as manifestations of relational and meaningful memories, (3) exerting existence and continued connection to others, (4) continued bond through physical presence, (5) evolving expressions of love and fatherhood. Findings highlight importance of involving fathers in making memories with their stillborn children and the creation of personal meaning linked to objects offered following stillbirth. The study emphasises the importance of validating and acknowledging fathers' experiences of the loss of their children, moving away from consideration of these men merely as partners of the mother who lost her own baby.

*Keywords*: Continuing bonds, fathers, interpretative phenomenological analysis, objects, stillbirth.

**EMPIRICAL PAPER** 

#### Introduction

Globally a baby is stillborn every 16 seconds (United Nations Inter-Agency Group for Child Mortality Estimation, 2020), leaving millions of parents facing perinatal bereavement. Definitions of stillbirth vary internationally and tend to arise from survival rates for birth at different weights or stages of gestation, ranging from 20 to 28 weeks (Da Silva et al, 2016; Fairbairn, 2018; World Health Organization, 2020). In response to medical advancements many now campaign for updated legal definitions of stillbirth to reflect the viability of babies lost as early as 20 weeks (Fairbairn, 2018).

There is a wealth of quantitative research into the psychological outcomes of stillbirth for mothers, which tend to investigate its impact on mental health symptomology. This research indicates that bereaved mothers experience increased anxiety following stillbirth (Campbell-Jackson & Horsch, 2014), with higher rates for mothers bereaved in the last half of pregnancy up to a month post birth, compared to mothers following a 'live birth' (Gold et al., 2014). The research also suggests bereaved mothers experience higher rates of depression (Campbell-Jackson & Horsch, 2014; Klier et al., 2002; Wall-Wieler et al., 2018) and posttraumatic stress disorder (PTSD) (Dubenetzky, 2017; Gravensteen et al., 2013). A recent systematic review of research on the psychological outcomes of stillbirth on parents, found that bereaved parents were significantly more likely to experience depression, anxiety and PTSD compared to parents following a live birth (Westby et al., 2021). This review however included only two studies with samples including fathers, limiting the review's implications for this population. There is a relative lack of research investigating psychological outcomes for fathers. However, research quantitatively investigating this in samples of mothers and fathers together offer comparisons of psychological impact between the two groups. Much of this research suggests that fathers experience these difficulties to a lesser extent, with lower rates of anxiety (Farren et al., 2018; Jones et al., 2019), depression (Lewis & Azar, 2015),

PTSD (Christiansen, 2017) as well as lower scores on measures of psychological impact for specific loss types such as miscarriage (Huffman et al., 2015).

Importantly, a systematic review of literature on men's health and wellbeing following pregnancy loss, suggested that although psychological outcomes seemed less intense and enduring compared to mothers, men were more likely to engage in increased alcohol and drug use (Due et al., 2017). This finding highlights an important critique of the quantitative literature previously explored; that the outcome measures used are perhaps more sensitive to the occurrence of psychological distress in women than men. Indeed, the hospital anxiety and depression scale is heavily used in the cited literature (Farren et al., 2018; Klier et al., 2002; Lewis & Azar, 2015), yet this does not measure substance use (Zigmond & Snaith, 1983) and has been suggested to have "questionable" validity in the male population (Nortvedt et al., 2006). More recently, a study found that fathers' scores on perinatal grief measures were indicative of a high degree of grief, following loss at any stage of gestation or birth (Obst et al., 2021). This suggests that men do not 'suffer less', rather their distress is not captured by the mental health outcome measures utilised in this research. It is also vital to highlight qualitative findings which outline a discrepancy, with quantitative findings indicating lesser distress, and fathers' reports evidencing highly emotive experiences of loss (Klier et al., 2002). Fathers report 'holding it together' to support their partner (Jones et al., 2019) and intense feelings of guilt, sadness, and emptiness (Aydin, & Kabukcuoğlu, 2021).

Qualitative research can offer insight to the experience of perinatal loss in a way that provides evidence for or challenges dominant theories of grief and bereavement. For instance, through exploring the experiences of parents, Rando (1995) made it clear that presentations of grief that were considered pathological, such as a continued emotional connection with the deceased, were in fact highly typical for bereaved parents. This experience was first coined as 'continuing bonds' by Klass, Silverman and Nickman (1996) and conceptualized the

experience parents reported of an ongoing relationship with their deceased child. Contemporary bereavement theory has continued to explore this idea, and continued bonds with the deceased has been increasingly recognised as central to the grief experience (Klass & Steffen, 2018). Although continued bonds theory is gaining recognition, empirical evidence to support their benefit is limited; for some the continued bond represents coping with bereavement but for others it may represent ongoing difficult grief reactions (Stroebe & Schut, 2005).

There is an abundance of qualitative evidence to support the theory of continuing bonds in mothers following perinatal loss (Field et al., 2013; Hunt, 2020; Jones, 2020; Yamazaki, 2010). These findings offer further challenge to historical theories of bereavement that suggest "grief work" as a requirement for adapting to a loss (Bowlby & Parkes, 1970) with importance placed on accepting the reality of the death, detaching from the deceased and reorganizing relationships with the living (Stroebe et al., 2017a). Contributing to the literature on continuing bonds in mothers is evidence for the use of objects, such as soft toys, in facilitating these continued bonds. Mothers have reported talking to their baby and interacting with objects such as footprints or photographs to feel close to their child (Yamazaki, 2010). These interactions have been conceptualized as an externalized continuing bond, where internalized continuing bond expressions involve an inner sense of closeness, as described by one mother as her child always being within her (Testoni et al., 2020). Contemporary research has also begun to consider objects collected in a grief context as transitional, with this explicit link to theory absent in previous research (Wakenshaw, 2020). Transitional objects have long been considered in children, where the attachments formed with inanimate objects facilitate a transition away from the mother (Winnicott, 1953). The use of transitional objects in bereaved parents is common and is suggested to be beneficial in coping following the loss of a child (Goldstein et al., 2020). These objects seem to facilitate the physical and

emotional aspects of parenting that are missing following perinatal loss (LeDuff, 2017), and as such may be a manifestation of two opposing concepts: a continued relationship with the baby and a transition away from them.

Though there is emerging evidence of continued bonds and use of objects in mothers, studies investigating the use of objects and continued bonds in fathers are absent. In the research that does exist, fathers report bathing, holding, and talking to their baby at the time of stillbirth and talking to and about their baby long after the loss (Bonnette & Broom, 2011). This presents some evidence for the existence of continued bonds in this group, however the use of objects was not explored. The use of objects was suggested to be beneficial for mothers and fathers in a recent review of literature on the use of transitional objects in parents experiencing perinatal bereavement (LeDuff et al., 2017). However, the balance in representation of mothers and fathers in the included studies is unclear as is the mechanism behind the effectiveness of the objects.

Despite quantitative findings that position fathers as 'suffering less', perinatal loss has a clear and substantial impact on fathers. The disparity in representation between mothers and fathers in perinatal bereavement research serves to further bias the group of research to the needs and expressions of grief for mothers. Though research has suggested expressions of continuing bonds and use of objects in fathers separately, research specifically investigating both phenomena is lacking. Furthermore, qualitative research investigating the mechanisms in which continued bonds and objects facilitate grief is sparse.

The aim of this study was therefore to qualitatively investigate fathers' lived experiences of stillbirth, through a lens of continuing bonds and use of objects.

#### Method

# Design

Given the personal and variable experience of stillbirth, it was important for the study design to identify themes reflecting the sample collectively and the varied experiences of each individual participant. Thus, Interpretative Phenomenological Analysis (IPA) was applied to data from semi-structured interviews. IPA is built upon idiographic phenomenology and hermeneutics; that is the exploration and interpretation of individual experience (Eatough & Smith, 2017). IPA involves in-depth exploration of how each participant makes sense of a given phenomenon (Smith, Flowers & Larkin, 2009) and strikes a balance between individual meaning making and similarities of experience across a group with a shared experience (Smith, 2004). IPA in this study will therefore give broad themes of fathers' experiences whilst identifying nuances of this between participants.

## **Sampling and Participants**

Participants were recruited following advertisement of the study through the professional social media accounts of the principal researcher and a set of perinatal loss charities that agreed to support recruitment. Organisations that support fathers were also contacted to request advertisement of the study within their online support groups.

Given the idiographic analyses of personal experience and inference of similarities across participants within IPA, a homogenous sample is important (Noon, 2018). For this reason, inclusion criteria specified participants must be fathers, aged 18 and above, who had experienced stillbirth from 20 weeks of gestation onwards, in the 10 years prior to interview. Fathers must also have identified as having interacted with meaningful objects, throughout this experience. In the present study stillbirth is defined as death after 20 weeks gestation in response to campaigns to update the definition from the current 24 weeks gestation in the United Kingdom, due to viability at this stage (Fairbairn, 2018). The cause of stillbirth was

not specified, allowing participants who experienced termination for foetal abnormality. The decision to include these participants was due to a shared experience of 20 weeks gestation and the birth of a deceased baby, despite variance in cause of death. Given that the psychological impact of perinatal loss seems to reduce from 6 months post-loss (Klier et al., 2002; Lewis & Azar, 2015), fathers who had experienced stillbirth in the 6 months prior to interview were excluded.

Six participants were recruited and interviewed. Five were aged between 36-45 and one participant was aged between 46-55. All participants identified as White British. The sample obtained was homogenous in terms of participants having experienced the stillbirth of their child however, each participant's personal circumstances and story of stillbirth differed as shown in Table 1.

### **Data Collection**

Participants completed an initial online survey to record their consent to take part and to provide anonymous demographic information. Interviews were conducted via Microsoft teams due to the coronavirus pandemic and consequent restrictions on face-to-face contact. The principal researcher devised an interview schedule by creating a set of questions aimed at exploring fathers' experiences of topics relevant to the research question (Appendix B). Guidance on creating an interview schedule in an IPA study was applied (Smith et al., 2009) and consultation on the interview schedule was sought from an academic researcher with experience in qualitative research and a clinical psychologist who is the patron of a perinatal loss charity. Follow-up questions not included in the schedule were asked where appropriate to obtain sufficient data to answer the research question. Interviews were recorded and transcribed verbatim.

# Table 1

Biographies of Each Participant in the Study Including a Summary of Their Experience of Stillbirth and Other Contextual Information

Pseudonym	Experience of stillbirth	Other contextual information
Nick	Nick lost his daughter at 37 weeks and 6 days in 2016.	Prior to the stillbirth, Nick had a son who is now aged 9 and has since had
		another daughter. Nick and his partner had not experienced any prior
		perinatal losses. Nick has been involved in fundraising for perinatal loss
		charities and supporting other bereaved fathers.
Phil	At 37 weeks Phil's partner felt that there was something wrong	Phil has 5 children, including a son born the week we met for the interview,
	and they unfortunately lost their daughter who was delivered a	a son born shortly after the loss of his daughter and two sons who were
	couple of days later in 2014.	aged 6 and 4 at the time of the stillbirth.
Lars	Lars and his wife were pregnant with a son who at 20 weeks	Prior to the stillbirth Lars had a son who is now aged 4. Lars and his wife
	was diagnosed with a heart condition that would make chances	also experienced multiple miscarriages including one at 11 weeks which
	of survival very slim and quality of life poor should he survive.	involved significant hemorrhaging. This meant that they had a harmony test
	Lars and his wife made the difficult decision to terminate, and	early on with the son they lost very early in the pregnancy which allowed
	their son was stillborn at 22 weeks in 2020.	them to know the gender much earlier than usual. At the time of the
		interview Lars and his wife were expecting another baby.

John	John and his then wife noticed reduced movement in the 37 <sup>th</sup>	
	week of pregnancy. Following this they attended a reassurance	
	scan and were informed that a heartbeat could no longer be	
	found. Their daughter was stillborn a few days later in 2014.	
Steve	Steve and his partner were expecting their first child together	
	in 2013. An induction had been planned for a Friday at 38	
	weeks and the Wednesday prior to this Steve' partner was	
	attending a routine appointment when he received a phone call	
	from her to ask him to come home because their son was	
	'gone'. Their son was delivered stillborn on the planned	
	induction date.	

Michael Michael and his wife found out they were pregnant with twin sons at 8 weeks gestation. Unfortunately, Michael's sons were diagnosed with twin-to-twin transfusion syndrome and were stillborn at 8 months in 2011. Prior to the stillbirth, John had 4 children and had a further child following the loss of his daughter. John and his then wife had experienced a prior miscarriage and his wife an ectopic pregnancy before they met. John and his wife went for multiple reassurance scans throughout the pregnancy. Steve has had 2 daughters following the loss of his son. In response to his experience of stillbirth, Steve became involved in charity then paid work in the field of perinatal loss.

Michael and his wife found conceiving difficult prior to finding out they were pregnant with twins after 2 years of trying. Michael and his wife had 4 children following the loss of his sons and also experienced miscarriage. Michael has found it helpful to write about his experiences through a blog and also volunteers as a befriender for other bereaved parents.

### Analysis

While there are a wide variety of authoritative texts that describe the tenets of IPA (Smith & Osborn, 2008; Shinebourne, 2011; Smith et al., 2009), as well as descriptions of how to conduct IPA (Murray & Wilde, 2020; Pietkiewicz & Smith, 2012; Smith et al., 2009), there is not one universally adopted approach. In the present study, to offer a fully auditable analysis with high adherence to the principles of IPA, the guidelines outlined by Murray and Wilde (2020) were adopted.

In a process by which each transcript was analysed individually, initial codes were created to summarise data pertinent to the research question without excluding meaning through simplification. Subsequently, codes were separated into small groups representing similarities of experience across the transcript. An example of this process is shown in Appendix C.

Thereafter, an interpretative summary was written for each group of codes that sufficiently described data through a coherent narrative. Each interpretative summary was given a title which became a theme of the data.

For the aforementioned stages of analysis, a subset of the data was analysed by the research supervisor to ensure inter-rater reliability and quality appraise the analysis. This process resulted in a reappraisal of themes with a stronger focus on the research question.

Following the analysis of each individual transcript, the researcher 'bracketed' any emerging themes to maintain ideography and avoid prior analysis creating bias in the analysis of further transcripts (Smith, Flowers & Larkin, 2009).

Finally, themes yielded across all participants were split into smaller groups of themes with similarities or relationships between them. New titles were then assigned to each group which became a final theme of the data. Appendix D displays contributing participant themes for each of the final themes of analysis.

### **Ethical Issues**

Full ethical approval for the study was obtained from the University Faculty of Health and Medicine Research Ethics Committee. To manage the potential distress of participants, warnings of this distress were given during recruitment and support was offered during and after the interview. Participants were informed that pseudonyms would be used, however participants in bereavement research have been found to request the use of their own or the deceased's name in the research, citing reasons of challenging stigma or memorializing the deceased (Scarth, 2016). For this reason, should a participant request it, they will have the opportunity to read the final set of results before giving informed consent for their chosen name to be used. All other identifying information was removed. Files containing identifiable information were stored securely.

#### Results

# Theme 1: "His Baby Didn't Die the Mum's Baby Died": Loss and Continued Bonds in a Mother-Mediated Dynamic

Most of the fathers expressed a sense of a father-infant relationship, mediated by, or viewed through a maternal lens. This experience was apparent in fathers' reports of pregnancy being physically owned by the mother with family members, friends and professionals focussing on the mother-infant relationship, neglecting the presence of a relationship between the father and his baby during pregnancy, following through to the birth experience and beyond. The fathers recounted a pregnancy in which their father-infant relationship was emotional, or "theoretical", in contrast to the physical and embodied mother-infant connection. As Steve reflected, "it's a weird one for dads isn't it because you don't have the same physical connection as the mums do so I think the bond isn't quite the same".

Steve also reflected on seminal moments in the building of a relationship with his baby prenatally that though powerful, were mediated through a physical connection with the mother: "putting your hands on your partners stomach and feeling a kick, but even then that's tangentially that's through somebody else". In this way, as Phil reflected, the first physical connection between father and infant, becomes a pivotal moment: "the memories were built once I held her. For me that's where that that's where it became real".

The fathers recounted their experiences in the hospital at the time of stillbirth, where staff offered them the opportunity to spend time with their babies. This offer was one that for some fathers, came with complication compounded by consideration of the mother's emotional needs. As conveyed by John: "trying to have that time with [baby], knowing that. That's not helping [mother] right now, 'cause of you know just how she was feeling". John expressed conflict between supporting his wife and building a relationship with his daughter, "knowing that you can't do either properly". For John this meant that he could not dress his baby: "shortly after she'd taken [baby] away I ended up sort of running around the hospital trying to find her to say, look can I, can I dress her, but they'd already done it".

Fathers tended to place more importance on the mother-infant relationship. For Lars, there was some conflict over whether this represented "denying" himself:

I did hold him a few times and things, but I didn't want to deprive her of time with him... I'm very much aware of whatever I was feeling you could probably times it by

a thousand and she would be feeling more, which might have been denying myself, I don't know.

In the time following their loss, most fathers conveyed a sense that their relationship with their baby and their level of distress and grief was subjugated to the experience of the mother. Steve reflected:

There's that sense of when your baby dies, the mum is the one that grieves and the dad's role is to look after the mum and nobody allows the dad to grieve, because that's not his job, his baby didn't die the mum's baby died.

This societal subjugation of the father-infant relationship in the context of grief serves to reinforce the conflict seen between fathers meeting their own relational needs in a mothermediated dynamic. In this way, perhaps as fathers respond to this societal view and 'deny' themselves, family members and professionals see an outward display of a 'lesser' fatherinfant relationship, despite clear internal desires from the fathers in the study to deepen their connection with their baby.

# Theme 2: "It's Connected to Your Baby but it's Not Connected to You and Your Baby Together": Objects as Manifestations of Relational and Meaningful Memories

All fathers in this study recounted experiences of a connection between objects and the father-infant relationship either through an imagined future or lived memories.

Several fathers commented on an imagined future relationship, for instance Steve reflected: "you draw back on the things that you did in anticipation of the relationship you were going to have". Steve described buying items such as a giant teddy bear, "in anticipation of plonking your child between the legs of this bear and cuddling up and reading a story". Similarly, Nick created a rug for his daughter during the pregnancy and reflected on this

object's connection to imagined memories: "when I was making it... I'd planned it all out... I'd already envisaged her being on it, taking photos of her on it, her physically being on it."

For some an exchange between father and infant was important. For Lars, this was represented in a keyring where part remained with him and part was placed with his son for cremation, "the actual heart itself they put in his hand and kept that with him while he was cremated so it could well be intact in his ashes". Others reflected on the deeply personal meaning of their collection of objects. Phil conveyed this with his memory box of poems and letters from his children to their stillborn sibling: "if I was to show them to someone else… it means nothing to them, but to me, my wife and kids, aye it means everything".

The fathers in the study conveyed the sense that this connection between objects and memories holds particular importance in the context of stillbirth, as Phil reflected:

Stillbirth is the hardest thing to take, because you have to build your own memories, likes of if someone passes away, someone who's close to you, ... you can think about them, things you've done with them, and you have them memories.

Subsequently, forging memories of father-infant interactions becomes significant. For some fathers involved in creating hand and footprints, such objects represented this shared experience, as Michael conveys: "We've got photos and handprints and 'cause those are the stories that we shared". Nick recounted not knowing when his daughter's footprints were taken, "so when I see them, I love them... but it doesn't give me a memory 'cause I wasn't there when they were being done". Similarly, Steve reflected "I don't have the experience of doing (baby's) hand and footprints, I have his hand and footprints". Steve conveys the impact of this lack of involvement where objects become void of meaning: "you just got home with a box that's full of a load of stuff and it's connected to your baby, but it's not connected to you and your baby together".

It is important to consider the objects that did not comfort fathers. John reflected that a teddy bear he received "mainly reminds me of her dying, rather than thinking of her". This contrasts Steve' experience of buying a teddy bear with his pregnant wife, conveying this as a shared memory with "the three of us". Importantly for John his desire to spend time with his stillborn baby was cut short as she was taken way to be dressed and have footprints taken. In this way, the lack of involvement in creating relational memories may have rendered objects collected as representations of his daughter's death rather than their relationship. John later created a ring with his daughter's ashes, an object that holds great significance for him. In this way to those fathers who forged meaning with objects at the time of stillbirth.

# Theme 3: "Their Death Does Not Erase Their Existence": Exerting Existence and Continued Connection to Others

All of the fathers in the study conveyed a desire for a continued bond between their baby and others. Fathers expressed desire to exert and gain acknowledgement of their baby's existence from society and their social networks. Through this, the father-infant relationship could also be acknowledged which may strengthen the fathers' continuing bond.

Their baby's perceived existence is of clear importance to the fathers, as Michael expressed: "their death does not erase their existence any more than the death of one of your family members will erase their existence". For Lars, the absence of a birth certificate was distressing: "He was about 22 weeks at that point but because he was born dead then he didn't get registered for a birth which did, I was a bit upset about... I wanted that acknowledgement". Lars powerfully reflected that if people were to trace his family history, his son would not be found and as such, this physical and legal manifestation of his son's existence through the medium of a birth certificate, becomes a powerful but absent object.

This societal dismissal seemed to filter into responses from the family and friends of the fathers in the study. Steve recalls comments from his mother, "she said I am not a grandmother yet thank you very much and what she meant was I am not a grandmother to living children yet". For Phil, the varied acknowledgement of his daughter's existence from family and friends, caused a reorganisation of the hierarchy of his social network. Phil reflects that a friend he was previously not close to became an important figure in his life because: "every year... he's the one that phones me" adding that, "my memory of my losses become part of his life".

This sense of dismissal is at clear conflict with the fathers' perceptions of their babies' personhood, as Michael expressed in early pregnancy: "we wouldn't refer to them as just like a blob or the twins, they had their own personal identity". Lars exerted his baby's personhood despite his death, "he might have died before he was born but he was still a person".

Given the conflict between fathers' perceptions of their babies' personhood and the varying acknowledgement of this by others socially and legally, the fathers in this study sought to maintain a continued bond between their baby and family and friends. Nick conveyed his daughter's presence around the home through objects as "a soft way of just reminding people that these children exist". This physical exertion of the baby's presence is also seen for Lars who expresses, "I wanted to take one of the 4 books out and give him that so that on the shelf we could always see that one was not there". Though initially this may seem a reminder of his son, the gap in the set of books is rather a statement of his son's presence through absence, a way to avoid forgetting that he is missing from the home. For some fathers, objects were used to engage their other children in a continued bond with their baby, through things like picking a present that their sibling may have liked. Michael recounts that "the children help pick out the present, what would a 10-year-old boy like?".

# Theme 4: "To Replace the Fact That She isn't Physically Here": a Continued Bond Through Physical Presence

This theme reflects four of the fathers' reports of objects representing a physical manifestation of their baby. For Steve "the physical manifestation of our baby who couldn't be here was the pinecone". Using this object, Steve was able to continue his relationship with his son after his death by taking a pinecone with him, "he can't come to my rugby matches with me because he's died, this is my way of him coming to my rugby matches with me through the medium of this pinecone". Michael felt his twin sons were represented in a teddy that his living child took on days out with him, "We said we're going out for your brother's birthday... so he packed the little backpack, and he packed the bears in them... for him, those bears... represented his brothers". The experiences of Steve and Michael contrast with the experience of John who conveyed his continuing relationship with this daughter through a tree as an object positioned in a static place to visit: "we've got somewhere to go and regardless of whether she's there or not... that's kind of like somewhere where we go to see [baby's] tree". John interacts with this object and place in a continued relationship with his daughter, particularly on special occasions "to take flowers for her birthday or Easter or Christmas". John recounted that his daughter's ashes were never scattered and so are not present at this tree however, the tree is in the gardens of the crematorium where his daughter was cremated. In this way, perhaps this tree's position represents a connection to his daughter physically, as her last position in the world before cremation.

For one father, the connection to a physical object seemed to transition over time. Nick expressed an initial connection to his daughter through the creating of a rug for her during pregnancy, he characterized the rug as "kind of growing and building as she was", suggesting this object was significantly connected to his baby. Following the birth, Nick recounted not feeling a connection with his daughter's body, "with her body, like for me it

was and it was just her body... I didn't have, I didn't have that connection". In this way his daughter's physical body is not where the father-infant relationship existed, rather it became an entity free from restricted physicality in one place. Nick describes a teddy bear that "for a while... was kind of our contact, our contact point with [baby]", suggesting that this connection had transitioned from her physical body to an object. Nick recounts interactions with this bear that mimic the interactions he may have with his daughter were she to have been born alive, "So every night we when we kiss [child] goodnight. we'd give [bear] a kiss as well". The father reflects that over time his "contact point" with his daughter transitions to a heart shaped patch of paint left in his daughter's room after it was redecorated:

I say goodnight to [child] and go in and say goodnight to [child] and then. I just kiss my hand and touch that (green heart). Uhm and yeah, it doesn't make me sad, it's just. Is. Yeah, it's just that connection.

Though the other fathers did not recount a clear transition between "contact points", perhaps the pinecone and tree represent a similar concept; the connection of their baby to themselves and the world through a physical manifestation of their presence. Through this physical manifestation, the fathers can continue their relationship with their baby by interacting with these objects in various ways.

# Theme 5: "Over Time the Relationship Shifts Too": Evolving Expressions of Love and Fatherhood

Present in all the fathers' interviews, this theme captures changing expressions of love and fatherhood, at different points across pregnancy, stillbirth and beyond. As Michael expresses, "overtime, the relationship shifts".

For Lars love was expressed in an urge to protect his son both in pregnancy "when I knew that he was ill and poorly and needed protecting I suppose, I really felt something kick

in" and after birth "when he was born and I saw him like that, that really kicked in again". For Lars the urge to protect seemed strongly connected to the roles and responsibilities of fatherhood, so much so that he wrote his son a letter after his death to say, "I was sorry I couldn't protect him like I was supposed to". In this way this expression of love through protection was manifested into the object of a letter.

For others this love was expressed through instinctual parenting of their stillborn baby. Steve reflected "it was my natural instinct as a dad to get some tissue paper and just block where his nose is bleeding". Importantly this interaction is represented by the tissue which was kept, "it's in the memory box because that tissue paper is the physical manifestation of when I wiped my sons nose when it was bleeding". For John, fatherhood was expressed through meeting his daughter's emotional needs, "I know it sounds daft, but I didn't want her to think that I didn't want to cuddle her because she wasn't born in the normal way". Importantly for Steve, there were missed opportunities to facilitate this expression of fatherhood, "one of my biggest regrets is that I never read him a story, because it never ever occurred to me". Steve was also not offered the opportunity to cut the cord and reflects: "if (baby) had been born alive somebody would have asked me if I wanted to cut the cord… it's a rite of passage for dads".

Expressions of fatherhood continued following loss. Nick reflected on running marathons for his daughter: "the stuff I do for [baby] is... more special I guess. 'cause I can't show her the love in the normal way". Others expressed love by reflecting on their baby's impact on their lives, as Phil expressed: "how can you forget someone that's such a big part of my life... changed me so much?". Michael expressed the way in which he continues a dynamic relationship with his sons:

Checking in with myself about that relationship 'cause I know one of the things I tend to do is... if I feel embarrassed... I would deflect with I miss my boys and I don't like doing that because... I don't want to use them as a shield'.

For some fathers there were clear moments in which the relationship shifted. For Phil this occurred at the birth of his last child, urging him to interact with the objects associated with his daughter:

The bond to me felt. Strongest on Friday... I just had a new baby and it was another boy and I just it just seemed to be like a feeling for me and that actually got the box out on Friday... I just felt I had to.

For John, the relationship shifted a decade after the loss of his daughter when he felt able to create an object: "I kind of really wanted to do that with the ring, and found that, like a connection that I was ready for". Importantly Michael reflected that his ongoing pain at the loss of his sons represented the love he continued to feel for them: "you're simultaneously trying to avoid pain whilst welcoming it... the pain is the reminder of the depth of love felt. The grief is the expression of that love".

This theme captures varying expressions of fatherhood including missed opportunities for this. Objects connected to such expressions became representations of the father-infant relationship. The theme conveys the dynamic nature of the ongoing relationship with fathers expressing varying levels of closeness to their baby over time.

### Discussion

The aim of this study was to qualitatively investigate fathers' lived experiences of stillbirth, through the lens of continuing bonds and the use of objects. IPA revealed 5 main

themes, which will be discussed in the context of existing research and their implications for clinical practice.

Findings indicated that the fathers in this study experienced their relationship with their baby being viewed through a mother-focused lens. This is consistent with a previous review of literature on men's experiences of pregnancy loss which found that fathers report being seen as a "partner" not a father mourning their own loss and feeling overlooked where the mother's pain was better recognised (Due et al., 2017). Fathers described a mother-infant relationship that is seen as more important than the father-infant relationship. Fathers expressed this hierarchy whilst stressing the strength of their father-infant bond, despite not sharing the same embodied connection.

Importantly, findings conveyed the father-infant relationship as mediated through the mother's physical body, adding to an emerging literature exploring fathers' prenatal attachment. Though moments in pregnancy such as feeling kicks and ultrasounds have been shown to support fathers' building attachments (Draper, 2002; Ekelin, Crang-Svalenius & Dykes, 2004), some research has suggested these experiences do not create equity between mother-infant and father-infant attachment (Harpel & Barras, 2017). The findings of the present study add a novel understanding of this, since the missing physical embodiment for fathers is unavoidable until the moment of birth and any experience in which their own attachment builds is mediated through the mother's embodiment until this point.

Despite not sharing mothers' direct embodied experience of pregnancy, the fathers in this study conveyed a deep connection with their baby. Importantly the moment this attachment was triggered varied for the fathers in the study, some felt this at the point they held their stillborn child and others this seemed linked to the baby's developing personhood during pregnancy. Indeed, some fathers in the study expressed changes to this relationship in

the years following their loss. It is known that fathers experience various "trigger points" to a building attachment with children born alive (Lagarto & Duaso, 2021), with the present study evidencing this concept in the context of stillbirth. Importantly the fathers interviewed experienced a range of pre-loss births, miscarriages and difficulties conceiving. It has been found that mothers who had experienced prior perinatal loss reported a suppression of their emotion towards their baby during pregnancy, with this experience relating to higher levels of anxiety about the pregnancy (Côté-Arsenault & Donato, 2011). It is therefore possible that the varying pre-natal attachment experiences expressed by the fathers in this study could relate to prior births, perinatal losses, or difficulties in conceiving.

This mother-mediated dynamic was also conveyed as an added complexity to the facilitation of the father-infant relationship and continued bond at the time of stillbirth. For some fathers this seemed linked to a sensed expectation of their role in supporting the mother, a finding consistent with previous research (Aydin & Kabukcuoğlu, 2021; Due et al., 2017; McGreight, 2004; Miller et al., 2019). This led some fathers to spend less time with their baby to meet the emotional needs of the mother. For others, the hierarchical placement of the mother-infant relationship in relation to the father-infant relationship meant that fathers perceived spending time with their stillborn child as depriving the mother. The fathers' representations of a hierarchy of relationships is mirrored in their reflections on societal subjugation of the father-infant relationship, consistent with a recent review highlighting the lack of social recognition of fathers' grief in the context of pregnancy loss (Obst et al., 2020). As such, a vicious cycle emerges whereby societal expectations and subjugation of fathers' grief leads initially to fathers suppressing their own needs to support the mother. Subsequently this gives the impression to an observer of a 'lesser' distress than the mother, thus continuing societal narratives surrounding the fathers' experience of perinatal loss.

In contrast to the notion of a 'lesser' father-infant relationship and subsequent 'lesser' distress, the fathers in this study conveyed the deeply meaningful and relational nature of objects collected. Though the use of objects in coping with perinatal loss is evidenced throughout the literature on mothers (Testoni et al., 2020) and through the limited literature involving fathers (Thornton et al., 2020), such research tends to position the objects as symbols or mementos that bring comfort, yet the mechanisms of their value remain unclear (LeDuff, 2017). The fathers in this study conveyed a sense that the significant objects were those permeated with memories in which they interacted with their baby either in reality or an imagined future relationship. In this way, the permeation of relational memories into objects transforms them into objects that acknowledge and confirm the existence of this relationship in a way that society negates. The literature exploring the use of objects in mothers suggests that seemingly mundane objects are transformed as they are permeated with deep, personal, and individualized meaning in a way that disrupts societal narratives of grieving, for instance through exerting a stillborn baby's existence (Fuller & Kuberska, 2020). Themes one and two of this study together offer evidence for this phenomenon in fathers, where the subjugation of the father-infant relationship is challenged with objects that represent memories of the relationship offering physical confirmation of its existence.

This connection between objects and highly personal meaning seemed particularly poignant in the context of memory making. The fathers in the study lost not only their baby but a lifetime of shared memories. In this way, the fathers forged their own memories, whether immediately with their stillborn baby or in the years after their death and manifested such memories into objects. Though consistent with research in mothers of stillborn babies that positioned objects as "memory triggers" (Bremborg & Rådestad, 2013), and research in mothers and fathers that positions objects as evidence of the baby's existence and affirmed parenthood (Thornton et al., 2020), the present study adds a novel understanding of objects as

connected to the father-infant relationship through a link with either an interaction with father, infant and object or an imagined future relationship in which the object featured.

The fathers in this study expressed a yearning to exert their babies' existence in the world and facilitate the continued bond between their stillborn baby and those around them. The fathers expressed distress when their babies' existence went unacknowledged by family and friends, supporting research that positions perinatal loss as a "disenfranchised grief", a loss that goes unacknowledged by society (Sawicka, 2017). Such research tends to focus on the experiences of mothers, although the present study found similarities in fathers' experiences. Crucially, a unique aspect of fathers' experiences relates to the way in which their fatherhood remains largely unacknowledged, adding a second layer to the disenfranchisement in which both their bereavement and identity as a father are invalidated. This combination of experiences is positioned as "double disenfranchisement" in Obst et al's (2020) theoretical model of paternal perinatal grief.

In the present study, fathers seemed to push against "disenfranchisement", through the facilitation of continued bonds between their baby and others and exerting their baby's existence as well as the presence of the father-infant relationship. The fathers achieved this through use of objects. For one father, the removal of an item from a set signaled his sons presence through absence, consistent with the proposed theory of "materialised absence" whereby the concept of absence is formalized through material objects (Hallam & Hockey, 2001). For others, objects in the home served to remind others of their baby's existence. In either case, since the objects most meaningful to fathers seem linked to relational memories, the use of such objects in exerting their babies' existence serves also to exert the existence of the ongoing father-infant relationship. These efforts to push against disenfranchisement by exerting continued bonds is something not yet explicitly explored in the literature and adds depth to the understanding of fathers' relational experiences of stillbirth.

For some of the fathers in the present study, objects took on a physical representation of their stillborn child allowing the use of such objects in the facilitation of a continued bond in day-to-day life. In the adult bereavement literature, some researchers have theorized that such objects are a materialization of the deceased used as "a way of reclaiming and rehousing... the remains of a life now gone" (Gibson, 2004, p. 297). The findings of the present study evidence the use of objects in this way for fathers, who rehoused their stillborn babies through objects within the home. However, the findings further this theory by evidencing the use of this object, their "rehoused" baby, in expressions of a continued relationship with objects traveling with fathers in life activities. The findings of the present study therefore provide a novel conceptual link between objects and continued bonds, where objects facilitate continued bonds through being a physical representation of the stillborn child.

This concept of an object as a physical manifestation of the stillborn child can be further understood as transitional, where an object is used to manage the emotional toll of separation from a significant other (Winnicott, 1953). Applying this theory to bereavement can offer some explanation as to the power of objects to the bereaved. Though there is abundant evidence of the use of objects as mementos and symbols by the bereaved, evidence explicitly linking this to transitional objects is lacking (Wakenshaw, 2020). In the present study, fathers interacted with objects in a way that managed the inevitable distance between themselves and their baby. The diminishing importance of certain objects over time is also seen, with alternative objects or rituals taking their place, consistent with Winnicott's (1953) theory in which transitional objects lose importance over time as the child gains safety away from the parent. However, it is also important to consider one father's expression that ongoing pain and grief represents the depth of love felt, with objects triggering expression of this emotion and pain. In this way, objects offer an opposing function to a transitional object,

through welcoming pain to remain close and express the closeness of the ongoing relationship. This raises an important consideration for the expected outcome of offering bereaved parents objects to support their grieving. Though it is clear from the findings of the present study that such objects are important to fathers and hold great personal significance and meaning, it is not clear whether the provision of such objects reduces distress and whether we should expect this or expect the facilitation of emotion and pain which represents the continuing relationship. This offers an important consideration in the idea that a continued bond may represent an ongoing grief reaction (Stroebe & Schut, 2005), that perhaps ongoing distress related to a continued bond is an ongoing positive expression of love rather than a negative grief reaction.

For some fathers in the present study the continued father-baby relationship shifted over time, as a result of life events like the birth of a new baby or the changing emotional state and 'readiness' of the father to engage with the relationship and objects. This is consistent with the proposed shifts in transitional objects, in which the object facilitates separation whilst being a source of closeness in times of distress or difficulty (Winnicott, 1953). This suggests objects are transitional, dynamic, and shift parallel with the continued bond that shifts and changes, as it would if the babies were born alive.

The father-baby relationship also seemed to shift over time in relation to expression of fatherhood, through interactions linked to their roles and responsibilities as fathers. Such expressions of fatherhood in the context of stillbirth are evident in the existing research where fathers bathe and dress their stillborn babies (Bonnette & Broom, 2011). The present study adds a depth to this understanding through its link to objects, whereby the fathers held onto objects that were manifestations of these expressions of instinctual parenting. These expressions continued long after the time of stillbirth with fathers expressing love for their children in varying ways.

### **Clinical Implications**

In considering the immediate context of stillbirth, hospital staff should facilitate acts of fatherhood such as cutting the cord or reading a story to their baby. Subtle adaptations to the provision of objects at this time, such as involving fathers in creating them and encouraging a process of personal meaning making, rather than providing a standard set of objects, will go some way to improving fathers' experiences of stillbirth. Furthermore, given fathers' reports of feeling the father-infant relationship is ignored, hospital staff should acknowledge and validate fathers as fathers, grieving the loss of their child, not merely the partner of a mother who lost her baby.

Though important, clinical implications for hospital staff represent a contained period of a father's journey of stillbirth. Following the loss, many professionals may work with fathers broadly or directly through bereavement work. Findings indicate the importance of these professionals validating the existence of the baby and the father-infant relationship which continues post-loss. Importantly, one father created an object several years following his loss and as such professionals can support fathers in engaging with objects at any point post-stillbirth.

### **Limitations and Implications for Future Research**

The present study has strength in the richness it adds to the existing research regarding fathers' deeply personal, meaningful, and relational use of objects within the context of stillbirth.

Nevertheless, the study has some limitations, particularly in the sample's bias to white British and westernized experiences of bereavement. It is important that professionals supporting fathers experiencing stillbirth listen to and consider the fathers' own cultural, individual, and possible traditional rituals and practices within bereavement (Hamilton et al.,

2022). It is important not to assume the findings present a universal way in which fathers experience stillbirth. Furthermore, all fathers in the study identified as male, cisgender, heterosexual fathers. In this way, the findings cannot be generalized to the experiences of fathers with different gender and sexual identities.

It is important to acknowledge the variance in the time elapsed since the fathers' children were stillborn. Those who experienced stillbirth almost a decade ago has markedly different experiences than those who experienced stillbirth in the past year. Bereavement care has developed significantly in this time and as such some of the practices described in this study may be less prevalent in bereavement care today. Nevertheless, the findings add depth to the understanding of how fathers experience relationships with their stillborn baby and the use of objects, across various provisions of aftercare and support from professionals.

Future research should explore the relational experiences of stillbirth and use of objects in culturally, gender and sexually diverse samples. Just as the experiences of fathers in the current study are "double disenfranchised" in the subjugation of perinatal bereavement and fathers in a female dominated field, the larger scale societal subjugation of these groups could be explored in relation to the added disenfranchisement fathers face in their bereavement. The continued bond between the baby and wider family and society was also an important finding. Future research could qualitatively explore the personal meaning making siblings, grandparents and other family members make of the continued relationship and use of objects.

### References

Aydin, R., & Kabukcuoğlu, K. (2021). Fathers' Experiences of Perinatal Loss: A Sample Meta-Synthesis Study. *Journal of Family Issues*, 42(9), 2083-2110. https://doi.org/10.1177/0192513X20966002

Bonnette, S., & Broom, A. (2011). On grief, fathering and the male role in men's accounts of stillbirth. *Journal of Sociology*, 48(3), 248-265. https://doi.org/10.1177/1440783311413485

- Bowlby, J., & Parkes, C. M. (1970) Separation and loss within the family. In E. J. Anthony &
  C. Koupernik (Eds.), *The child in his family: International Yearbook of Child Psychiatry and Allied Professions* (pp. 197-216). New York: Wiley.
- Bremborg, A. D., & Rådestad, I. (2013). Memory triggers and anniversaries of stillborn children. Nordic Journal of Religion and Society, 26(2), 157-174. https://doi.org/10.18261/ISSN1890-7008-2013-02-04
- Campbell-Jackson, L., & Horsch, A. (2014). The psychological impact of stillbirth on women: A systematic review. *Illness, Crisis & Loss*, 22(3), 237-256. https://doi.org/10.2190/IL.22.3.d
- Christiansen, D. M. (2017). Posttraumatic stress disorder in parents following infant death: A systematic review. *Clinical Psychology Review*, 51, 60-74. https://doi.org/10.1016/j.cpr.2016.10.007
- Côté-Arsenault, D., & Donato, K. (2011). Emotional cushioning in pregnancy after perinatal loss. *Journal of Reproductive and Infant Psychology*, 29(1), 81-92. <u>https://doi.org/10.1080/02646838.2010.513115</u>

Da Silva, F. T., Gonik, B., McMillan, M., Keech, C., Dellicour, S., Bhange, S., Tila, M., Harper, D. M., Woods, C., Kawai, A.T., Kochar, S., Munoz, F.M., & Brighton Collaboration Stillbirth Working Group. (2016). Stillbirth: Case definition and guidelines for data collection, analysis, and presentation of maternal immunization safety data. *Vaccine*, 34(49), 6057-6068.

https://doi.org/10.1016/j.vaccine.2016.03.044

- Draper, J. (2002). 'It was a real good show': the ultrasound scan, fathers and the power of visual knowledge. Sociology of Health & Illness, 24(6), 771-795. https://doi.org/10.1111/1467-9566.00318
- Dubenetzky, S. Y. (2017). Stillbirth: Psychosocial Implications of an Unrecognized Issue. *Journal of Prenatal & Perinatal Psychology & Health*, 31(3). <u>https://birthpsychology.com/journals</u>
- Due, C., Chiarolli, S., & Riggs, D. W. (2017). The impact of pregnancy loss on men's health and wellbeing: a systematic review. *BMC pregnancy and childbirth*, 17(1), 1-13. <u>https://doi.org/10.1186/s12884-017-1560-9</u>
- Eatough, V., & Smith, J. A. (2017) Interpretative phenomenological analysis. In: Willig, C. & Stainton-Rogers, W. (Eds.) *The SAGE Handbook of Qualitative Research in Psychology Second Edition*. pp. 193-211. SAGE.
- Ekelin, M., Crang-Svalenius, E., & Dykes, A. K. (2004). A qualitative study of mothers' and fathers' experiences of routine ultrasound examination in Sweden. *Midwifery*, 20(4), 335-344. https://doi.org/10.1016/j.midw.2004.02.001
- Fairbairn, C. (2018). Registration of stillbirth (05595). House of commons library. <u>https://www.parliament.uk/globalassets/documents/commons-library/Registration-of-</u> stillbirth-SN05595.pdf

- Farren, J., Mitchell-Jones, N., Verbakel, J. Y., Timmerman, D., Jalmbrant, M., & Bourne, T. (2018). The psychological impact of early pregnancy loss. *Human Reproduction Update*, 24(6), 731-749. https://doi.org/10.1093/humupd/dmy025
- Field, N. P., Packman, W., Ronen, R., Pries, A., Davies, B., & Kramer, R. (2013). Type of continuing bonds expression and its comforting versus distressing nature:
  Implications for adjustment among bereaved mothers. *Death Studies*, 37(10), 889-912. https://doi.org/10.1080/07481187.2012.692458
- Fuller, D., & Kuberska, K. (2020). Outside the (memory) box: how unpredictable objects disrupt the discourse of bereavement in narratives of pregnancy loss. *Mortality*, 27(1), 1-17. <u>https://doi.org/10.1080/13576275.2020.1783221</u>
- Gibson, M. (2004). Melancholy objects. *Mortality*, *9*(4), 285-299. https://doi.org/10.1080/13576270412331329812
- Gold, K. J., Boggs, M. E., Muzik, M., & Sen, A. (2014). Anxiety disorders and obsessive compulsive disorder 9 months after perinatal loss. *General hospital psychiatry*, 36(6), 650-654. <u>https://doi.org/10.1016/j.genhosppsych.2014.09.008</u>
- Goldstein, R. D., Petty, C. R., Morris, S. E., Human, M., Odendaal, H., Elliott, A. J.,
  Tobacco, D., Angal, J., Brink, L., & Prigerson, H. G. (2020). Transitional objects of
  grief. *Comprehensive psychiatry*, 98, 152161.
  https://doi.org/10.1016/j.comppsych.2020.152161
- Gravensteen, I. K., Helgadóttir, L. B., Jacobsen, E. M., Rådestad, I., Sandset, P. M., & Ekeberg, Ø. (2013). Women's experiences in relation to stillbirth and risk factors for long-term post-traumatic stress symptoms: a retrospective study. *BMJ open*, 3(10), <u>http://dx.doi.org/10.1136/bmjopen-2013-003323</u>

- Hallam, E., & Hockey, J. (2001). *Death, Memory and Material Culture. Routledge*. https://doi.org/10.4324/9781003085164
- Hamilton, S., Golding, B., & McCarthy, J. R. (2022). Do we need to decolonise bereavement studies?. *Bereavement*, 1. <u>https://doi.org/10.54210/bj.2022.20</u>
- Harpel, T. S., & Barras, K. G. (2017). The impact of ultrasound on prenatal attachment among disembodied and embodied knowers. *Journal of Family Issues*, 39(6), 1523-1544. <u>https://doi.org/10.1177/0192513X17710774</u>
- Huffman, C. S., Schwart, T. A., & Swanson, K. M. (2015). Couples and miscarriage: The influence of gender and reproductive factors on the impact of miscarriage. *Women's Health Issues*, 25(5), 570-578. <u>https://doi.org/10.1016/j.whi.2015.04.005</u>
- Hunt, C. (2020). Narratives of loss and resolution: Continuing bonds in the maternal experience of stillbirth. [Doctoral dissertation, University of London]. City research online. <u>https://openaccess.city.ac.uk/id/eprint/25595/1/</u>
- Jones, E. E. (2020). *Continuing bonds: parent's experience of an ongoing relationship with their sillborn baby.* [Doctoral dissertation, University of Sunderland]. Sure Sunderland. https://sure.sunderland.ac.uk/id/eprint/11544/
- Jones, K., Robb, M., Murphy, S., & Davies, A. (2019). New understandings of fathers' experiences of grief and loss following stillbirth and neonatal death: a scoping review. *Midwifery*, 79 (102531). https://doi.org/10.1016/j.midw.2019.102531
- Klass, D., Silverman, P. R., & Nickman, S. (1996). *Continuing bonds: New understandings of grief.* Taylor & Francis.
- Klass, D., & Steffen, E. M. (2018). *Continuing bonds in bereavement: New directions for research and practice*. New York: Routledge.

Klier, C. M., Geller, P. A., & Ritsher, J. B. (2002). Affective disorders in the aftermath of miscarriage: a comprehensive review. *Archives of Women's Mental Health*, 5(4), 129-149. https://doi.org/10.1007/s00737-002-0146-2

Kübler-Ross, E. (1973). On death and dying. Routledge.

Lagarto, A., & Duaso, M. J. (2021). Fathers' experiences of fetal attachment: A qualitative study. *Infant Mental Health Journal*, 43(2), 328-339. https://doi.org/10.1002/imhj.21965

- LeDuff, L. D., Bradshaw, W. T., Blake, S. M., & Ahern, K. (2017). Transitional objects to facilitate grieving following perinatal loss. *Advances in Neonatal Care*, 17(5), 347-353. https://doi.org/10.1097/ANC.00000000000429
- Lewis, J., & Azar, R. (2015). Depressive symptoms in men post-miscarriage. Journal of Men's Health, 11(5). https://doi.org/10.31083/jomh.v11i5.12
- McCreight, B. S. (2004). A grief ignored: Narratives of pregnancy loss from a male perspective. Sociology of Health & Illness, 26(3), 326–350. <u>https://doi.org/10.1111/j.1467-9566.2004.00393.x</u>
- Miller, E. J., Temple-Smith, M. J., & Bilardi, J. E. (2019). There was just no-one there to acknowledge that it happened to me as well': A qualitative study of male partner's experience of miscarriage. *PLoS ONE*, *14*(5). https://doi.org/10.1371/journal.pone.0217395
- Murray, C. D., & Wilde, D. J. (2020). Thinking about, doing and writing up research using interpretative phenomenological analysis. In *Handbook of Theory and Methods in Applied Health Research*. (1<sup>st</sup> ed., pp. 140-167). Edward Elgar Publishing.
   <a href="https://doi.org/10.4337/9781785363214.00015">https://doi.org/10.4337/9781785363214.00015</a>

Noon, E. J. (2018). Interpretive phenomenological analysis: An appropriate methodology for educational research. *Journal of Perspectives in Applied Academic Practice*, 6(1). https://www.researchgate.net/profile/Edward-Noon-

2/publication/324866327\_Interpretive\_Phenomenological\_Analysis\_An\_Appropriate \_Methodology\_for\_Educational\_Research/links/5ae88c440f7e9b837d3ae8db/Interpre tive-Phenomenological-Analysis-An-Appropriate-Methodology-for-Educational-Research.pdf

Nortvedt, M. W., Riise, T., & Sanne, B. (2006). Are men more depressed than women in Norway? Validity of the Hospital Anxiety and Depression Scale. *Journal of psychosomatic research*, 60(2), 195-198.

https://doi.org/10.1016/j.jpsychores.2005.07.002

- Obst, K. L., Due, C., Oxlad, M., & Middleton, P. (2020). Men's grief following pregnancy loss and neonatal loss: a systematic review and emerging theoretical model. *BMC pregnancy and childbirth*, 20(1), 1-17. https://doi.org/10.1186/s12884-019-2677-9
- Obst, K. L., Oxlad, M., Due, C., & Middleton, P. (2021). Factors contributing to men's grief following pregnancy loss and neonatal death: further development of an emerging model in an Australian sample. *BMC Pregnancy and Childbirth*, 21(1), 1-16. <u>https://doi.org/10.1186/s12884-020-03514-6</u>

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological journal*, 20(1), 7-14.

https://www.researchgate.net/publication/263767248\_A\_practical\_guide\_to\_using\_In terpretative\_Phenomenological\_Analysis\_in\_qualitative\_research\_psychology

- Rando, T. A. (1995). Grief and mourning: Accommodating to loss. In H. Wass & R. Neimeyer (Eds.), *Dying: Facing the Facts* (pp. 211-242). Washington, DC: Taylor and Francis.
- SANDS (2021, October 12). Sands United FC. SANDS. https://www.sands.org.uk/getinvolved/sands-united-fc
- Sawicka, M. (2017). Searching for a narrative of loss: interactional ordering of ambiguous grief. *Symbolic Interaction*, 40(2), 229-246. https://doi.org/10.1002/symb.270

Scarth, B. J. (2016). Bereaved participants' reasons for wanting their real names used in thanatology research. Research Ethics, 12(2), 80-96. https://doi.org/10.1177/1747016115599569

Shinebourne, P. (2011). The Theoretical Underpinnings of Interpretative Phenomenological Analysis (IPA). *Existential Analysis*, 22(1). <u>https://link.gale.com/apps/doc/A288874145/HRCA?u=anon~a9bd21e2&sid=googleS</u> <u>cholar&xid=241cc024</u>

Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1(1), 39-54.
<a href="https://www.tandfonline.com/doi/citedby/10.1191/1478088704qp0040a?scroll=top&n">https://www.tandfonline.com/doi/citedby/10.1191/1478088704qp0040a?scroll=top&n</a> eedAccess=true

- Smith, J. A., Flowers, P., & Larkin, M. (2009). Interpretative Phenomenological Analysis: Theory, Method and Research. SAGE.
- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In S. A. Smith (Eds.) *Qualitative psychology: a practical guide to methods* (pp. 53-80). London: Sage.

- Stroebe, M., & Schut, H. (2005). To continue or relinquish bonds: A review of consequences for the bereaved. *Death studies*, 29(6), 477-494. https://doi.org/10.1080/07481180590962659
- Stroebe, M., Schut, H., & Boerner, K. (2017). Cautioning health-care professionals: Bereaved persons are misguided through the stages of grief. *OMEGA-Journal of death and dying*, 74(4), 455-473. https://doi.org/10.1177/0030222817691870
- Stroebe, M., Schut, H., & Boerner, K. (2017a). Models of coping with bereavement: an updated overview. *Psychology Studies*, 38(3), 582-607. https://doi.org/10.1080/02109395.2017.1340055
- Testoni, I., Bregoli, J., Pompele, S., & Maccarini, A. (2020). Social Support in Perinatal Grief and Mothers' Continuing Bonds: A Qualitative Study with Italian Mourners. *Affilia*, 35 (4). https://doi.org/10.1177/0886109920906784
- Thornton, R., Nicholson, P., & Harms, L. (2020). Creating evidence: Findings from a grounded theory of memory-making in neonatal bereavement care in Australia. *Journal of Pediatric Nursing*, 53, 29-35. https://doi.org/10.1016/j.pedn.2020.04.006
- United Nations Inter-Agency Group for Child Mortality Estimation. (2020). A Neglected Tragedy: The global burden of stillbirths. https://data.unicef.org/resources/aneglected-tragedy-stillbirth-estimates-report/

Wakenshaw, C. (2020). The use of Winnicott's concept of transitional objects in bereavement practice. *Bereavement Care*, 39(3), 119-123. https://doi.org/10.1080/02682621.2020.1828770

- Wall-Wieler, E., Roos, L. L., & Bolton, J. (2018). Duration of maternal mental health-related outcomes after an infant's death: A retrospective matched cohort study using linkable administrative data. *Depression and Anxiety*, 35(4), 305-312.
  https://doi.org/10.1002/da.22729
- Westby, C. L., Erlandsen, A. R., Nilsen, S. A., Visted, E., & Thimm, J. C. (2021).
  Depression, anxiety, PTSD, and OCD after stillbirth: a systematic review. *BMC pregnancy and childbirth*, 21(1), 1-17. <u>https://doi.org/10.1186/s12884-021-04254-x</u>
- Winnicott, D. W. (1953). Transitional objects and transitional phenomena: A study of the first not-me possession. *The International Journal of Psycho-Analysis*, 34 (89).
   https://ashrampsy.com/wp-content/uploads/2021/02/winnicott.pdf
- World Health Organization. (2020, October 8). One stillbirth occurs every 16 seconds, according to first ever joint UN estimates. <u>https://www.who.int/news/item/08-10-</u> <u>2020-one-stillbirth-</u>occurs-every-16-seconds-according-to-first-ever-joint-unestimates
- Yamazaki, A. (2010). Living with stillborn babies as family members: Japanese women who experienced intrauterine fetal death after 28 weeks gestation. *Health Care for Women International*, 31(10), 921-937. <u>https://doi.org/10.1080/07399332.2010.503289</u>
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta psychiatrica scandinavica*, 67(6), 361-370. <u>https://doi.org/10.1111/j.1600-0447.1983.tb09716.x</u>

# Appendix A

### **Omega Journal of Death and Dying Instructions to Authors**

# **Instructions for Authors**

Manuscripts can be submitted in APA style to https://mc.manuscriptcentral.com/omega.

Please refer to the latest Publication Manual of the American Psychological Association. A synopsis of this manual is available from the American Psychological

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### **Appendix B**

### **Interview Schedule**

### Overview

The interview will cover the following topics:

- 1. Experiences of building relationships in pregnancy
- 2. Experiences of stillbirth itself (how did fathers relate to the baby within this)
- 3. Experience of relationship with the baby following the loss (both immediate and long term)
- 4. Exploration of the use of objects at each stage outlined above

If the following topics have not arisen naturally as part of the interview, fathers will also be asked about:

- 1. Prior perinatal losses
- 2. Any other children they are a father to

The inclusion of questions about prior loss and/or living children could convey the distressing message of 'at least you have other children' if not handled sensitively. As such, these questions will be asked sensitively with a message such as:

'The experience of stillbirth is a difficult one no matter what your circumstance. Often it is assumed that the experience is 'easier' if you have living children or are able to become pregnant again. In reality, everybody experiences difficult events like this in varied ways and where for some this would bring comfort, for others it may do quite the opposite. Nevertheless, for the study to appraise these issues, it is important to have a sense of the broad experiences of the participants in terms of prior perinatal losses, live births and the presence of living children.'

### **Interview Schedule**

**1. Introduction Points** Introduce self. Ensure participant has found safe space to complete interview and feels comfortable talking about personal things in this space. Ensure participant has read and understood the participation information sheet. Give time to ask questions about this. Gain verbal consent to complete the interview. Remind the participant of the confidentiality agreement, obtain verbal consent for this. 2. Introductory question (to give Could you tell me your story of stillbirth, from when open opportunity to tell story you found out you were going to have a baby, up until before prompts for further the loss and what happened afterwards? information)

This will be followed with prompt questions covering the topics of

the interview:

3. Experiences of building relationships in pregnancy

Could you tell me a bit about your experience of forming a relationship with your baby during the pregnancy?

Could you tell me a bit about what this relationship in pregnancy meant to you? Could you tell me a bit about anything that helped or got in the way of you forming this relationship? Could you tell me about any objects that you collected/used during pregnancy to build this relationship of feel close to your baby?

Prompt- some parents collect baby toys orclothesor the ultrasound scans etc. and eitherhold these orsmell these or just keep them nearby tofeel close totheir baby, is there anything like this thatyou usedto feel close?Could you tell me about anything else you did to feel

Could you tell me about anything else you did to feel close to your baby?

*Prompt-* sometimes parents don't use objects, but do things like feel the baby kicking, talk to the baby in mums belly, sing songs to the baby etc. as a way of interacting with them/connecting to them, did you do anything like this during the pregnancy?

Sometimes, people can identify the point at which they felt like a father to their child, or felt that connection as a father and child, did you have this moment? can you tell me a bit more about this moment?

## 4. Experiences of stillbirth itself

Questions in this section will begin with a sensitive reminder that the participants do not have to share anything that doesn't feel comfortable, can share things at their own pace, and ask to move onto the next topic at any point should they wish to. I will not ask any questions directly about the stillbirth to leave the amount of detail shared up to the participant and their level of comfort/their appraisals of what is important to share about their experience.

I wonder if you could tell me about the time leading up to the point you discovered that your baby had passed away?

Could you tell me about how you felt around the time you found out your baby had passed away? Would you be able to tell me about your feelings towards/connection with the baby at the time you found out they had passed away?

did these feelings change at all over time? Thinking about the relationship you described to me that you built in the pregnancy, could you tell me a bit about your thoughts/feelings/experience of this throughout the stillbirth?
 Thinking about the ways you built this relationship
 (objects/practices), did you use these (objects/practices)
 throughout the stillbirth?
 If so: what impact did that have?
 What did it mean to you to be able to hold onto this
 object through this experience?
 Can you tell me about any ways you felt close (or tried to feel close) to the baby during the stillbirth?
 **Experience of relationship with** If wonder if you could describe the time after the loss to me, what was this like?

Could you tell me about any of the ways you managed with the emotional impact of this? Can you tell me about any of the ways that you have maintained a connection/relationship with your baby? What has this meant for you? Can you tell me a bit about how this continued connection/relationship has changed over time?

If you still engage with (objects/practices), what does this mean to you?

Are there any new objects or practices that you have come to associate with your baby/the relationship?

Thinking about everything we've spoken about so far and the journey from pregnancy to now, could you tell me a bit about how things between you and the baby have changed over time?

What sense do you make of these changes?

6. Other information, if this has not arisen naturally

'The experience of stillbirth is a difficult one no matter what your circumstance. Often it is assumed that the experience is 'easier' if you have living children or are able to become pregnant again. In reality, everybody experiences difficult events like this in varied ways and where for some this would bring comfort, for others it may do quite the opposite. Nevertheless, for the study to appraise these issues, it is important to have a sense of the broad experiences of the participants in terms of prior perinatal losses, live births and the presence of living children.'

Could you tell me a bit about other children you had prior to this baby (name)?

7. Debrief

Could you tell me a bit about any other experiences you have of losing a baby?

Participants will be asked how they are feeling, and how they found the interview. The debrief sheet will be outlined to the participant and emailed following the interview.

# Appendix C

# **Example of Interpretative Phenomenological Analysis from One Participant**

# Table C1

# Initial Data Coding: Extract from Lars' Transcript Alongside Initial Codes

Transcript Exert	Initial Coding
1 P: oh we, so we got, sorry, yeah we went in the next day, and they just induced [wife] a	• Impact of not registering the birth, comfort in name
little bit, and then erm, they gave us a nice separate suite if you like, a room of our own	written for this reason, confirming his existence 'I like
which was sort of our home for 24 hours, yeah he was delivered, he was, they obviously	seeing his name written down now, like he did exist'
had to check for you know birth certificate legal reasons and things, because he was right	
on the cusp of the date, I think he was about 22 weeks at that point but because he was	• Wanted acknowledgement of son's existence
born, erm, born dead then he erm didn't get registered for a birth, which did, I was a bit	- Wanted acknowledgement of son 5 existence
upset about well not upset but I felt it was a bit of a shame because I wanted that	
acknowledgement. So then, erm, because of that I think I do like seeing his name written	
down now, like he did exist	

2 I: what does it mean to you when you see his name written down, what does it kind of make you feel when you see it?

3 P: ah it just, yeah it just gets me right there [gesture to chest], I think because we'd, you know, you look at lists of names and it becomes a visual and you're like yeah that one, that one there, that's gonna be his name, and you start imagining, you see his name his full name with his surname, thinking of his name and our little boy (name)'s name together and thinking yeah they look good together, and yeah I dunno its funny his name (name) it just er, the word stars gets me as well. Erm, and we erm, I'm sure we'll come onto it as you specifically mentioned objects, but we had a little star made, for a Christmas decoration with (name) written in the middle, so we're gonna get that out every year, but yeah just seeing a star now will set me off.

• Assigning personhood in utero through his name

- Imagining a future
- Linking baby's name to his brother's. forging family relationships in pregnancy.

• Objects representing and/or including the baby's actual

name in them becoming a symbol for the baby

4 I: like a symbol of him?

5 P: yeah a little bit yeah, and erm, I very much, quite odd, early on, I very much found solace in sad songs, and erm and er yeah I dunno I just liked songs that made me feel you know, and I found comfort in the songs and lyrics and I was finding meaning in songs that were not written to be that kind of meaning, but there was, there was a couple of songs, one of them specifically mentioned in the stars as well, yeah that was but I don't think for me , I don't think it was about heavenly, celestial, it think it was just the spelling of the word, I think it was the fact that it rhymed and the last 3 letters were the same, which is quite odd

6 I: yeah it makes sense. So if its alright with you I might kind of just go through the journey from start to end and kind of maybe explore little bits of each bit along the way, so we've already talked a little bit about.. it sounds like when you chose his name (name) that kind of that gave a bit of, I suppose you were saying it was a really lovely experience to get excited about that so I suppose I was just wondering about the experience of

- Finding solace in sad songs that evoke feelings 'I like songs that make me feel'
- Non-physical manifestation of symbol that can hold the same power as a physical object

• Objects logically representing the baby rather than spiritual symbology

pregnancy itself and kind of how you built a sort of relationship with (name) whilst he was sort of, well while in pregnancy?

7 P: yeah, erm, that's quite interesting, I suppose erm having the woodly experience, having, you know we were lucky enough to already have (name) and during that pregnancy I was excited and kind of time seemed to go slow but very much kind of like a thinking about what this meant for life, this is a life changing event, life is never going to be the same again and everyone is telling you these things and erm, I dunno I suppose its the sense of impending doom almost, people make it sound like, you're gonna.. you know.. ooh well you've done it now, erm. Kind of a , I dunno a erm, I dunno, no going back kind of feeling, but erm, but erm yeah I was excited and very happy and he was planned it was deliberate, but I did, I didn't feel a I dunno, I didn't know it at the time but when he was born, I didn't sort of love him straight away if you like, it took it really did take me about 6 months to really I dunno feel that bond or connection, like I knew it was my job to look after him and protect him and my wife but I dunno it was almost like I was very happy to take a back seat and let my wife and him bond because I knew that was the

 Previous pregnancy experience building new expectations for life, losing aspects of current life and preparing for this

• In previous pregnancy (live child) took time to form connection and bond

most important relationship and I think I didn't want toi impede that in any way by getting in the way, so er, yeah I dunno, because I have very close relationship with my mum and when I was a kid a fairly distant relationship with my dad, in terms of, he lived. You know we all lived together, they still live together, but erm he worked a lot, he was a farmer actually, so er long hours and things like that and like just a bit, you know, a bit gruff, so er, when I was a kid he didn't really know how to er, I dunno how to... he's terrible with kids I think, you know, he just doesn't get them, erm, so suddenly when you turn 18 he knows how to speak to you and its like where have you been all my life. So erm, so yeah, I was keen for, erm I dunno, I suppose I felt like that never did me any harm and I was always very grateful to have this very close relationship with my mum so and er I suppose I just figured that that's important because that's my only reference point really. Erm, but yeah and then erm, so with that in mind erm with, that was while [wife] was pregnant with X, I was more conscious of that I suppose, but erm, but yeah really excited about us having a more complete family if you like, we spoke about how we wanted another child so that when we're old and decrepid and even gone, that F will have a you know, a sibling

 Knew logically that job as father is to look after and protect- logical but not emotional connection there initially

• Taking a back seat to allow mother and baby to bond as that's 'the most important relationship'

 Own childhood as reference point for mother-son relationship coming above father-son and knowing that this did him (dad interviewed) no harm

and someone close, erm and I mean my wife is actually pregnant again now, she's 16

weeks pregnant...

• Importance of baby's relationship in the wider family,

with sibling more so than himself as parent

# Table C2

# Audit Trail for Lars's Transcript Displaying the Process of Initial Codes Being Grouped into Themes with Title's and Narrative Summaries

Codes grouped in the theme	Theme title	Narrative summary	Illustrative quotes
• Appraisal of building relationship in	'I was very	This theme encompasses codes that	'as a result of that test (harmony test)
pregnancy as 'getting carried away' (page 2,	happy to take a	highlight the many complexities,	we then knew the sex of the baby,
code 6)	back seat': a	dilemmas and difficulties in building a	earlier than the 20 week scan, so we'd
• 'getting hopes up' and sharing the news of	hierarchy of	relationship with your baby within the	got carried away and picked a name'
pregnancy seen as stupid/silly (page 3, code	parent-infant	context of prior perinatal losses, as well as	
8)	relationships	during relational experiences in a current	'and then had this really strange sort of
• Noticing the feeling of taboo and challenging		pregnancy or in interacting with your	feeling of, when we lost [baby], of like
this and the self-judgement of sharing the		stillborn child. Negative appraisals of	sort of like egg on the face almost you
news of pregnancy too early 'why should we		sharing the news and getting excited about	know, like how could we have been so
feel embarrassed' (page 3, code 9)		the pregnancy come through in the	stupid to have got our hopes up and to
• In previous pregnancy (live child) took time		participants story, highlighting that the	have started telling people and things
to form connection and bond (page 5, code		participant on some level felt that it is a	like that, but it's weird, why should we
20)		mistake to become excited about the	feel embarrassed about it?'

- Taking a back seat to allow mother and baby to bond as that's 'the most important relationship' (page 5, code 22)
- Own childhood as reference point for motherson relationship coming above father-son and knowing that this did him (dad interviewed) no harm (page 5, code 23)
- Prior miscarriage at 11 weeks was mum's loss. Concern for her health blocked dad's relationship from building (page 5, code 25)
- Feels unclear at what point dad's get the connection (page 5, code 26)
- Prior loss encouraging bonding with subsequent pregnancy (page 6, code 27)
- Dad's role as support/cheering up wife in this pregnancy subsequent to miscarriage lead to a

## pregnancy or form relationships with the

baby too early on, as something bad may happen. Though the participant seems to be responding to a societal taboo on talking about pregnancy/sharing the news too early, he also challenges this and wonders why he should be embarrassed to get excited so early. This theme also highlights the balance between a father building his own relationship with the baby whilst placing the baby's relationship with the mother at a higher level of importance, which both consciously and subconsciously may serve to interrupt his own building relationship, with dad neglecting his own need/desire to build a

'I was very happy to take a back seat and let my wife and him (live child) bond because I knew that was the most important relationship and I think I didn't want to impede that in any way by getting in the way'.

'(wife) had already lost one before to miscarriage... that was more of a safety and wellbeing of (wife) that I was concerned about because of the amount of blood she lost so... I felt absolutely no bond or anything... at that point' shared relationship building with baby i.e. lets think about names etc. (page 6, code 28)

- Finding out gender and harmony test giving permission to get excited and to form the relationship (page 6, code 29)
- knowing the bond can come later helps to manage the feelings when being cautious about building the bond/hope in pregnancy that occurred after prior perinatal losses (page 6, code 30)
- Trained to be a father from a previous child, learning how to relate to your child (page 8, code 36)
- Previous early miscarriage had a pull to support his wife and felt less of a loss for himself (page 10, code 54)

### relationship in order to support the

mother-baby relationship. This is the case both in prior pregnancies where no loss occurred but also in prior miscarriages where the loss was seen as the mothers only and dad did not yet feel the connection with the baby. This blocking of names' the forming relationship is also seen when dad's focus is on the wellbeing and health of the mum. However, it seems that the participant has some ambivalence about this as he acknowledges both that he feels the mother-infant relationship is most important and that being closer to his mum did no harm whilst also wondering aloud whether he was denying himself by giving

'the shared experience is what I was keen to enjoy... to make it a positive, I was trying to you know, kind of cheer (wife) up whenever I could... I'd be like it will be fine, let's talk about names' 'when we knew it was going to be another boy... we let ourselves get, see

another boy... we let ourselves get, see I make it sound like a bad thing we let ourselves, but that was when we started to get a bit like ooh its gonna happen'

- Takes time to build the relationship and the longer the pregnancy the more relationship has formed (page 11, code 55)
- Let my guard down and allowed the bond to be built (page 11, code 58)
- Excitement when monitoring the baby's growth- then pregnancy goes slow and the birth can't come quick enough (page 12, code 60)
- Wanting to hold him without depriving the mother, was I denying myself? (page 13, code 66)

relationship. The difficulty in sharing the relationship to the baby between two parents is apparent, and may explain why the participant felt it takes time for his relationship with his children to form. However, this concern/supporting role for the mother served to assist the development of a relationship where dads conscious efforts to cheer mum up in a pregnancy subsequent to loss meant that he himself got excited, thinking about names and sharing the experience of a building relationship with his wife. In this way though there is a tension between the mother-child and father-child relationship,

more time for the mother-infant

'[after stillbirth] I did hold him a few times and things but I didn't want to deprive her of time with him... because I'm very much aware of whatever I was feeling you could probably times it by a thousand and she would be feeling more, which might have been denying myself, I

don't know'

\_\_\_\_

			with questions over which is the most	
			important or which deserves the most	
			time, the sharing of this relationship	
			seemed to lessen the interruption to dad	
			building relationship with the baby.	
•	Importance of time with the baby (page 8,	The	This grouping encompasses codes that	'I did make sure I had time holding
	code 39)	importance of	demonstrate the importance of exchanging	him and we had a little chat'
•	Teddy bear stayed with baby for the post-	exchanging	between father and the stillborn baby. This	
	mortem 'one for us and one for him' (page 9,	between father	exchange does refer mostly to objects, but	'we swapped the aching arms teddies,
	code 41)	and baby	the father expresses his initiations of	he had the one we'd had up until that
•	Holding and talking to baby important (page		exchange of time and language between	point and we had his and still have
	14, code 67)		father and son as expressed through	his that was nice, I don't know why
•	Difficult to find something that meant enough		wanting to spend time with his son,	these things are comforting but yeah it
	to give him (page 15, code 80)		writing to his son and talking to him, this	was nice'
•	Swapping teddies with baby was comforting		seems relational despite the inability of his	
	(page 15, code 81)		son to reciprocate language. The	

- Although he's not alive it felt like we'd exchanged something (page 16, code 82)
- Difficult to find objects that meant enough to give to the baby (page 16, code 84)
- Writing a letter to give to the baby, expressing communication/relationship (page 16, code 86)
- Less about objects to remember him by but objects to facilitate relationship through giving him something, feeling the urge to give him something (page 17, code 89)
- 'if it had come to it I felt like I would have cut my hand off just to give him something' (page 17, code 90)
- Objects not to remember him as I think about him every day (page 18, code 92)

participant talks throughout the interview about wanting to give something to his son, in often extreme measures stating he would have been willing to cut off his hand just to give him something. The participant talks about the objects as a gift for his son rather than an object to help him cope with the loss or remember his son, and in this way to mean something he feels the gift should take something from him. The participant struggled with finding something that meant enough to give to his son, highlighting that the objects dad has collected/used are much more than just objects but a manifestation of an exchange between him and his son.

we'd exchanged something' 'I was quite upset I didn't have anything that I was quite so fond of... I found myself scrambling around the house trying to find something to give him that meant enough' 'I just had this overwhelming sensation and urge to give him something... I was rummaging around the house to

'although he's not alive, it felt like

try and find something that meant enough that I could lose, if it had come to it I felt like I would have cut my hand off.. just to give him something'

- Importance not on having an object to remember by, but to give baby a gift and to have meaning/be previous a gift needs to mean the giver losing something (page 18, code 93)
- Knowing that the heart they gave to him might still be intact in his ashes bringing comfort (page 19, code 98)
- 2 parts to an object serving as a possible connection to be completed in the future (page 20, code 100)

### This exchange seems not just to be in the

moment in which the exchange took place but outlasting the stillbirth itself and continuing. For instance, dad imagining the heart that was cremated with his son. which came from the same item he keeps half of, still being intact within his sons ashes. Similarly, dad feels generally strook in there' by items where there are 2 pieces and has imagined reconnecting these pieces in the future when he also passes away. In this way the exchange is not an isolated event but continues in the participant's present thoughts and imaginations about the future, where his son can partake in the exchange of the keyring parts.

'the actual heart itself (popped out from keyring parents kept other half of) they put in his hand and kept that with him while he was cremated so it could well be intact in his ashes... I think we like thinking that it might be in there'

"when one of us... whoever is the first to go, leave this earth... this might get me again... I want her to put that in with me (parents half of keyring) so that I might be able to find him... and might well complete it"

٠	Baby became part of the family early, found	Connecting to	This grouping represents the fathers	'we picked a name and we involved
	out the gender and named him with the help	family in the	efforts to connect his baby to the present	our little boy'
	of his brother (page 2, code 5)	present: 'we'll	moment and to his family. The participant	
•	Objects not to remember him as I think about	keep you here	acknowledges that the baby didn't get the	'you start imagining, you see his full
	him every day	and remember	chance to be part of the family in a	name with his surname, thinking of his
•	Linking baby's name to his brother's. forging	you here'	traditional way, and that rather than the	name and our little boy's name
	family relationships in pregnancy. (page 3,		event, what has happened, its what hasn't	together and thinking yeah they look
	code 14)		and never will happen that is upsetting. He	good together'
•	Importance of baby's relationship in the		expresses a wish to make him feel part of	
	wider family, with sibling more so than		the family in a way that was not possible.	'we spoke about how we wanted
	himself as parent (page 5, code 24)		One way this is expressed is through	another child so that when we're old a
•	Imagining future relationships between		objects linked to the baby in which in the	decrepit and even gone, that [son] will
	siblings (page 6, code 32)		present world, something is missing which	have a sibling and someone close'
•	Held onto baby's ashes (page 9, code 45)		links this object and his baby to the	
			present moment. For instance, the father	'when it came to it and we received his
			picked one book from a set to give to the	ashes, we didn't want to let go of him,

- Post stillbirth, not wanting to let go of him (ashes) and not wanting to leave him behind when moving house (page 9, code 47)
- Giving baby chance to be in the family by keeping the ashes (page 10, code 48)
- Mourning a lost future (page 6, code 31)
- 'we felt like he never had a chance to be in our family... rather than we'll go there to remember you... we'll keep you here and remember you here' (page 10, code 49)
- Giving him something that would mark the space he would have/does occupy is meaningful (page 16, code 85)
- Involving sibling in objects to facilitate the bond between them, not just the bond for himself and his child (page 17, code 91)

baby before he was cremated, leaving a visible gap in this set of books. Though initially this could be considered a reminder of his son, it seems that the gap is rather a statement of his sons presence in the house and family, not a reminder of him so much as a way to avoid pretending that nobody is missing from the family/house. In the same way, the participant changed his mind about scattering his sons ashes as he did not want to leave him behind when the family moved house, by bringing the ashes with them, marking spaces in the house that represent the baby and by including him in family items (such as a necklace with

and I think we, we were moving at the time as well and we didn't want to leave him, as beautiful as where we lived was'

'we felt like he never had a chance to be in our family and that somehow this will be hard for me to say... somehow we should... keeping him in the family, remembering him in our home rather than trying to push him away, we'll go there to remember you, no we'll keep you here and remember you here'

- Not to notice him missing to remember him but to **not** pretend that he wasn't missing (page 18, code 94)
- Objects bring more comfort than religion/spirituality 'we like objects, that means more to us than thinking he's in heaven' (page 19, code 97)
- An object where a piece goes to the baby and is visibly missing strikes a chord (page 20, code 99)
- Including baby in family items is important i.e. necklace representing wife and both children (page 20, code 103)
- I wanted to make him feel like part of the family (page 20, code 104)

representations of wife and both sons) the baby lost to stillbirth has a continued presence and connection with the family in the present. It is apparent this connection is for more than just the father in his expressions of involving his live child in forming a bond with the baby in pregnancy through helping to chose a name, imagining their names together and expressing a wish for both of his sons to support each other long after their parents have passed away. The stillbirth does not interrupt this possible relationship with his brother and father expresses hopes for the future for his son to see photos of his brother.

'its not so much what happened that's upsetting its what hasn't and what never will'

'I wanted to take one of the 4 books out and give him that so that on the shelf we could always see that one was not there'

''I've put it on this necklace (wedding ring and ring with childs handwriting)
and then again because I wanted to
make (baby) feel part of the family...
we've got these hand and footprints...
I took a picture... and sent them to
someone who made a necklace pendant

- 'I've popped that on the necklace too... and I don't really wear it but it sits on my bedside table and the three of them are there together (wife and 2 children) (page 21, code 105)
- Sibling relationship was also building in pregnancy (page 23, code 108)
- Keeping objects with his name visible is
  - important (page 20, code 101)
- We like to talk about him (page 22, code 107)

and I don't really wear it but it sits	3
--	---

on my bedside table and the three of

them (wife and two sons) are together'

•	Gender and named as part of enjoying the	'he might have	This grouping encompasses codes	'because he was right on the cusp of
	pregnancy (page 3, code 7)	died before he	representing the participants expression of	the date, I think he was about 22 weeks
•	Impact of not registering the birth, comfort in	was born but	his baby's developing personhood, how	at that point but because he was born
	name written for this reason, confirming his	he was still a	this personhood was known by him but	dead then he didn't get registered for a
	existence 'I like seeing his name written	person':	not validated by society and how he exerts	birth which did, I was a bit upset about,
		exerting my	his baby's existence through objects,	well not upset, but I felt it was a bit of

	down now, like he did exist' (page 3, code	baby's	symbols and speech. Initially this	a shame because I wanted that
	11)	existence to	personhood grew in pregnancy as news	acknowledgement. So because of
•	Assigning personhood in utero through his	and in the	came that the baby was healthy and the	that I think I do like seeing his name
	name (page 3, code 12)	world.	family picked a name and found out they	written down now, like he did exist'
•	Objects representing and/or including the		were having a son, in dad's description of	
	baby's actual name in them becoming a		this time it seems this is when the	'you're like yeah that one, that one
	symbol for the baby (page 4, code 15)		relationship with his son began to build.	there, that's gonna be his name'
•	Non-physical manifestation of symbol that		The stillbirth posed a threat to this	
	can hold the same power as a physical object-		personhood, where the birth was not	'he was born dead but we got to meet
	referring to play on baby's name (page 4,		registered and the participant experienced	him'
	code 17)		difficulty knowing that this mean in the	
•	Objects logically representing the baby rather		eyes of historical records and society, his	'it will only be mentioned if we bring it
	than spiritual symbology- referring to play on		son did not exist. Dad seems to cope with	up and we're quite happy to, I suppose
	baby's name (page 4, code 18)		this through exerting his sons existence,	I want to let people know that he did
•	'he was born dead but we got to meet him'		by using his name and by keeping objects	exist and he meant something to us and
	(page 8, code 38)		that represent his son and his name visible	he still does and he might have died

- Ashes kept in nice box, with his name and date of birth (page 9, code 46)
- Coping in a way different to parents generation and challenging the taboo (page 10, code 51)
- Wanting to let people know he did exist and he does matter and he does mean something to us (page 10, code 52)
- 'he might have died before he was born but he was still a person' (page 10, code 53)
- Building personhood with gender helped build the relationship (page 11, code 56)
- 'he's a he and he is doing well' (page 11, code 57)
- Surprise at baby looking so human at 22 weeks (page 13, code 62)

in the home. His son's name came to mean before he was born but he was still a a lot to the participant, in part due to a person' societal lack of recognition of his personhood, so much so that songs 'the other ones (previous perinatal including words that sounded like his sons loss) we didn't know gender, so name became meaningful and created suddenly we knew he was a little symbology representing his son. The boy... so you're like he's a he and he's participant himself had his conceptions of doing well' personhood challenged when his son was stillborn at 22 weeks, where he expected 'it seemed to surprise her and I him to look alien, and non-human he was suppose surprised me as well, didn't surprised to see his son as a tiny, little know what he was going to look like person. Dad also seemed surprised that a and you kind of imagine is he going to funeral for his son was a possibility and look like a little alien is he going to valued this, as he expected a very look like sort of, a misshapen

invalidating disposal of his son, in a way

- Is he going to look like a little alien, but no he just looked like a tiny, little person (page 13, code 63)
- It really punched me in the chest that he was our little boy, and he really was a little boy (page 13, code 64)
- Couldn't decide if lost a child or the chance to have a child (page 14, code 71)
- Not getting a birth certificate contributing to conflict over whether loss of baby or chance of a baby (page 14, code 72)
- Comfort when baby's existence validated i.e funeral (page 14, code 73)
- Expected invalidating disposal of body (page 14, code 74)

that would not be the case for any other person. Nevertheless, dad does still seem to have experienced conflict over whether he lost a child or the chance to have a child which was compounded by not receiving a birth certificate. Through the process of seeing his son's name written, having a funeral and using objects this participant seemed to reclaim his son's personhood and exert his existence to others. This whole processed challenged the way his parent's generation managed perinatal loss by hiding it away and not talking about the baby.

unformed human but nah, he just looked like a tiny little person'

'it really hit me in the face, punched me in the chest that that was our little boy and he really was a little boy, his tiny little fingers and translucent skin'

'I couldn't decide if we lost a child or if we lost the chance to have a child, it's such a strange time to experience loss because... coming back to the validity of him not getting a birth certificate so we actually found it really nice when... they had an arrangement with a local funeral

- We know the rest of the world don't acknowledge him and that to them he hasn't existed (page 15, code 76)
- Difficulty knowing there is no public or formal record of his existence (page 15, code 77)
- You don't have a name unless you existed... people don't write your name on things unless you deserved it and he deserved it so that meant a lot'. (page 15, code 78)
- Written name gives the baby validity, acknowledges existence (page 15, code 79)
- Saying his name to exert his existence (page 18, code 95)
- Objects on display, not hidden away because he existed and he is here ( page 18, code 96)

directors and they paid for cremation... we didn't expect that would be an option, we thought that if we wanted them to deal with it that they would just put him in a bag and sling him in the incinerator'

'we're very firm on that (viewing lost baby as their child not chance of a child) but we... not just think but know that the rest of the world doesn't, the rest of the world doesn't acknowledge him and he hasn't existed to the rest of the world'.

'you think of ansestory.com and people looking up genealogy in the future and no one will find him' 'they had a little plaque engraved with his name on it and that was the first time we'd seen his name... that's got me as well... that was the first time we'd seen his full name written down on anything other than what we'd

written and that meant so much because again it was that validity... he existed... you don't have a name

unless you existed and people don't

write your name on things unless you

				deserve it and he deserved it so that
				meant a lot'
•	Imagining a future (page 3, code 13)	'I really felt	This grouping encompasses codes that	'you look at lists of names and it
•	'dare to dream', when it feels safe, imagining	something kick	represent the participants expressions of	becomes a visual and you're like yeah
	the future with your child (page 11, code 59)	in':	love, attachment and a relationship	that one, that one there, that's going to
•	Previous pregnancy experience building new	expressions of	between himself and his son. Although not	be his name and then you start
	expectations for life, losing aspects of current	fatherhood in a	represented by typical language in this	imagining'
	life and preparing for this (page 4, code 19)	continuing	area like 'I felt a bond with him', the way	
•	Building an <b>anticipated</b> relationship in	bond	the participant talks about his son at	'I was sort of anticipating it (the
	pregnancy rather than a relationship in that		different time points sheds light on the	relationship)'
	present moment (page 7, code 33)		developing relationship and how this is	
•	Knew logically that job as father is to look		expressed. During the pregnancy it is clear	'I didn't sort of love him straight away
	after and protect- logical but not emotional		that the participant did not feel as much of	it did take me about 6 months to
	connection there initially (page 5, code 21)		a connection and felt ok about this due to	really feel that bond or connection
•	Increased protectiveness when baby unwell,		his prior experiences of building this bond	like I knew if was my job to look after
	when diagnosed, when role of father as a		much later on in the child's life. Though	him and protect him [live child]'

protector gave him a pull to protect his child. Wondering if he's done the right thing for his baby. (page 7, code 34)

- Rationalising decisions as protector to cope with the difficult decision to terminate, weighing up what is/was best for his child (page 8, code 35)
- The difficulty of going through the trauma of birth with no possible positive outcome (page 13, code 61)
- Suddenly coming to terms with a different future than that imagined future built over pregnancy (page 14, code 70)
- Struggled with 'tackiness' of some objects,
  i.e. keyring (page 9, code 42)

### he does reflect on an 'anticipated'

relationship where he had begun to imagine his child's name written next to his sons, and 'dared to dream' of their future together. The participant talks about moments in pregnancy when the potentially fatal diagnosis is made and the family face the decision of termination as well as when his son is stillborn and he sees him for the first time, in which he felt an urge to protect his son. Although this urge to protect is not a direct expression of feeling attached to or bonded with the baby, it represents a strong feeling in dad that 'kicked in'. This urge to protect may be this dad's expression of that

' when I knew, when we found out he wasn't well and there was something wrong with him, immediately felt very protective... a father is meant to protect his children and did I really do that'
'birth is quite emotional, quite traumatic, but you had that positive at the end that you're hoping for so it was a very strange experience to go through

that with no possible positive outcome'

'would that [continuing with
pregnancy] just be us clinging on for

- Difficulty finding special, quality urn for ashes, not wanting something tacky (page 9, code 44)
- When he was born and he saw him, the urge to protect him kicked in, in a similar way to when the diagnosis was made (page 13, code 65)
- 'he was beautiful and he just looked so right' (page 14, code 68)
- Feeling unconditional love, despite baby's appearance from early delivery (page 14, code 69)
- Relational repair? Communicating with the baby his pull as a father to protect him and apologising for not fulfilling this (page 16, code 88)

relationship and continues after his son's death in the way the father appraises his decision making and through his expression of this love to his son through a written letter in which he apologises for not protecting him in the way he feels he should have. The father also talks about his son as 'beautiful', 'looked so right'

and expresses his unconditional love for his baby despite his appearance impacted by such an early delivery. Finally, the dad expresses a dislike for 'tacky' objects to represent his son or house his ashes and in this way is expressing his desire to give his son the best and most meaningful items, providing for him and wanting the our own self-gratification or would it have actually been better for him'

'I really liked the idea of that but for some reason I really struggled with the fact that it was a keyring, I found that a bit tacky'

'when I knew that... that he was ill and poorly and needed protecting I suppose, I really felt something kick in... feeling protective... and then when he was born and I saw him like that, that really kicked in again'

best for him. All of the above experiences	'I was just very much thinking about
could be appraised in terms of this	how perfect he was he was
participants expressions of fatherhood, of	beautiful he just looked so right
protecting, apologising when he felt he	obviously his proportions were a little
hadn't protected and of his unconditional	bit out and things but I didn't hold that
positive regard for his son.	against him'

'I put (in the letter) that I was sorry I couldn't protect him like I was supposed to'

### Appendix D

## **Contributing Participant Themes to Each Overarching Theme of Analysis**

# Table D1

# Individual Participant Themes Contributing to Each Overarching Theme of Analysis

Pseudonym			Overarching Themes		
	Theme 1: Loss and	Theme 2: Objects as	Theme 3: Exerting	Theme 4: A continued	Theme 5: Evolving
	continued bonds in a	manifestations of relational	existence and continued	bond through physical	expressions of love
	mother-mediated dynamic	and meaningful memories	connection to others	presence	and fatherhood.
Steve	'I've heard that she said she	'its connected to your baby but	'if people remember him	'this is my way of him	'something that any
	felt a kick but I haven't felt	it's not connected to you and	then it's not just me':	coming to my rugby	parent would
	my baby': a mother-	your baby together': objects as	continued connection to	matches with me':	instinctively do whether
	mediated physical	physical manifestation of	others and society	continued relationship	their child was alive or
	connection.	relational memories		facilitated through	dead'
				objects	
	'His baby didn't die the	'you draw back on the things			'the closest you will
	mum's baby died': societal	that you did in anticipation of			ever get to those shared

	views on masculinity and	the relationship you were going		experiences with your
	father-baby relationships	to have'		child is the things that
				you are given the
				opportunity to do in that
				moment': need for staff
				to encourage memory
				making
Michael		Holding only onto objects that	'you're never really dead	'overtime, the
		are meaningful, symbolic linked	until the last person who	relationship shifts too':
		to shared experiences	knows you dies, so you tell	dynamic continued
			people stories about them':	bond
			sharing stories to keep	
			babies memory alive	'pain is the reminder of
				the depth of love felt.
			'We don't hide them, the	The grief is the
			children grew up knowing	expression of that love':

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			about them': facilitating	continuing bond
			continued relationship	through love and pain
			with siblings	
				Protecting and being
			'Their death does not erase	mindful of baby's
			their existence':	feelings
			reclaiming babies life after	
			their death	'They were not
				beautiful they were
			'they had their own	really quite
			personal identity':	frightening': managing
			developing personhood in	the shock of their
			utero	appearance
Phil	'once I held her that's	'when I turn to the to a box and I	'my memory or my losses	'as the years go by, the
	where it became real.'	look at pictures and I look at	become part of his life':	bond becomes
				stronger': use of objects

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clothing they're my memories':	importance of continued		in a dynamic
objects represent memories	connection to others		relationship
			Baby's continued
			impact on fathers life
			'it was a beautiful
			time': time with the
			baby deepening and
			continuing the bond
'when I go through her box, it	'reminding people that	'it was just her body	'I'm really proud of the
literally transports you to it.	these children exist':	I didn't have that	person that she's
Good, bad, or indifferent':	continued connection to	connection':	changed me into': a
objects connected to memories	others	Connecting through	continuing influence
		transitional objects	

Nick

'to replace the fact that	'I can't show her the
she isn't physically	love in the normal
here, to have her name	way.': expressions of
around': objects to	love in the context of
connect to present	loss

John	'knowing you can't do	'it reminds me of her dying,	Facilitating baby's	'we've got somewhere	'a connection that I was
	either properly trying to	rather than thinking of her':	continued relationship	to go regardless	ready for': changing
	have that time with [baby]	object functions and connections	with others	whether she's there or	states and readiness for
	knowing that that's not			not': connection	relationship and objects
	helping [mother]':		`{baby's name] was a	through a place	
	continued relationships in		baby she was just a few		'I didn't want her to
	complex family systems		weeks away form being		think that I didn't want
			full term': assigning		to cuddle her because
	'trying to find her to say can		babyhood in late		she wasn't born in the
	I dress her but they'd		pregnancy'		

#### EMPIRICAL PAPER

	already done it': the hospital			normal way.': Equity of
	context as a barrier to			love with other children
	continued relationships			
Lars	'I was very happy to take a	The importance of exchanging	Connecting to family in	'I really felt something
	back seat': a hierarchy of	between father and baby	the present: 'we'll keep	kick in': building and
	parent-infant relationships		you here and remember	continuing the bond
			you here'	with my baby
			'he might have died before	'the time that we had
			he was born but he was	with them was going to
			still a person': exerting my	be the only time we
			baby's existence to and in	were going to have with
			the world	them': making the most
				of our time

## **Section Three: Critical Appraisal**

Critical reflections on researching fathers' experiences of perinatal bereavement.

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<sup>&</sup>lt;sup>3</sup> See Appendix A for submission guidelines

#### Critical reflections on researching fathers' experiences of perinatal bereavement.

The critical appraisal will supplement both research papers presented through in-depth and critical reflection. It will explore the strengths and critically engage with limitations, offering my own reflections on the challenges and my experiences of conducting this research. It will offer further space to explore the clinical and research implications of both papers.

Presented in the first section of this thesis, a systematic review of the literature explored and synthesized fathers' experiences of support following perinatal loss, including miscarriage, stillbirth, and infant death. Most notably, this review outlined fathers' experiences of masking their grief and emotions due to traditional societal gender scripts, with fathers reporting the existence of their support needs, despite outward appearances. In line with notions of masculinity, fathers also reflected on the dynamic of being a protector for the mother of the baby whilst managing their own grief reactions. Fathers felt they were suppressing their own emotions as both themselves and others felt showing their emotions would upset the mother, and that the mother's wellbeing was of higher importance. Such experiences were felt in hospital and care settings, with fathers conveying a sense of being unacknowledged, ignored and treated like "luggage that the wife brings", rather than fathers with their own equally important support needs. Finally, fathers reflected on the support offered, both the positives and drawbacks to this, with suggestions of new more male centric methods of offering support to bereaved fathers.

The research presented in the second section of this thesis provides a novel, interpretative account of fathers' lived experiences of stillbirth, with a focus on relationships, continued bonds, and the use of objects. The findings of the research highlight the highly emotive, relational, and meaningful experience of fathers through several themes. Fathers experience the loss in a context by which the mother-infant relationship is privileged, and men's fatherhood diminished and unacknowledged. Working against this mother-mediated dynamic, fathers reflected on the evolving expressions of fatherhood between themselves and their babies over time. Expressions such as protecting, loving, and caring for their babies were present throughout pregnancy, loss and afterwards, with objects linked to these interactions becoming particularly powerful. The fathers reflected on various uses of objects; as a connection to the relationship between themselves and their babies, to replace their baby's physical presence in the home and to continue the bonds between their baby, the world and their family and friends.

#### Strengths and Limitations of the Research

#### Systematic Literature Review

The systematic literature review brought strength in its synthesis of findings specific to fathers' experiences of support following perinatal loss, a synthesis as far as the author is aware that has not previously been published. The findings contributed to a novel conceptualization of fathers' experiences of support following perinatal loss, conveying the cyclical nature of barriers to being offered and accessing support.

It is important to note the inclusion of all types of perinatal loss in the search strategy, including miscarriage, stillbirth, and infant death. This approach was chosen due to the dearth of research investigating fathers' experiences of any individual loss type, with a search comprising all loss types yielding significantly more studies resulting in a set of relevant studies for the review. Although different, each type of loss shares the common element of societal stigma around the loss and the limited social connection between the baby and the world which creates likely disenfranchised grief (Lang et al., 2011). However, miscarriage, stillbirth, and infant death are all very different contexts in which to experience bereavement and as such the experiences of support following each loss type may vary.

The decision to exclude papers comprising interviews with parents who identified as men or fathers but were not the partner of the parent carrying the pregnancy, was one that came with a difficult dilemma. The phenomenon of study for the review was the experiences of fathers who typically occupy the role of partner to the person carrying the baby. Upon reading papers in which transexual men or non-binary parents were interviewed about their experiences of perinatal loss, my initial decision was to include such papers as the parents identified as fathers. However, on further reading, most parents interviewed carried the pregnancy and so despite meeting the criteria for identifying as male or a father, their experiences of loss are likely to be intrinsically linked with the physical experience of carrying of the pregnancy. After discussion with my research supervisor, we decided that this experience presents as unique to that of cisgendered fathers, particularly considering the findings from the empirical paper that highlighted the difficulties of a dynamic in which the person carrying the pregnancy receives the most consideration and support. For this reason, such papers were excluded from the review.

Despite not being included in this review, it is important to consider the similarities and differences in experience for gender diverse fathers. The majority of transexual men and non-binary parents interviewed found that hospital staff were supportive in their use of gender affirming language and reassurance that the loss was not due to their gender diversity but was a common pregnancy outcome overall (Riggs et al., 2020). Such findings are clearly unique to the experiences of this population. However, similar experiences were found where parents felt that they received little support following their loss and parents who did not carry the pregnancy, felt that any support that was available was aimed towards the person carrying the baby (Riggs et al., 2020). Building on the experiences of cisgender men, it seems the participants in the study also experienced dismissal and lack of understanding from family, however the added judgement and stigma associated with pregnancy within a gender diverse context served to further compound this lack of support (Riggs et al., 2020). Given the similarities in findings surrounding the experiences of support, it is likely the exclusion of this paper had little impact on the results for the literature review. However, the unique findings highlight the need for research to understand the experiences of perinatal loss in gender diverse populations.

Finally, although the present research had strength in its inclusion of international papers representing participants from 8 countries, the majority of papers were conducted in western countries. Consequently, the application of findings should not be considered as the universal experiences of fathers across cultures.

#### **Empirical Paper**

The empirical paper added a richness and depth to the existing literature on fathers' experiences of stillbirth, with novelty in the consideration of this through a lens of continuing bonds and use of objects. The use of interpretative phenomenological analysis (IPA) was paramount to achieving this richness of analysis, with findings rooted in an interpretation of the fathers' own meaning making around their experiences. The depth of analysis allowed for the discovery of themes with meaningful clinical implications. Furthermore, the act of conducting interviews with fathers gave them a platform to explore their experiences. Through focusing solely on fathers' experiences, a key clinical implication of the paper was manifested from the start, through acknowledging, validating, and strengthening stories of fatherhood in the context of loss.

Nevertheless, the study had limitations. Importantly, the sample was biased towards white, western experiences of stillbirth. It is essential to consider the cultural variations in bereavement practices and rituals. This approach to studying bereavement aims to avoid the binary and medicalized view of grief where responses to loss are "policed", with the construction of appropriate grief intrinsically liked to a history of colonialism in which dominant, western views of grieving were positioned as the right way (Hamilton et al., 2022). Rooted in this colonial thinking, a distinction between typical and complicated grief was made, with diagnosis of "complicated grief disorder" becoming possible (Horowitz et al., 2003).

The existence of such a diagnosis is problematic when considering the cultural variations in grief response. The suggestion of a universal right way to grieve is perhaps a social construction rooted in a colonially biased way of thinking (Neimeyer, 2006; Rosenblatt, 2017). In considering the theory of continued bonds specifically, though this may seem a new way to think about bereavement in western society, in many cultures around the world contact with the deceased and a continued relationship with them is encouraged and a highly typical grief response (Rothaupt & Becker, 2007). In this way it becomes important to recognise that the experiences of the fathers in the present study, particularly the desire for fathers to facilitate a continued bond between their baby and others, may seem unique to a western sample because this continued relationship is not seen as typical by western society. It is also vital to acknowledge the communities across the world in which this concept of continuing bonds is inherent in their culture and has historically been viewed as atypical or has been pathologized through a western and colonial lens.

Further limiting the sample was the self-selecting online methodology of recruitment which resulted in a sample biased to fathers who were involved in perinatal loss community networks online and in person. This meant that for most of the fathers interviewed, their stories of stillbirth had been spoken about several times through involvement in multiple projects in the past. Though a strength in allowing the fathers to bring eloquent and highly meaningful reflections on their experiences, the transcripts from these fathers did feel much easier to analyse and interpret than those fathers who were not as involved in the perinatal loss community. These fathers seemed less able to quickly articulate the deep meaning behind their experiences and took time to warm up to explore things in this way. I noticed and reflected on these differences throughout interviews using a reflective journal. This excerpt from my journal highlights how I ensured a balanced representation of each of the participants in analysis:

In today's interview it felt more difficult to get to deeper meaning behind the father's experiences, and the interview was much shorter than others. On reflection, I think the length of interview is ok as I got enough data to contribute to answering the research question. I need to take care to ensure I represent this participant's voice in equal measure to others who may have spoken in more depth and detail

In embracing IPA as an overall approach to the analysis, it was possible to focus on achieving a balance between individual participant stories and a "phenomenological core" of the experience across participants (Larkin et al., 2006, p. 117). In this way I was able to draw together the similarities across fathers' experiences despite differences in individual meaning making or how experiences were communicated.

It is also important to acknowledge the sample size of six fathers and to critically reflect on the homogeneity of the group. The study aimed to interview between 6-12 participants and achieved this aim. Crucially, an IPA approach, and in turn this study, does not aim to offer an objective truth of a given phenomenon, rather it assumes that the data collected illuminates a person's experience of a given phenomenon in a rich, reflective and personal account (Smith et al., 2009). To allow this rich personal meaning to be studied and for commonalities and divergencies to be appraised for a group of participants, I sought a homogenous group of fathers who had experienced stillbirth, defined as loss after 20 weeks gestation. This definition of stillbirth was chosen due to efforts from the baby loss

community to recognise losses that occur earlier than the national definition of 24 weeks, that involve the delivery of a baby who would have been viable (Fairbairn, 2018). As such, although the fathers in the study experienced loss from a range of time points, some as early as 22 weeks, others as late as full term, all fathers shared the experience of their partner going through labour, and their baby being born at a point where survival could have been possible. In this way the sample was homogenous in that the participants had a shared experience that could contribute to answering the research question (Brocki & Wearden, 2006). However, there were variations in experience that are important to consider. Most notably, for one father loss occurred after a fetal diagnosis was made and he and the mother were advised to seek medical termination. Although this differed from the other fathers' experiences, who discovered their baby had passed away via routine ultrasounds or other medical examinations, this father's experiences of loss, continued bonds and use of objects did not differ significantly from that of the other fathers. In this way, though the experience was different, the father was able to contribute to answering the research question in the same way as other participants, by sharing his experiences of a relationship with his baby and his use of objects.

Finally, the interviews were conducted within the context of a global pandemic and resulting restrictions in place meant that interviews were conducted remotely. It is important to consider the strength this brought to the research in that participants did not have to travel to attend interviews widening the geographical pool of participants. However, a recent study compared the amount of useful data collected in remote compared to face-to-face interviews, concluding that remote interviews compromised the richness of data collected (Johnson et al., 2019). It is important to consider however that the interviewers in Johnson et al (2019) rated the quality of interviews equally across the remote and face-to-face group. Furthermore, remote video interviews have been rated as preferable to face-to-face or telephone interviews

by those who have participated in remote interviews (Archibald et al., 2019). Importantly the global context that followed the publication of these studies forced researchers to use remote interviews and to think creatively about overcoming any limitations in this approach. Guidelines for conducting remote research in the COVID-19 context have since been published (Engward et al., 2022; Hensen et al., 2021) and were followed throughout the interviews conducted. Namely, I was sensitive to signs of distress that may be more subtle through a video interview and was aware of the added invasiveness of conducting an interview within the participant's own space, encouraging participants to find a safe space to attend the video meeting.

#### **Personal Reflections**

#### My Position in the Research

My initial interest in this area of research was influenced by my passion for perinatal psychology, with perinatal loss not something I had specifically worked in previously. The initial idea for the study was one investigating experiences of receiving an object following perinatal loss, however through reviewing the existing literature, it became apparent that fathers were a neglected group, sparking an interest for me to bridge this gap.

As I approached this research study, I was acutely aware of my position as a female who has not experienced perinatal loss, seeking to investigate male fathers' experiences of this deeply distressing event. During some interviews I thought back to sudden bereavements I have experienced in my life, and the profound impacts these have had on me. This meant that although perinatal loss seemed distant, the experience of a sudden and traumatic bereavement is something I have personal experience of. I believe having experienced the death of my dad and brother at a young age meant that I had an appreciation and understanding of bereavement that is unexpected. There were experiences described that did

mirror my own, particularly fathers conveying difficulty when asked how many children they have and knowing that for some they could include their stillborn baby and talk about them, where for others they may avoid this topic. I had an ease of understanding this, having experienced being asked how many siblings I have throughout my adult life and grappling with the same dilemma. Throughout the research I noted and reflected on these similarities in a reflective diary as the excerpt below shows:

Today's interview felt more emotive than others, perhaps because his experiences of finding out his baby had died mirrored the ways I found out Matthew had died, suddenly, over the phone, and completely unexpected, in a different city and having to travel home as quickly as I could. I felt quickly able to empathise with this dad, so I need to keep an eye on how this impacts my understanding and analysis of his experiences compared to other participants

Noticing and journaling about these similarities helped me to keep in mind my position in the research and how this may impact my analysis, as well as in managing my emotions whilst investigating a distressing topic.

Given my personal position, and the highly emotive and personally meaningful experiences the fathers explored within interviews, the process of completing interviews was at times emotional on a personal level. Hearing stories of death, loss and bereavement is upsetting in and of itself, but thinking about the taboo and stigma the fathers experienced when faced with perinatal bereavement and the experience of their babies' lives being dismissed, was difficult to hear. Despite throughout the interview feeling able to manage these emotions, showing empathy and not hiding my feelings, whilst maintaining a protective personal distance from them, following interviews and throughout the process of completing the thesis I have noticed myself thinking much more about infertility, loss and stillbirth both

for myself and a friend who is currently pregnant. Although difficult at times, I am grateful for this impact of the research. I am now more aware of and able to challenge the stigma and taboo around perinatal loss, talking about it openly and I would like to think I am in a much better position to be a support to friends should they experience perinatal loss.

#### **Reflections on the Research Process**

In approaching the research as somebody new to research broadly, particularly research into male experiences and emotion, I had an assumption that recruitment may be difficult and that the fathers who did take part may be reluctant to talk about their feelings. This assumption was rooted both in my bias as a female but was also borne out in narratives of research which suggest that fathers are a "hard-to-reach" group (Leach et al., 2019; Mitchell et al., 2007). To overcome this, I approached the study with fathers in mind, making sure to aim recruitment at fathers alone, to not rely on mothers as a gatekeeper to fathers and to display flexibility that may allow fathers to engage more easily. Such strategies have been put forward by researchers experienced in recruiting fathers as a way of overcoming barriers, such as fathers feeling their opinions are less valued, and logistical conflicts with work and childcare (Macfadyen et al., 2011). Importantly, using father specific, rather than gender neutral terminology when recruiting for research increases engagement from fathers (Leach et al., 2019). My experience of conducting research with a group of fathers challenged my prior assumption regarding men and expression of emotion. The fathers interviewed were able to access and articulate deep and personal meaning and emotion freely, discussing this openly without need for immense effort on my part to access this.

#### **Clinical Implications and Future Research**

The clinical implications of this research are vast, both in terms of clinical services offering support but also on a societal level. It is clear from the findings of both the empirical

paper and literature review that fathers feel unacknowledged in their fatherhood and grief. As such it is important to challenge societal narratives of masculinity, fatherhood and perinatal loss, reclaiming the right for fathers to grieve for their babies and for them to be included in the efforts to support families post-loss. Although one could argue challenging societal narratives lies outside the remit of a clinical psychologist, many believe in equipping clinical psychologists to work for social justice and societal change where societal inequalities impact the individual's wellbeing (Toporek & Suyemoto, 2014). Interestingly, men are rarely considered as a group in need of this social justice work, though throughout this work I have come to realise the power of feminist social justice in this context for men as well as women. Societal gendered expectations for men, to be strong, support women and show no emotion in this context serve to harm fathers who suppress their own feelings to support their partners. Dismantling the patriarchal system that sets such expectations is of benefit to women in many ways, but in this context has been used for the benefit of men in attending to the issues of gender roles and masculinity within feminist therapy for men (Mintz & Tager, 2013).

In terms of service provision, the research provides important insights into fathers' experiences of loss and subsequent support. Such insights provide useful recommendations for any professionals supporting fathers who have experienced perinatal loss. Importantly, involving fathers in the memory making processes around the time of the loss can be a powerful experience in which fathers can express their fatherhood and collect objects that are strongly linked not just to their baby but to the relationship between themselves and their baby. Given strong findings in both papers that fathers can feel ignored, neglected and less important than the mother, it becomes imperative that professionals strive to include fathers in offers of support and all conversations around the loss experience. Doing so not only offers fathers the opportunity to engage with support but acknowledges their fatherhood and importance in the experience, conveying the message that their grief experience is valid and

important. Professionals can further validate fatherhood by talking to fathers about their stillborn babies, recognising that the relationship they built with them during pregnancy may continue to grow and develop.

Future research should aim to fill the gaps in my own research, particularly in the sample of study. Both the empirical paper and the systematic review failed to include parents who identified as gender or sexually diverse. Furthermore, in cases where conception was achieved with support, the relationship between a parent and the baby may be physically distant in a similar way to the fathers in this study. For instance, through the use of a surrogate, the experience of loss presents a different context in which a third person 'owns' this physical connection to the baby, which may impact both parents in similar or perhaps different ways.

Finally, to address the support needs of fathers in absence of a robust evidence-base of interventions and service provision, a community psychology, co-production approach could prove useful. In such an approach, a group of fathers would co-produce a support service with service providers, with their knowledge and expertise on fathers' experiences of loss paramount to the development of the service. Not only would this develop a service in line with fathers' needs but given the suggestion that indirect support can be helpful to fathers, involvement in such a project may serve as an avenue of support for fathers in and of itself. Investigating the effectiveness of such a process would prove useful building an evidence base for effective support for fathers experiencing perinatal loss.

#### Conclusion

This thesis is the result of a significant amount of time, effort, and passion to highlight the experiences of a group of parents whose experiences and feelings are often left neglected. Though the work presented with challenge, I have greatly valued the opportunity to critically

engage with and add to the literature base and to develop a deeper understanding of loss, continued bonds, and the use of objects within the context of stillbirth. I hope the research proves useful for professionals supporting fathers who have experienced loss. Moreover, I hope the findings can be used to continue to challenge societal narratives that position fathers as less effected by perinatal loss and less attached to their babies, and to strengthen the narrative that positions fathers as fathers, mourning the loss of their child.

#### References

- Archibald, M. M., Ambagtsheer, R. C., Casey, M. G., & Lawless, M. (2019). Using zoom videoconferencing for qualitative data collection: perceptions and experiences of researchers and participants. *International journal of qualitative methods*, 18. https://doi.org/10.1177/1609406919874596
- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and health*, 21(1), 87-108. https://doi.org/10.1080/14768320500230185
- Engward, H., Goldspink, S., Iancu, M., Kersey, T., & Wood, A. (2022). Togetherness in Separation: Practical Considerations for Doing Remote Qualitative Interviews
   Ethically. *International Journal of Qualitative Methods*, 21.
   <a href="https://doi.org/10.1177/16094069211073212">https://doi.org/10.1177/16094069211073212</a>
- Fairbairn, C. (2018). Registration of stillbirth (05595). House of commons library. <u>https://www.parliament.uk/globalassets/documents/commons-library/Registration-of-</u> stillbirth-SN05595.pdf
- Hamilton, S., Golding, B., & McCarthy, J. R. (2022). Do we need to decolonise bereavement studies?. *Bereavement*, 1. https://doi.org/10.54210/bj.2022.20

- Hensen, B., Mackworth-Young, C. R. S., Simwinga, M., Abdelmagid, N., Banda, J.,
  Mavodza, C., Doyle, A. M., Bonell, C., & Weiss, H. A. (2021). Remote data collection for public health research in a COVID-19 era: ethical implications, challenges and opportunities. *Health Policy and Planning*, *36*(3), 360-368. https://doi.org/10.1093/heapol/czaa158
- Horowitz, M. J., Siegel, B., Holen, A., Bonanno, G. A., Milbrath, C., & Stinson, C. H.
   (2003). Diagnostic criteria for complicated grief disorder. *Focus*, 1(3), 290-298.
   <a href="https://doi.org/10.1176/foc.1.3.290">https://doi.org/10.1176/foc.1.3.290</a>
- Johnson, D. R., Scheitle, C. P., & Ecklund, E. H. (2019). Beyond the in-person interview? How interview quality varies across in-person, telephone, and Skype interviews. *Social Science Computer Review*, 39(6), 1142-1158. https://doi.org/10.1177/0894439319893612
- Lang, A., Fleiszer, A. R., Duhamel, F., Sword, W., Gilbert, K. R., & Corsini-Munt, S. (2011).
  Perinatal loss and parental grief: The challenge of ambiguity and disenfranchised grief. *OMEGA-Journal of Death and Dying*, 63(2), 183-196.
  https://doi.org/10.2190/OM.63.2.e
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative research in psychology*, 3(2), 102-120. https://doi.org/10.1191/1478088706qp062oa
- Leach, L. S., Bennetts, S. K., Giallo, R., & Cooklin, A. R. (2019). Recruiting fathers for parenting research using online advertising campaigns: Evidence from an Australian study. *Child: Care, Health and Development*, 45(6), 871-876. https://doi.org/10.1111/cch.12698

- Macfadyen, A., Swallow, V., Santacroce, S., & Lambert, H. (2011). Involving fathers in research. *Journal for Specialists in Pediatric Nursing*, 16(3), 216-219. https://doi.org/10.1111/j.1744-6155.2011.00287.x
- Mintz, L. B., & Tager, D. (2013). Feminist therapy with male clients: Empowering men to be their whole selves. In E. N. Williams & C. Z. Enns (Eds), *The Oxford Handbook of Feminist Multicultural Counselling Psychology* (pp. 322-339). Oxford University Press.
- Mitchell, S. J., See, H. M., Tarkow, A. K., Cabrera, N., McFadden, K. E., & Shannon, J. D. (2007). Conducting studies with fathers: Challenges and opportunities. *Applied Development Science*, 11(4), 239-244. https://doi.org/10.1080/10888690701762159
- Neimeyer, R. A. (2006). Defining the new abnormal: Scientific and social construction of complicated grief. OMEGA-Journal of Death and Dying, 52(1), 95-97. https://doi.org/10.2190/31RV-DBPG-Q1M3-PEDA
- Riggs, D. W., Pearce, R., Pfeffer, C. A., Hines, S., White, F. R., & Ruspini, E. (2020). Men, trans/masculine, and non-binary people's experiences of pregnancy loss: an international qualitative study. *BMC pregnancy and childbirth*, 20(1), 1-9. https://doi.org/10.1186/s12884-020-03166-6
- Rosenblatt, P. C. (2017). Researching grief: Cultural, relational, and individual possibilities. *Journal of Loss and Trauma*, 22(8), 617-630. https://doi.org/10.1080/15325024.2017.1388347
- Rothaupt, J. W., & Becker, K. (2007). A literature review of Western bereavement theory: From decathecting to continuing bonds. *The Family Journal*, *15*(1), 6-15. <u>https://doi.org/10.1177/1066480706294031</u>

Smith, J. A., Flowers, P., Larkin, M. (2009). Interpretative Phenomenological Analysis: Theory, Method and Research. Sage.

Toporek, R. L., & Suyemoto, K. L. (2014). Social justice in counseling and clinical psychology. In C. V. Johnson, H. L. Friedman, J. Diaz, Z. Franco, & B. K. Nastasi (Eds.), *Social justice and psychology. The Praeger handbook of social justice and psychology: Vol. 3. Youth and disciplines in psychology* (pp. 119–142). Praeger/ABCCLIO.

#### Appendix A

#### **Omega Journal of Death and Dying Instructions to Authors**

#### **Instructions for Authors**

Manuscripts can be submitted in APA style to https://mc.manuscriptcentral.com/omega.

Please refer to the latest Publication Manual of the American Psychological Association. A synopsis of this manual is available from the American Psychological

Association. <u>http://apa.org/</u>

*Originality* Authors should note that only original articles are accepted for publication. Submission of a manuscript represents certification on the part of the author(s) that neither the article submitted, nor a version of it has been published, or is being considered for publication elsewhere.

*Format* Prepare manuscripts according to the latest Publication Manual of the American Psychological Association. A synopsis of this manual is available from the American Psychological Association. <u>http://apa.org</u>

*Manuscripts* Manuscript must be word processed, double-spaced, with wide margins. Paginate consecutively starting with the title page, which should be uploaded as a separate file. The organization of the paper should be indicated by appropriate headings and subheadings. Please be sure to remove all self-identifying information from the manuscript file before submitting. Author information should only be included on the title page.

*Style* Technical terms specific to a particular discipline should be defined. Write for clear comprehension by readers from a broad spectrum of scholarly and professional backgrounds. Avoid acronyms and footnoting, except for acknowledgments.

*Permissions* Authors are responsible for all statements made in their manuscript and for obtaining from copyright owners to reprint or adapt a table or figures, or to reprint a quotation of 500 words or more. Authors should write to original author(s) and publisher to request nonexclusive world rights in all languages to use the material in the article and in future editions. Provide copies of all permission and credit lines obtained at the time of manuscript submission.

#### **Manuscript Submission Guidelines:**

Manuscript must be word processed using Word or Open Office Writer, double-spaced, with wide margins. Paginate consecutively, starting with the title page.

Title Pages should be uploaded as a separate file and include the follow as is applicable:

• Full article title

- Acknowledgements/credits
- Each author's complete name and institutional affiliation(s)
- Grant numbers and/or funding information
- Corresponding author (name, address, phone/fax, e-mail)
- Up to five keywords as it should appear if it were to be published.

Abstracts of 100 to 150 words are required to introduce each article.

Most articles are between 5000-7500 words and while we accept long pieces that mandates additional evaluation because of space limitations.

Manuscripts should be saved in a Word .doc or .docx file type. The organization of the paper should be indicated by appropriate headings and subheadings.

Please be sure to remove all self-identifying information from the manuscript file before submitting.

When possible, all illustrations, figures, and tables are placed within the text at the appropriate points, rather than at the end. If this is not possible:

Figures should be referenced in text and appear in numerical sequence starting with Figure 1. Line art must be original "drawings" in black ink proportionate to our page size. Indicate top and bottom of figure where confusion may exist. Labeling should be 8 point type. Clearly identify all figures. Large figures should be drawn on separate pages and their placement within the text indicated by inserting:

#### \*Insert Figure 1 here\*

Tables must be cited in text in numerical sequence starting with Table 1. Each table must have a descriptive title. Any footnotes to tables are indicated by superior lower case letters. Large tables should be typed on separate pages and their approximate placement indicated within text by inserting:

\*Insert Table 1 here\*

**Section Four: Ethics Proposal** 

# Ethics proposal for the empirical study: "fathers' relational experiences of stillbirth: Pre-natal attachment, loss and continuing bonds through us of objects"

Word count (excluding references, tables and appendices): 5322

Amy Burgess Doctorate in Clinical Psychology Division of Health Research, Lancaster University

June 2022

# **Application for Ethical Approval**

# Faculty of Health and Medicine Research Ethics Committee (FHMREC) Lancaster University

# **Application for Ethical Approval for Research**

# *for additional advice on completing this form, hover cursor over 'guidance'.* Guidance on completing this form is also available as a word document

**Title of Project**: Fathers' relational experiences of stillbirth: pre-natal attachment, loss and continuing bonds through use of objects

Name of applicant/researcher: Amy Burgess

ACP ID number (if applicable)\*:

Funding source (if applicable)

Grant code (if applicable):

\*If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [link].

# Type of study

Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one**, *two* and four of this form

Includes *direct* involvement by human subjects. Complete sections one, *three* and four of this form

#### **SECTION ONE**

**1. Appointment/position held by applicant and Division within FHM** Trainee Clinical Psychologist

#### 2. Contact information for applicant:

E-mail: Contact details removed for submission

**Telephone**: Contact details removed for submission

Address: Contact details removed for submission

3. Names and appointments of all members of the research team (including degree where applicable)

Amy Burgess, Principal Researcher (DClinPsy Student)

Dr Craig Murray, Research Supervisor

Dr Anna Clancy, Field Supervisor

<b>3. If this is a student project, please indicate what type of project</b> by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete <b>FHMREC form UG-tPG</b> , following the procedures set out on the <u>FHMREC</u> website				
PG Diploma   Masters by research   PhD Thesis   PhD Pall. Care				
PhD Pub. Health   PhD Org. Health & Well Being   PhD Mental Health     MD				
DClinPsy SRP [ [if SRP Service Evaluation, please also indicate here: ]] DClinPsy Thesis [				
<b>4. Project supervisor(s), if different from applicant</b> : Dr Craig Murray				

5. Appointment held by supervisor(s) and institution(s) where based (if applicable): Senior Lecturer, Lancaster University

# **SECTION TWO**

Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates	(month and year)
Start date:	End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

# Data Management

For additional guidance on data management, please go to <u>Research Data Management</u> webpage, or email the RDM support email: <u>rdm@lancaster.ac.uk</u>

3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms' n o

4c. If yes, where relevant has permission / agreement been secured from the website moderator? no

4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users? no

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

6a. Is the secondary data you will be using in the public domain? no

6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder

7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

# 8. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes

b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

# SECTION THREE

# Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words):

There is a large amount of research into mothers' experience of stillbirth, with some studies looking specifically at the expression of continuing bonds. A continuing bond is an ongoing relationship with the deceased following the loss. One expression of continuing bonds is through use of objects, such as photos, footprints, or soft toys. Research looking at fathers' experiences of stillbirth and expression of continuing bonds is lacking. Therefore, the study aims to investigate the formation of pre-natal relationships and continuation of these post-loss through use of objects in fathers following stillbirth. The study will also appraise the ways in which fathers cope with the psychological impact of the loss. Interviews with 6-12 fathers will explore the psychological impact of the loss, with data analysed through Interpretative Phenomenological Analysis (IPA) to identify fathers' unique experiences and meaning making. This will have important implications for services working with fathers experiencing stillbirth, informing the support offered.

# 2. Anticipated project dates (month and year only)

Start date: March 2021

End date: March 2022

## **Data Collection and Management**

*For additional guidance on data management, please go to* <u>Research Data Management</u> *webpage, or email the RDM support email:* <u>rdm@lancaster.ac.uk</u>

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

Between 6 and 12 fathers who have experienced stillbirth. Stillbirth will be defined as a baby born 20 weeks and later, showing no signs of life.

It is important to note that there are varying definitions of stillbirth. The world health organisation specifies this as birth with no signs of life after 28 weeks, the NHS specifies the same, but after 24 weeks. The perinatal loss community however recognise that such definitions are based in dated research on chances of survival, prior to advancements in medicine that mean babies are now viable much earlier on in pregnancy. As such there are campaigns to change the definition to birth after 20 weeks showing no signs of life. As such,

the study will define stillbirth as stated above (post 20 weeks). This will allow a wider pool of participants who have experienced the stillbirth of a baby that would have been viable should they have been born early but healthy.

Inclusion Criteria

Participants will:

• Identify as male

• Have experienced a stillbirth in the last 10 years (defined as the loss of a baby from 20 weeks onwards).

• Identify as having used an object to facilitate an ongoing relationship post-stillbirth/cope with the loss.

• Be aged 18 or older.

**Exclusion** Criteria

Participants will not:

• Have experienced the most recent stillbirth in the 6 months prior to taking part in the study

Should the above criteria result in too few participants; criteria will be widened to include practices as well as objects. This inclusion criteria will become 'Identify as having used either an object or a practice (such as lighting candles) to facilitate an ongoing relationship post-stillbirth/to cope with the loss'.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (e.g. adverts, flyers, posters).

Participants will be recruited through two sources: through recruiting organisations and online. Two organisations so far have agreed to support recruitment: 'Aching Arms' (a charity providing transitional objects to bereaved parents) and 'Dad Matters' (an organisation that works with fathers in the perinatal period). An information sheet and poster will be shared with fathers via the recruiting organisations. This will allow recruitment of fathers who may not see advertisement via online platforms. The information sheet will be shared through professional (not personal) social media accounts to further advertise the study. The principal researcher will also use a professional Twitter account to connect with further relevant organisations to promote the study. Advertisements and the participant information sheet will clearly state the criteria for taking part (i.e. time since loss, type of loss) to avoid fathers who do not meet this criteria volunteering. Advertisements for the study will request that fathers email or call the principal researcher to volunteer to take part in the study. The advertisements will include a number for a research mobile phone provided by the university to keep the principal researcher's number private. The principal researcher will then phone

the participant to confirm that they meet criteria for taking part before sending further participation information documents and arranging the video or phone call for interview. Recruitment will continue until enough interviews have been competed to meet the intended sample size. Participants will be informed of this on the participation information sheet which will outline that it may not be possible for everyone who expresses interest to take part in the study.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

After the principal researcher has confirmed with the potential participant that they meet criteria for taking part in the study, a link to a short demographic survey will be emailed to them to complete online. This will also contain the participation information sheet, with statements of consent which participants will confirm their agreement with.

Semi-structured interviews will follow an interview schedule, which will outline the topics to be explored with potential questions to use to do this, and flexibility to explore topics beyond the questions listed.

Topics that will be covered in each of the interviews are as follows:

-Experience of building relationship in pregnancy

-Experience of stillbirth itself (with exploration of how fathers related to the baby within this)

-Experience of relationship with the baby following the loss (both immediate and long term)

-An exploration of the use of objects at each of the stages outlined above.

-If not explored during discussion of above topics, fathers will be asked about prior experiences of perinatal loss and of any of children they have

It is possible that during exploration of the above topics, fathers will talk about any other children they have or any other experiences of perinatal loss. This information will be important both in exploring the experiences of the fathers and in describing the homogeneity of experiences within the sample. Should the fathers not share this information naturally, I will ask questions such as the following, sensitively, to obtain the information:

1.Other than the most recent stillbirth you have experienced, do you have otherexperiences of perinatalloss? (either miscarriage, stillbirth or infant death upto the age of 1)

2.Do you have any other children?

3.if yes to Q2: were any of these children born following your child that was stillborn?

4.How long (in years, months) has it been since your most recent experience of stillbirth?

It is possible that the inclusion of such questions could convey the distressing message often given to bereaved parents of 'at least you have other children' or 'at least you know you can have children'. To mitigate this potential distress, discussions of such topics will be handled sensitively, with a message such as the following:

'The experience of stillbirth is a difficult one no matter what your circumstance. Often it is assumed that the experience is 'easier' if you have living children or are able to become pregnant again. In reality, everybody experiences difficult events like this in varied ways and where for some this would bring comfort, for others it may do quite the opposite. Nevertheless, for the study to appraise these issues, it is important to have a sense of the broad experiences of the participants in terms of prior perinatal losses, live births and the presence of living children.'

Interviews will be conducted via telephone or video link (Microsoft Teams) due to the COVID-19 pandemic. Video link software will be used whenever accessible to the participant. Microsoft teams will be used for video calls where calls can be recorded. A 'pick-up' device will be used to record phone calls with the principal researcher personal mobile (using withheld number). Following each interview, the recording will be saved to an encrypted memory stick for future analysis. As soon as possible recordings will be transferred from the memory stick onto the University file store (H: drive).

Since interviews will be conducted remotely it is likely that participants will be taking part from their own homes. Participants will be asked to consider this, both when scheduling a date for the meeting and through the participation information sheet. Similarly, the distress caused from discussing the sensitive topic of stillbirth may be heightened in a virtual rather than face to face meeting. This will also be outlined to participants both in the consent procedure and in requesting participants pick a comfortable space for the interview.

The principal researcher will individually transcribe and type each interview without the use of software, to develop familiarity with the data and prepare this for further analysis. Each transcript will then be analysed using Interpretative Phenomenological Analysis, through the following steps, taken from Pietkiewicz & Smith (2014), in an iterative process:

- 1.Read transcript and create initial codes
- 2. Group the codes, appraise relationships between codes and groups
- 3. Creative interpretative narrative summaries for the groups
- 4. 'bracket' the emerging themes before moving onto next transcript.

Each transcript will be analysed in isolation, with emerging themes 'bracketed' before the next transcript is analysed. This reduces potential bias that the researcher may bring from the analyses of one father's experience to the next.

A second researcher will code one transcript to compare analysis, identifying potential assumptions made by the principal researcher about the data.

One all transcripts are analysed individually, similarities and differences across the transcripts will be appraised and analysed.

Interpretative Phenomenological Analysis will allow for the unique experiences of fathers, and their own meaning making around these experiences, to be central to research findings. This approach has been chosen to address the methodological flaws in the existing literature on perinatal loss and fathers, with the use of bias outcome measures in quantitative studies and limited qualitative research with focus on fathers' unique experiences.

Descriptive statistics will be conducted on the demographic information to present the key characteristics of the sample.

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

Demographic information will be collected from each participant for the purpose of reporting the demographic make-up of the sample in my report. This data will be collected electronically in an anonymised survey using the Universities software, Qualtrics. Within an email inviting participants to complete the survey, participants will also be given a unique participant number to enter within this survey. Data from this survey will be downloaded and stored in an excel spreadsheet. The unique participant code will allow the principal researcher to link survey responses with the corresponding client, however the participant code will not be shared outside of the research team, so the data held within the excel spreadsheet will remain anonymous. This spreadsheet will be stored on the university file store (H: Drive), only the principal researcher will have access to this file.

Audio and video recordings will be transferred to an encrypted USB immediately postinterview, and to the university file store as soon as possible thereafter. The interviews will be transcribed by the principal researcher who will save transcriptions onto the University file store (H: drive), both the principal researcher and research supervisor will have access to the transcripts.

The research supervisor will act as custodian for the data for the duration of the study. The principal researcher will hold responsibility for the collection and safe storage of the data data until the end of the DClinPsy course. Following this the data will be transferred to the Research Coordinator (Sarah Heard), who will be responsible for the deletion of the data 10 years following completion of the project.

7. Will audio or video recording take place?	no no	🔀 audio	🛛 video
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a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data.

The principal researcher's personal laptop will be used to record phone calls (via a pickup device) and video calls conducted through Microsoft Teams. The recording function on Microsoft Teams will give the person who records the meeting (i.e. the interviewer) the option to download the recording and delete it from the Microsoft Teams system. This laptop is encrypted, and password protected. The principal researcher also has access to an encrypted USB, which recordings will be transferred to immediately following an interview. Recordings will remain on this USB until it is possible to transfer them to the University file store (H:drive) which if working from home can be done via the VPN.

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Audio and Video data will be stored on the University file store (H:drive) until the completion and publication of the project, since the principal researcher may need to access these during the process of examination on the project and during the process of publication. At this point the principal researcher will destroy all video and audio recordings.

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

The data will be transferred to the Research Coordinator (Sarah Heard) at the end of the DClinPsy course using password protected files. The Research Coordinator will be responsible for the deletion of the data 10 years following completion of the project. The supervisor (Craig Murray) will act as data custodian and along with the research team will make decisions on who can access the data.

8b. Are there any restrictions on sharing your data ?

Due to the small sample size, and sharing of findings with recruiting organisations, it is possible that even after full anonymisation that participants will be identifiable by those reading the published research or attending presentations of the findings. As such, data will not be shared and requests for data will be handled by the Faculty of Health and Medicine.

#### 9. Consent

a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent?

Following expression of interest and confirmation that participants meet criteria for involvement, participants will be sent an email containing a participant information sheet and asked to take adequate time to read and consider this information before confirming they wish to take part in the study via a survey linked in the email. The survey will ask participants to indicate their agreement for a series of statements of consent. At the start of each interview participants will be asked if they have read and understood the participant information sheet and invited to ask any questions they have about this information, before confirming with verbal consent to participate. Verbal consent will be recorded and stored as a separate audio file from the interview.

10. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

The topic of stillbirth is a sensitive one, particularly for those with first-hand experience of this. Furthermore, since some research has suggested that fathers mask their distress in order to support the mother of the stillborn child (Armstrong, 2001), it is possible that the fathers interviewed have not spoken about the experience of stillbirth in the depth that the interview may be. Therefore, there is potential for psychological distress to arise both during and following an interview. To minimise this distress, the interview schedule has been sent to the field supervisor for stakeholder feedback on the sensitivity of the questions and topics, with

confirmation from the field supervisor that the interview schedule is appropriately sensitive. Participants will be informed of the potential for distress to arise prior to completing the interview and reminded of this at the start of the interview.

Since interviews will be conducted via video link or over the phone, signs of potential distress in the participant may be less easily noticed. For this reason, the interviewer will pay attention to more subtle signs of distress such as long pauses and silences. Participants will be informed at the start of an interview that their level of distress will be monitored, and that since these can be more difficult to pick up over the phone or video the interviewer may ask them occasionally how they are feeling.

Should any signs of potential distress arise, the interview will be paused, and the participant will be asked how they are feeling. If the participant reports feeling able to continue the interview, this will continue. If the participants report distress, the participant will be asked if they feel able to continue talking about their experiences. At this point the participant can decide whether to take a short break before continuing, take a break and continue the interview another day or finish the interview entirely. The interviewer will use their clinical skills to manage any distress that arises during the interview.

Within the consent procedure, and at the start of each interview a confidentiality agreement will be explored. This will inform the participant that should the interviewer become concerned for the safety of themselves or of others that they may have to break confidentiality.

All participants will be given and/or emailed a debriefing document, following the interview, that will outline the potential for distress to arise in the time after the interview, with contact details for sources of support should the participant wish to seek this. If distress arises during the interview, participants will be reminded that they will receive this document following the interview and should contact support services should they require them. Participants that display distress will also be offered a follow-up call later that day or the next day, to check in with them.

The main support service fathers will be signposted to is Stillbirth and Neonatal Death charity (SANDS) who offer a helpline and email contact for support as well as local support groups, an online community, and a bereavement support app.

The interviewer will complete a training course from SANDS which is freely available and aims to offer suggestions and guidance on talking to parents who have experienced the loss of a baby. This is available online at <u>https://www.sands.org.uk/about-sands/media-centre/news/2019/09/national-bereavement-care-pathway-launches-e-learning-module</u>

Since interviews will be conducted remotely, it is possible that fathers will be taking part in the interview from their own homes. Participants will be reminded of this and asked to find a quiet and private space at home to take the call. Participants will be reminded that the interview will involve discussing very personal experiences of stillbirth and that they will be responsible for finding a space to take the interview call that will allow them to talk openly.

Participants will be informed that they have the right to withdraw from the study at any point leading up to and including the interview and will have 2 weeks following this to withdraw their consent and data from the research. Participants will be informed that following this time it is likely that their data has been analysed and can no longer be withdrawn from the study.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

The topic of study is a sensitive and potentially upsetting one. Discussing experiences of stillbirth with bereaved parents may be upsetting to the interviewer and as such it will be important to utilise support networks available. These include the research supervisor and clinical tutor on the DClinPsy course. It is also possible that issues of risk arise from the participants (for example, risk of self-harm/suicide), the interviewer can again make use of support networks available to manage this. Particularly the interviewer can seek support and advice from the research supervisor. Since the interviewer may need timely support following an interview, and the research supervisor may not always be immediately available due to other work commitments, the interviewer may also contact one of three Doctorate in Clinical Psychology course directors for support, should any immediate issues arise, and the research supervisor is unavailable.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

It is possible that the fathers who take part in the study have not spoken about their experiences of stillbirth in as much depth as the interview will encourage. As such it may be beneficial for participants to have the opportunity to share their experiences.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

No incentives or payments will be made to participants.

14. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes

b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

Participants will be informed that identifiable data will be omitted or anonymised upon data storage and thereafter, including analysis, presentation of findings and publication. Audio and video recordings will be saved under a participant number and interview date rather than a name. Demographic information from the Qualtrics survey will be recorded in a spreadsheet against participant codes. Demographic data will be presented in a table to outline the gender, age etc. of each participant, though this individual data will be anonymised and confidential in the report. Participants will be informed that video/phone call recordings as well as demographic data will be stored safely on the University file store with only the research team able to view this file. Participants will be informed however, that it is impossible to anonymise their identities within the recording themselves, due to either their face being visible over teams or their voice over a phone call.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

The participant documents (including recruitment poster, participant information sheet and interview schedule) were shared with the field supervisor for stakeholder feedback, including from fathers who have experienced perinatal loss, with amendments made based on such feedback.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

The research will form an empirical paper which will be submitted as part of my thesis for the DClinPsy course. It is intended that the findings from the research are published into a peer reviewed journal. Potential journals that may be targeted for dissemination are OMEGA-Journal of Death and Dying, Death Studies or the Journal of Prenatal & Perinatal Psychology & Health. The findings will also be presented to stakeholders in the project, and any charities that support recruitment. Similarly, any organisations that support the study through social media will be informed of findings through sharing the published study though social media. A summary of the study will also be offered to participants from the study via email.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

Are there any matters about which you wish to seek guidance from the FASS-LUMS REC?

Since the topic of study is a sensitive one, it may be important to consider a period of time following the stillbirth in which fathers can participate in the study with minimised distress. Having looked at published research on perinatal loss, it seems this amount of time has been indicated as 6 months. There is also research on the psychological impacts of perinatal loss reducing from around 6 months post loss. The field supervisor who has experience in the field of perinatal loss has reviewed the research proposal and agrees that 6 months would be a sensible time since loss to minimise distress. The field supervisor is not aware of a time since loss typically used in perinatal loss research to minimise distress. As such a 6-month time period has been decided on, though I would welcome any further guidance on this.

#### **SECTION FOUR: signature**

Applicant electronic signature: Amy Burgess

Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review

Project Supervisor name (if applicable): Dr Craig Murray 13/10/2020

Date application discussed

Date 20/10/2020

#### Submission Guidance

- Submit your FHMREC application <u>by email</u> to Becky Case (<u>fhmresearchsupport@lancaster.ac.uk</u>) as two separate documents:
  - FHMREC application form.
     Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line.*
  - Supporting materials.
     Collate the following materials for your study, if relevant, into a single word document:
    - a. Your full research proposal (background, literature review, methodology/methods, ethical considerations).
    - b. Advertising materials (posters, e-mails)
    - c. Letters/emails of invitation to participate
    - d. Participant information sheets
    - e. Consent forms
    - f. Questionnaires, surveys, demographic sheets
    - g. Interview schedules, interview question guides, focus group scripts
    - h. Debriefing sheets, resource lists

Please note that you DO NOT need to submit pre-existing measures or handbooks which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

- 2. Submission deadlines:
  - i. Projects including direct involvement of human subjects [section 3 of the form was completed]. The *electronic* version of your application should be submitted to <u>Becky Case</u> by the committee deadline date. Committee meeting dates and application submission dates are listed on the <u>FHMREC website</u>. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.
  - The following projects will normally be dealt with via chair's action, and may be submitted at any time. [Section 3 of the form has *not* been completed, and is not required]. Those involving:
    - a. existing documents/data only;
    - b. the evaluation of an existing project with no direct contact with human participants;
    - c. service evaluations.
- 3. <u>You must submit this application from your Lancaster University email address, and copy</u> your supervisor in to the email in which you submit this application

#### **Ethical Approval Letters**



Applicant: Amy Burgess Supervisor: Dr Craig Murray Department: Division of Health Research FHMREC Reference: FHMREC20032

18 December 2020

#### Re: FHMREC20032

Father's relational experiences of stillbirth: pre-natal attachment, loss and continuing bonds through use of objects.

Dear Amy,

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Email: fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

ABCD.

Annie Beauchamp, Research Ethics Officer, Secretary to FHMREC.

#### Research Ethics Application Form v1.7.3

#### Research Ethics Application Form v1.7.3 AmendPaper



# Fathers' relational experiences of stillbirth: pre-natal attachment, loss and continuing bonds through use of objects - Approved

Information Regarding this Research Project		
Are you conducting a research project?		
(for more information on research projects please see our ethics pages)		
Yes C No     No		
Does your research only involve animals?		
C Yes C No		
Are you undertaking this research as/are you filling this form out as:		
C Academic/Research Staff		
C Non Academic Staff		
Staff Undertaking a Programme of Study		
<sup>6</sup> PhD or DClinPsy student		
C Undergraduate, Masters, Master by Research, MPhil or other taught postgraduate programme		
Which Faculty are you in?		
Faculty of Health and Medicine		
Which department are you in?		
Health Research		

Will your project require NHS REC approv	/al? (If you are not sure please read the guidance in the information button)
C Yes C No	
Yes No	
Do you need Health Research Authority (H	IRA) approval? (Please read the guidance in the information button)
C Yes C No	
Yes No	
Have you already obtained, or will you be	applying for ethical approval, from another institution outside of Lancaster University? (For
example, an external institution such as: an	nother University's Research Ethics Committee, the NHS or an institution abroad (eg an
IRB in the USA)? Please select one of the	
No, I do not need ethical approval from 0	
C Yes, I have already received ethical ap	
<ul> <li>Yes, I will be applying for ethical appro my Faculty Research Ethics Committee</li> </ul>	oval from an external institution after I have received confirmation of ethical approval from ee (FREC) at Lancaster University, if the FREC grants approval.
Is this an amendment to a project previous	ly approved by Lancaster University?
© Yes ⊂ No	
Was this previously approved project appli	cation completed using the REAMS system?
C., G.,	
C Yes C No	
Project Information	
Please confirm/amend the title of this proje	ect
Fathers' relational experiences of stillbirth: pre-na	atal attachment, loss and continuing bonds through use of objects
Estimated Project Start Date	01/07/2022
Estimated End Date	31/08/2022
and an	UNITED T
11 August 2022	Deve 2 of 7
Reference #: FHM-2022-1018-AmendPaper-1	Page 2 of 7

Is this a funded	Project?
C Yes	<sup>€</sup> No
Yes	No
-	
Research Site	e(s) Information
Will you be reco	uiting participants from research sites outside of Lancaster University? (E.g. Schools, workplaces, etc; please read
	the information button for more information)
C Yes	<sup>™</sup> No
Applicant Det	tails
Are you the lead	d applicant in the original application?
-	
Yes	C No
Are you the nam	ned Principal Investigator at Lancaster University?
Yes	∩ No
Please check yo	our contact details are correct. You can update these fields via the personal details section located in the top right of the
	your name and email address in the top right to access "Personal details". For more details on how to do this, please
read the guidan	ce in the information button.
First Name	
Amy	
Sumame	
Burgess	
Department	
Department	
Doctorate in Clinica	al Psychology
	· •

11 August 2022

Reference #: FHM-2022-1018-AmendPaper-1

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Faculty
faculty of health and medicine
Email
a.burgess5@lancaster.ac.uk
Please enter a phone number that can be used in order to reach you, should an emergency arise.
07780451978
Principal Investigator
You have stated that you are the Principal Investigator for this project.
First Name
Апу
Sumame
Burgess
Department
Doctorate in Clinical Psychology
Email
a.burgess5@lancaster.ac.uk

#### Supervisor Details

Search for your supervisor's name. If you cannot find your supervisor in the system please contact rso-systems@lancaster.ac.uk to have them added.

First Name

Craig

11 August 2022

Reference #: FHM-2022-1018-AmendPaper-1

Page 4 of 7

Surname
Murray
Department
Health Research
Faculty
Faculty of Health and Medicine
Email
c.murray@lancaster.ac.uk
Do you need to add a second supervisor to sign off on this project?
C Yes C No

Which system was the previous application approved on?

Please note that this option is for amendments for applications that went through the previous paper based application system.

I confirm that this is an amendment to a paper based application.

Paper based system

Please enter your FREC/UREC ID as seen on your original approval email.

FHMREC20032

11 August 2022

Reference #: FHM-2022-1018-AmendPaper-1

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Please upload the approved UREC/FREC application with all additions highlighted and deletions struck through.

Documents			
	OCU	TT HAT	<b>C</b> 5

Туре	Document Name	File Name	Version Date	Version	Size
Previous Approved Ethics Applications	Amended Amy Burgess FHMRECapplicationform2018	Amended Amy Burgess FHMRECapplicationform2018.docx			328.5 KB

#### Please summarise your changes and the reasons why you are making them.

I am seeking an amendment of my ethics to include some participant names in the write up of my research as per participant request to do so during interviews and discussions r.e. informed consent for this. During interviews whilst discussing anonymity/confidentiality and the plan to use pseudonyms in the write up of the research, some of the participants requested they be referred to by their own real name and one participant requested he be referred to by his stillborn son's name. In each instance the reasons for anonymity were discussed and the fathers reflected on the importance of using their real names citing reasons of not wanting to hide, not feeling they should be ashamed etc. One participant wanted their stillborn son's name to be written down and recorded to exert his existence, this is of significance given the findings of my study into fathers experiences of stillbirth. Participants were aware this meant they may be identified and although I gained informed consent in this way with all of the fathers making this request, I wanted to ethics application to reflect this and ensure the research is abiding by ethical standards. If the ethics board are interested, I have come across studies exploring this issue in bereavement research, for instance Scarth (2016) discussed the ethical issues with denying requests to use real names and the dilemma this brings with traditional standards of ethics and onnymity. I would be open to any guidance on this. Scarth, B. J. (2016). Bereaved participants' reasons for wanting their real names used in thanatology research. Research Ethics, 12(2), 80-96. https://doi.org/10.1177/1747016115599569

# If you have made changes to any supporting documents (such as PIS or consent forms) please upload them with changes and deletions clearly marked.

If you have created new documents as a result of this amendment (e.g. questionnaire as a new methodology) please upload them here.

- I have no further uploads.
- Advertising materials (posters, emails)
- Letters/emails of invitation to participate
- Consent forms
- Participant information sheet(s)
- Interview question guides
- Focus group scripts
- Questionnaires, surveys, demographic sheets
- Workshop guide(s)
- Debrief sheet(s)
- Transcription (confidentiality) agreement
- Other

Please upload the documents in the correct sections below:

Please ensure these are the latest version of the documents to prevent the application being returned for corrections you have already made.

#### Declaration

11 August 2022

Reference #: FHM-2022-1018-AmendPaper-1

All research at Lancaster university must comply with the LU data storage and governance guidance as well as the General Data Protection Regulation (GDPR) and the UK Data Protection Act 2018. (Data Protection Guidance webpage)

I confirm that I have read and will comply with the LU Data Storage and Governance guidance and that my data use and 5 storage plans comply with the General data Protection Regulation (GDPR) and the UK Data Protection Act 2018.

Have you that you have undertaken a health and safety risk assessment for your project through your departmental process? (Health and Safety Guidance)

R I have undertaken a health and safety assessment for your project through my departmental process, and where required will follow the appropriate guidance for the control and management of any foreseeable risks.

When you are satisfied that this application has been completed please click "Request" below to send this application to your supervisor for approval

Signed: This form was signed by Dr Craig Murray (c.murray@lancaster.ac.uk) on 02/07/2022 22:11

Please read the terms and conditions below:

- · You have read and will abide by Lancaster University's Code of Practice and will ensure that all staff and students involved in the project will also abide by it.
- · If appropriate a confidentiality agreement will be used.
- · You will complete a data management plan with the Library if appropriate. Guidance from Libra
- · You will provide your contact details, as well as those of either your supervisor (for students) or an appropriate person for complaints (such as HoD) to any participants with whom you interact, so they know whom to contact in case of questions or complaints?
- · That University policy will be followed for secure storage of identifiable data on all portable devices and if necessary you will seek guidance from ISS
- That you have completed the ISS Information Security training and passed the assessment.
- That you will abide by Lancaster University's lone working policy for field work if appropriate.
- · On behalf of the institution you accept responsibility for the project in relation to promoting good research practice and the prevention of misconduct (including plagiarism and fabrication or misrepresentation of results).

  To the best of your knowledge the information you have provided is correct at the time of submission.
- · If anything changes in your research project you will submit an amendment.

Applicant Only: To complete and submit this application please click "Sign" below:

Signed: This form was signed by Amy Burgess (a.burgess5@lancaster.ac.uk) on 01/07/2022 21:42

11 August 2022

Reference #: FHM-2022-1018-AmendPaper-1

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Appendices

#### **Appendix A: Research Protocol**



#### **Research Protocol**

#### Fathers' Relational Experiences of Stillbirth: Pre-natal Attachment, Loss and Continuing Bonds.

Amy Burgess, Lancaster University

Dr Craig Murray, Lancaster University

Dr Anna Clancy, Lancashire Care NHS Foundation Trust

#### Introduction

Stillbirth is defined in the UK as a baby born after 24 weeks gestation showing no signs of life (Fairbairn, 2018) and occurs in 1 in 250 births (Office for National Statistics, 2019). The definition of stillbirth is a dated one; although medical advancements have allowed babies to survive when born prior to 24 weeks, the legal definition remains the same (Fairbairn, 2018). As such, many perinatal loss charities believe the legal definition should be changed to 20 weeks and have campaigned passionately for this.

There is an abundance of research demonstrating worsened psychological outcomes for mothers following stillbirth. This includes increased anxiety, depression, and PTSD in this population (Campbell-Jackson, & Horsch, 2014; Wall-Wieler, Roos, & Bolton, 2018). However, similar research for fathers is limited.

Quantitative research consistently reports that fathers' experience less severe psychological outcomes than mothers following stillbirth. That is, fathers' seem to experience lower levels of anxiety, depression and PTSD post-stillbirth when compared to mothers (Christiansen, 2017; Farren et al, 2018). The research in this area is however limited, with outcome measures administered being more sensitive to displays of distress in women (Burden et al, 2016; Jones, Robb, Murphy, & Davies, 2019). Furthermore, research in this area tends to use gender bias mixed samples with fathers investigated as 'men whose partner has suffered a perinatal loss' (Nguyen, Temple-Smith, Bilardi, 2019). Investigation of psychological outcomes for fathers that uses such limited methodology, inhibits reports of fathers' unique perinatal loss experiences.

Qualitative research indicates that fathers' do indeed 'suffer', with fathers' reporting their intense emotional experiences of stillbirth (Klier et al., 2002). Further qualitative research

suggests that fathers suppress their own distress to support their partner (Armstrong, 2001). Fathers' have reported feeling unimportant throughout the pregnancy, during the birth and beyond (Daniels, Arden-Close, & Mayers, 2020). This grief suppression, exclusion from support and lack of recognition as a father can lead to difficult grief experiences (Jones, Robb, Murphy, & Davies, 2019).

Continuing bonds has emerged as a prominent theory in the broader bereavement literature, conceptualizing the continued relationship with the deceased following the loss (Klass, 1993). In perinatal loss specifically, mothers have reported that their baby is represented in symbolic or small objects such as butterflies or hearts (Testoni, Bregoli, Pompele, Maccarini, 2020). Transitional objects, such as teddy bears, are often provided as mementos to patents, and have been shown to support mothers following perinatal loss (LeDuff, Bradshaw, Blake, & Ahern, 2017). This research found that the object filled the physical void upon leaving the hospital, validating the recipient's identity as a parent. Research explicitly investigating continuing bonds and use of objects in fathers is sparse, though qualitative research on the experiences of stillbirth does indicate fathers' expressions of continuing bonds. For example, speaking with and about the deceased child post-loss (Bonette & Broom, 2011).

The proposed research would address the gaps and limitations in the literature by aiming to investigate fathers' experiences of stillbirth and use of transitional objects, from a psychological perspective. This would take a theoretical approach, appraising such experiences through a relational, attachment and continuing bonds lens. The research will consider together the experiences of the fathers' relationship to the baby in pregnancy, the experience of stillbirth itself and of continued post-loss relationships through use of objects. Since fathers' report being 'forgotten' in pregnancy, birth, and post-loss (Bonette & Broom, 2011; Jones, Robb, Murphy, & Davies, 2019), it is important to understand experiences at each time point and their impact on the continuing relationship with the baby and the grief experience more broadly. The research will be qualitative, allowing fathers' experiences and meaning making surrounding the stillbirth to be central to findings. This mitigates the methodological flaws of the quantitative studies presented above. The findings from this research will increase understanding of how fathers' experience and process stillbirth, informing tailored support.

The research will address this aim through investigating the following research questions:

- 1. How do fathers experience relationships with their baby in pregnancy, stillbirth and following the loss?
- 2. How do fathers use objects during pregnancy and post-loss and how do these influence relational experiences explored in question 1.
- 3. How to fathers manage the psychological impact of the stillbirth?

#### Method

## Procedure

To investigate fathers' experiences of stillbirth, semi-structured interviews will be conducted with a sample of fathers who have experienced such. Interviews will be completed either over the phone or through Microsoft Teams.

Interviews will take place as and when participants are recruited to the study, recruitment will continue until enough interviews have been completed to meet the sample size. Participants will be informed of this through the participant information sheet which will outline that it might not be possible for everyone who expresses interest to take part. Once a participant expresses interest, a telephone call will be conducted to ensure participants meet inclusion/exclusion criteria before sending the demographics survey and participation information documents. The date and time for the interview will then be scheduled.

Prior to the interview, demographic information will be collected through a Qualtrics online survey. Participants will be given a unique participant code to enter into this survey to ensure that the principle researcher can link the survey responses with the corresponding participant. Only the principal researcher and the participant will know this code, allowing the file containing the survey data to remain anonymous. This online survey will also contain the participant information sheet and consent form with subsequent survey questions which will allow participants to consent to take part in the study. The participant information sheet and consent form will outline a procedure by which participant names will be anonymized in the publication of the research. However, given that participants in bereavement research have been found to request the use of their real names in previous research, citing rationale such as wanting to memorialize the deceased or challenge the stigma associated with their experiences (Scarth, 2016), should participants request for their real names to be used, the principal researcher will discuss this with the participant and seek informed consent for their name to be used in the writing of the research. This approach will be taken to respect the wishes of the participant and their rationales for wanting this. It is possible for some participants this will relate to wanting to exert the existence of their child in the world or to work against the stigma bereaved fathers may face. In this way although ethical standards traditionally advocate for full anonymity, in this instance the ethics of anonymising participants who wish to be named comes with challenge. With informed consent, the more ethical decision may be to respect participant wishes and include real names. This will be done with care, only first names will be used and all other identifying information will be omitted.

The interview will explore fathers' experiences of building relationships with their child through pregnancy, the experience of the loss itself and of continued relationships with the child following the loss. The interview will also explore the use of objects at each of these stages, and their influence on relationship development and continuing bonds post-loss. Interviews will be recorded via teams or a 'pick up' device for phone calls. Recordings will immediately be saved to an encrypted USB, and to the university's secure file store as soon as possible.

Recordings will be transcribed and subsequently analysed using Interpretative Phenomenological Analysis (IPA). This approach involves investigation of participants' lived experiences, with interpretation by both the participant and researcher of such experience (Eatough & Smith, 2017). This analysis will allow for an idiographic exploration of each fathers' unique experience before bringing together a comparative analysis of the sample overall. As such, the experiences and 'meaning-making' of each participant will be explored, with inferences as to common 'meaning-making' and experiences amongst them. The use of this approach to analysis will centre the findings of the research on fathers' experiences and meaning making, addressing the gaps in the current literature in which fathers' experiences of continuing bonds have not been explored in a meaningful way.

Where participants have displayed distress during the interview, a follow up phone call will be offered. This will be an opportunity to check on the fathers' emotional reaction to taking part in the study, with signposting to further support where appropriate.

## Participants

Though there is no strict consensus on the recommended sample size for IPA research, it has been suggested that an IPA study sample can range between 2 and 25 (Alase, 2017). For the purposes of this study it is important to determine a sample size that would both be feasible to analyze given time constraints, and be large enough to allow for an in depth understanding of the unique experiences of each participant whilst drawing inferences about commonalities. Therefore, there will be an aim to recruit between 6 and 12 participants to take part in the study.

Participants will be recruited using two methods: through recruiting charities and organisations and online. Two recruiting organisations have been contacted and have agreed to support recruitment. One such organization supports parents who have been bereaved perinatally, through provision of transitional objects. The other is an organisation that supports fathers in the perinatal period. Although this organisation does not work specifically with fathers who are bereaved, given the prevalence of perinatal loss it is likely that the organisations will have contact with fathers who have experienced stillbirth. The recruiting organisations will advertise the study internally with any fathers' they are in contact with and through advertisements on their online platforms. Further online recruitment will occur through the principal researcher's professional twitter account, in which connections with perinatal loss charities and organisations will be made to share advertisements for the study as widely as possible.

Since Interpretative Phenomenological Analysis (IPA) will be used, it is important to obtain a homogenous sample (Alase, 2017). To address the aims of this study, a sample of fathers who have experienced the use of objects to facilitate continuing bonds post-stillbirth is required. However, since there are existing barriers to fathers' participation in research (Doyle, Weller, Daniel, Mayfield, & Goldston, 2016), there may be difficulty in recruitment. Widening the criteria for participation at the outset may limit the homogeneity of the sample unnecessarily. As such, recruitment will take a phased approach. In the first phase the inclusion and exclusion criteria will be as follows:

## **Inclusion Criteria**

Participants will:

• Identify as male

• Have experienced a stillbirth in the last 10 years (defined as the loss of a baby from 20 weeks onwards in response to calls from the perinatal loss community to change this definition)

• Identify as having used an object to facilitate an ongoing relationship post-stillbirth/to cope with the loss.

• Be aged 18 or older.

# **Exclusion Criteria**

Participants will not:

• Have experienced the most recent stillbirth in the 6 months prior to taking part in the study

Should the above phase result in too few participants, criteria will be widened to include practices as well as objects. This inclusion criteria will become 'Identify as having used either an object or a practice (such as lighting candles) to facilitate an ongoing relationship post-stillbirth/to cope with the loss'.

Previous bereavement research has excluded participants who have experienced the loss less than 6 months ago to manage the potential distress of talking about loss soon after it occurs (Keen, Murray, & Payne, 2013). Furthermore, quantitative research in psychological outcomes for parents following perinatal loss indicate a decline in depressive symptoms over time (Farren et. Al, 2018). Levels of anxiety also seem to decrease over time, with levels similar to controls by between 6 and 30 months post-loss (Campbell-Jackson, & Horsch, 2014; Farren et al., 2018; Wall-Wieler et al., 2018). Therefore, although it is impossible to ascertain a time by which fathers' will 'recover' from the psychological distress from the stillbirth experience, it is hoped that by 6 months post loss fathers' will at least feel able to talk about such experiences.

Participants will not be selected based on age, ethnicity or nationality, although this information will be collected in order to report on the demographics of the study sample. No conclusions will be drawn in relation to any of the demographic data, however collection of this allows an appraisal of the representation of diverse groups in the research. This could allow for recommendations for further research to address underrepresentation of particular groups.

## Design

The study will adopt a qualitative approach to explore the experiences of fathers' who have experienced stillbirth. Data will be collected through semi-structured interviews conducted via video or telephone calls.

## Materials

Participants will be given a participation information sheet (either electronically via email or printed through the recruiting organisation). Participants will be asked to read the information sheet before accessing an online survey which will contain a series of statements of consent. Participants will be asked to enter their unique participant code into the survey to allow the principal researcher to link responses with the corresponding participant, whilst maintaining anonymity in data storage. Participants will be asked to confirm their consent to take part in the study by selecting 'agree' for each of these statements.

During this online survey participants will be asked to provide some basic demographic information including age and ethnicity.

Participants will be provided with a debrief sheet following completion of the interview. This will include contact information for support organisations and services available to the

participants. This debrief sheet will also include a reminder of the 2-week deadline to withdraw from the study and information and how to do this.

Interviews will follow an interview schedule which will outline the topic areas to explore, with some illustrative questions and prompts for each topic. Illustrative questions are adapted from existing research in perinatal loss using Interpretative Phenomenological Analysis (Nuzum, Meaney, & O'Donoghue, 2018) and question styles which help elicit the kinds of information pertinent to an IPA study (Pietkiewicz, & Smith, 2014) Topics that will be covered in each of the interviews are as follows:

- Experience of building relationship in pregnancy
- Experience of stillbirth itself (with exploration of how fathers related to the baby within this)
- Experience of relationship with the baby following the loss (both immediate and long term)
- An exploration of the use of objects at each of the stages outlined above.
- If not explored during discussion of above topics, fathers will be asked about prior experiences of perinatal loss and of any of children they have

## **Proposed analysis**

The principal researcher will transcribe each interview by hand to develop familiarity with the data and prepare this for further analysis. Each transcript will then be analysed through the following steps taken from Pietkiewicz & Smith (2014), in an iterative process:

- 1. Read transcript and create initial notes /codes
- 2. Group the codes into emerging themes, appraise relationships between codes and emerging themes
- 3. Creative interpretative narrative summaries for the themes
- 4. 'bracket' the emerging themes before moving onto next transcript.

Each transcript will be analysed in isolation, with emerging themes 'bracketed' before the next transcript is analysed. This reduces potential bias that the researcher may bring from the analyses of one father's experience to the next.

A second researcher will code one transcript to compare analysis, identifying potential assumptions made by the principal researcher about the data.

One all transcripts are analysed individually, similarities and differences across the transcripts will be appraised and analysed.

Descriptive statistics will be conducted on the demographic information to present the key characteristics of the sample.

## Practical issues (costs, logistics)

A research mobile phone will be used as a contact number given to participants to express interest in the study and as a point of contact. Participants will also be given the principal researchers university email address to express interest in the study. Participation information documents will also be sent from this email address. Interviews will be conducted using the principal researcher's personal mobile phone with a withheld number. This allows phone calls to be recorded with equipment that has been tested and works with this phone, whilst using the principal researchers unlimited minutes phone contract.

Qualtrics survey software will be used for the collection of data on demographic variables, and the obtaining of consent to take part in the study. Participants will be directed to the survey via a distribution link that they can open in their browser, this will be sent from the principal researchers email address. Participants will first see the participant information sheet and consent form. Participants will be asked to select 'I agree' to a series of statements within the survey to consent to take part in the study. Since I will be completing interviews, The interviewer will also confirm this consent verbally at the beginning of each interview. Identifying information (names, contact details) will not be collected within this survey, as such all data will be anonymous. Responses to this survey will be downloaded from Qualtrics and stored in excel format on the university file store.

Transcripts will be created electronically and stored on the university file store. The transcripts may be printed to aid with analysis. Once a printed transcript has been fully analysed, the transcript will be scanned and stored electronically on the university file store. The physical copy will then be destroyed.

Upon completion of the study, data will be transferred to the research coordinator for the Doctorate in Clinical Psychology at Lancaster University for long term storage. The research coordinator will be responsible for destroying this electronic data after 10 years.

Since interviews may be conducted via Microsoft Teams, and this may not be familiar software to participants, an information sheet on how to use teams and access the video call for the interview will be created. This will be attached to the email invitation to the interview with contact details for participants to get in touch if they have any difficulties accessing teams. Should there be technical difficulties accessing teams, participants will be asked to complete the following steps:

- 1. Close teams and start again
- 2. Restart computer and try again

Should neither of these options work, the interviewer will offer the participants either a rearranged interview or the opportunity to complete the interview over the phone instead.

Similarly, should the teams or phone call be interrupted or have bad connection which creates difficulties in communication, the interviewer will first wait for two minutes for the connection to improve before offering either a rearranged interview or to complete the interview over the phone.

Interviews will be recorded either via teams or a pick-up device and the principal researcher's personal laptop voice recording application. All interview recordings will be transferred to an encrypted USB immediately following the interview and will be uploaded to the university file store as soon as possible.

Since interviews will be conducted remotely, participants will not need to be reimbursed for travel. Participants will not be reimbursed for their time, as such there should be no costs involved in conducting the study. However, should costs incur these will be taken from the

principal researchers continuing professional development budget, funded by the Doctorate in Clinical Psychology course.

#### **Ethical concerns**

The topic of study is sensitive and could potentially cause distress for fathers' describing their experiences of a difficult life event. The following distress protocol will allow for the detection and management of distress that may arise during an interview. Since interviews will be conducted remotely, it will be important for the interviewer to be particularly alert to signs of distress (such as long pauses in answering questions, strained voice etc.). Should the interviewer notice distress, the participant will be told to take their time, and reminded that they can stop the interview at any point if things become too upsetting. The interviewer may also deem it appropriate to pause the interview if the participant becomes distressed, giving time for the participant to process the emotion and offering either continuation of the interview, termination or rearrangement of the interview if the participant would prefer. The principal researcher will use their clinical skills to manage distress as appropriate. Should the interview be terminated early or rearranged, participants will be reminded of the support services outlined on the debriefing sheet. The debriefing sheet will be given to participants early if an interview is stopped midway and continued at a later date. All participants will be given the debrief sheet upon completion of the interview regardless of whether distress was shown during the interview.

If a participant displays signs of distress during an interview, they will be offered a follow up call either on the same day or the following day. This will allow the interviewer to check in with the participants distress levels and signpost to further support where necessary.

Participants will be informed during the consent process, that should the interviewer feel concerned about their safety or the safety of others, they will have to break confidentiality to share their concerns with other professionals. The interviewer will also advise the participant to visit their GP if deemed appropriate, with information for out of hours support services also given.

The principal researcher can seek advice from either of the research and field supervisors for situations of distress to discuss options for offering support. These informal discussions can remain anonymous, with participant details only shared where there is risk to self or others (with agreement from the participant in the confidentiality agreement).

Since interviews will be conducted remotely, it is possible that fathers' will be taking part in the interview from their own homes. Participants will be reminded of this and asked to find a quiet and private space at home to take the call. Participants will be reminded that the interview will involve discussing very personal experiences of stillbirth and that they will be responsible for finding a space to take the interview call that will allow them to talk openly.

The interview will focus on experiences of stillbirth. It is possible that within this, fathers may speak about prior perinatal losses or other children they have who survived. It is however possible, that this information will not arise naturally during the interview. It is important to appraise this information, since it will help to describe the sample in terms of homogeneity. As such, questions to obtain this information will be asked where the topics have not arisen naturally. It is possible that the inclusion of such questions could convey the distressing message often given to bereaved parents of 'at least you have other children' or

'at least you know you can have children'. To mitigate this potential distress, discussions of such topics will be handled sensitively, with a message such as the following:

The experience of stillbirth is a difficult one no matter what your circumstance. Often it is assumed that the experience is 'easier' if you have living children or are able to become pregnant again. In reality, everybody experiences difficult events like this in varied ways and where for some this would bring comfort, for others it may do quite the opposite. Nevertheless, for the study to appraise these issues, it is important to have a sense of the broad experiences of the participants in terms of prior perinatal losses, live births and the presence of living children.

## Timescale

The timescale of the project is as follows:

- January-March 2021: Gain ethical approval. Begin recruitment.
- April-June 2021: Draft introduction and method. Begin data collection. Begin data analysis.
- July-September 2021: Complete data collection, continue data analysis.
- October-December 2021: Complete data analysis. Draft results and discussion.
- January-March 2022: Final formatting of thesis, submit final thesis.
- April-August 2022: Viva, complete thesis corrections.
- August 2022- February 2023: Pursue publication of findings.

#### References

Alase, A. (2017). The Interpretative Phenomenological Analysis (IPA): A Guide to a Good Qualitative Research Approach. *International Journal of Education and Literacy Studies*, *5*(2), 9-19.

Armstrong, D. (2001). Exploring fathers' experiences of pregnancy after a prior perinatal loss. *MCN: The American Journal of Maternal/Child Nursing*, 26(3), 147-153. Doi: 10.1097/00005721-200105000-00012.

Bonnette, S., & Broom, A. (2011). On grief, fathering and the male role in men's accounts of stillbirth. *Journal of Sociology*, 48(3), 248-265. doi: 10.1177/1440783311413485

Burden, C., Bradley, S., Storey, C., Ellis, A., Heazell, A. E., Downe, S., Cacciatore, J., & Siassakos, D. (2016). From grief, guilt pain and stigma to hope and pride–a systematic review and meta-analysis of mixed-method research of the psychosocial impact of stillbirth. *BMC Pregnancy and Childbirth*, 16(1), 9. doi: 10.1186/s12884-016-0800-8

Campbell-Jackson, L., & Horsch, A. (2014). The psychological impact of stillbirth on women: A systematic review. Illness, *Crisis & Loss*, 22(3), 237-256. Doi: doi.org/10.2190/IL.22.3.d

Christiansen, D. M. (2017). Posttraumatic stress disorder in parents following infant death: A systematic review. *Clinical Psychology Review*, 51, 60-74. Doi: <u>10.1016/j.cpr.2016.10.007</u>

Daniels, E., Arden-Close, E., & Mayers, A. (2020). Be quiet and man up: a qualitative questionnaire study into fathers who witnessed their Partner's birth trauma. *BMC Pregnancy and Childbirth*, 20(1), 1-12. <u>https://doi.org/10.1186/s12884-020-02902-2</u>

Doyle, O., Weller, B. E., Daniel, S. S., Mayfield, A., & Goldston, D. B. (2016). Overcoming barriers to fathers' participation in clinically relevant research: Recommendations from the field. *Social Work Research*, 1-5. Doi: 10.1093/swr/svw015

Eatough, V., & Smith, J. A. (2017) Interpretative phenomenological analysis. In: Willig, C. and Stainton-Rogers, W. (eds.) *Handbook of Qualitative Psychology*. (2<sup>nd</sup> ed., pp. 193-211). Sage.

Fairbairn, F. (2018). Registration of Stillbirth. Publication No. 05595. Retrieved from <u>https://www.parliament.uk/documents/commons-library/Registration-of-stillbirth-</u><u>SN05595.pdf</u>

Farren, J., Mitchell-Jones, N., Verbakel, J. Y., Timmerman, D., Jalmbrant, M., & Bourne, T. (2018). The psychological impact of early pregnancy loss. *Human Reproduction Update*, 24(6), 731-749. Doi: 10.1093/humupd/dmy025

Jones, K., Robb, M., Murphy, S., & Davies, A. (2019). New understandings of fathers' experiences of grief and loss following stillbirth and neonatal death: a scoping review. *Midwifery*, 79 (102531). Doi: 10.1016/j.midw.2019.102531

Keen, C., Murray, C. D., & Payne, S. (2013). A qualitative exploration of sensing the presence of the deceased following bereavement. *Mortality*, 18(4), 339-357. Doi: 10.1080/13576275.2013.819320

Klass, D. (1993). Solace and immortality: Bereaved parents' continuing bond with their children. *Death Studies*, 17(4), 343-368. Doi: 10.1080/07481189308252630

Klier, C. M., Geller, P. A., & Ritsher, J. B. (2002). Affective disorders in the aftermath of miscarriage: a comprehensive review. *Archives of Women's Mental Health*, *5*(4), 129-149. Doi: 10.1007/s00737-002-0146-2

LeDuff, L. D., Bradshaw, W. T., Blake, S. M., & Ahern, K. (2017). Transitional objects to faciliate grieving following perinatal loss. *Advances in Neonatal Care*, 17(5), 347-353. <u>https://doi.org/10.1097/ANC.0000000000429</u>

Nguyen, V., Temple-Smith, M., & Bilardi, J. (2019). Men's lived experiences of perinatal loss: A review of the literature. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 59(6), 757-766. Retrieved from https://obgyn.onlinelibrary.wiley.com/doi/abs/10.1111/ajo.13041

Nuzum, D., Meaney, S., & O'Donoghue, K. (2018). The impact of stillbirth on bereaved parents: A qualitative study. *PLoS One*, 13(1), e0191635. https://doi.org/10.1371/journal.pone.0191635

Office for National Statistics. (2019, August 1). Statistical Bulletin:Births in England and Wales:2018. Retrieved from

https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthsummarytablesenglandandwales/2018

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological journal*, 20(1), 7-14. DOI:10.14691/CPPJ.20.1.7

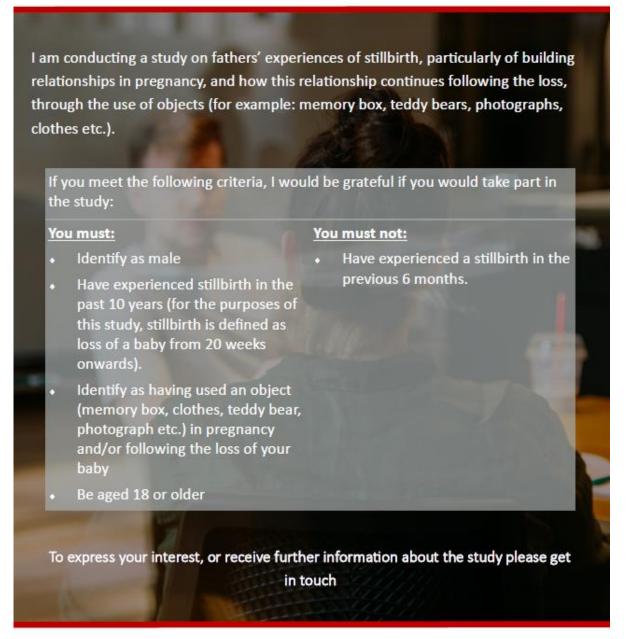
Testoni, I., Bregoli, J., Pompele, S., & Maccarini, A. (2020). Social Support in Perinatal Grief and Mothers' Continuing Bonds: A Qualitative Study With Italian Mourners. *Affilia: Journal of Women and Social Work* 1-18. Doi: 10.1177/0886109920906784

Wall-Wieler, E., Roos, L. L., & Bolton, J. (2018). Duration of maternal mental healthrelated outcomes after an infant's death: A retrospective matched cohort study using linkable administrative data. *Depression and Anxiety*, 35(4), 305-312. Doi: <u>10.1002/da.22729</u>

#### **Appendix B: Study poster**

# Are you a father who has Clinical Psychology Clinical Psychology Clinical Psychology experienced stillbirth in the past 10 years?

If so we would really appreciate hearing from you...



Contact details removed for submission

## **Appendix C: Participant information sheet**



#### **Participant Information Sheet**

#### Fathers' Relational Experiences of Stillbirth: Pre-natal Attachment, Loss and Continuing Bonds Through Use of Objects

My name is Amy Burgess and I am conducting this postgraduate research as a student on the Doctorate in Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

#### What is the study about?

The purpose of this study is to investigate fathers' experiences of stillbirth. In particular, the study will explore the ways that fathers' build relationships with their baby in pregnancy, and how they might foster continuing relationships with their baby following the loss. I am also interested in the way objects (like the baby's clothes, photographs or a memory box) are used to facilitate this relationship.

#### Why would you like me to take part?

I am interested in talking to fathers' who have experienced stillbirth. If you fit with the following criteria for inclusion in the study, then I would be extremely grateful if you could express interest as per instructions below.

#### **Inclusion Criteria**

You must:

Identify as male

• Have experienced a stillbirth in the last 10 years (defined as the loss of a baby from 20 weeks onwards in response to calls from the perinatal loss community to change this definition)

• Identify as having used an object to facilitate an ongoing relationship post-stillbirth/cope with the loss.

Be aged 18 or older.

#### **Exclusion Criteria**

You must not:

• Have experienced the a stillbirth in the 6 months prior to taking part in the study

#### What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to attend an interview with myself via video or phone call. The interview will involve questions about your experiences of building a relationship with your baby in pregnancy, your experiences of stillbirth, experiences of a continued relationship with your baby following the loss and questions on your use of particular objects (such as soft toys, baby clothes) throughout this. The length of time to complete the interview may vary from person to person but should take no longer than 90 minutes. The interview will involve discussing very personal experiences of stillbirth. For this reason, it is recommended that you find a quiet, safe space to take the call, in which you can talk openly about your experiences.

#### Do I have to take part?

No, it is completely up to you whether you decide to take part. If you do decide to take part and change your mind, you can choose to opt out. You can opt out of the study at any point up to and including your interview by emailing me at the address outlined at the end of this information sheet. You may also choose to opt out of the study during the interview by letting me know you would like to do so. If you choose to opt out of the study the data collected up until that point will not be used in the findings. If after completing the interview you wish to withdraw your data from the study, you may do so up to 2 weeks following your interview date by emailing me to request this. You will not be able to withdraw your data following this 2-week post-interview deadline as the data may have already been included in analysis.

#### Will my data be Identifiable?

Demographic information that you provide through an online survey before taking part in the study will remain anonymous, only the principal researcher will be able to identify this data ss yours through a unique participant code and the presentation of this data in the report will remain completely anonymous. The interview will be video, or audio recorded and transcribed. Audio and video recordings will be stored securely until the project has been submitted for publication, at which point these files will be destroyed. The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- Though you will be unavoidably identifiable in the audio and video recordings (and any identifiable information you share in the interview will appear in recordings) these will be stored securely and privately and will only be accessed by the researchers. Recordings will also be destroyed upon publication of the project. Transcripts of these interviews will not include any identifying information, including your name.
- At the end of the study, electronic files (including transcripts of interviews) will be kept securely for ten years. At the end of this period, they will be destroyed.
- Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I need to do this.

#### What will happen to the results?

The data from your interview will be pooled with data from other participants, analysed and written up in a paper as part of my doctoral thesis. The results may also be written up to be published in an academic or professional journal, and for written or verbal presentation to organisations involved in supporting fathers in the perinatal period and/or following perinatal loss. A summary of the results from this study will be made available to participants on request, following completion of the study. It is expected that summaries will be available from August 2022. If you would like a summary of the results, please contact me by email; *Contact details removed for submission* 

#### Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress during the interview you may wish to take a break or stop the interview early. At this point we can either rearrange the interview for another day, or you will have the option to withdraw from the study if you would like to. I will also offer follow up calls in the days after an interview to check how you are feeling. If you experience any distress following participation you are encouraged to inform the researcher and/or contact the resources provided below:

- If you feel you need support, please contact your GP who will be able to help further and signpost you to appropriate services if necessary.
- SANDS (Stillbirth and Neonatal Death Charity) provide a range of support for parents who have experienced the loss of a baby. <u>https://www.sands.org.uk/support-you/how-we-offer-support</u>
- Aching Arms are a charity supporting parents who have experienced perinatal loss and can arrange support from a trained 'befriender'. Please get in touch with <a href="mailto:support@achingarms.co.uk">support@achingarms.co.uk</a> if you would like to seek support.
- The International Stillbirth Alliance has a webpage with useful resources of support for parents who have experiences stillbirth, on the following webpage <a href="https://www.stillbirthalliance.org/parents/">https://www.stillbirthalliance.org/parents/</a>
- Mind (mental health charity) offer information and support for anybody experiencing mental health difficulties <u>https://www.mind.org.uk/</u>

#### Are there any benefits to taking part?

We hope that you will find the interview interesting, and might find benefit from talking about your experiences, which will hopefully lead to a better understanding of fathers' experiences of stillbirth, informing support. However, there are no direct benefits in taking part in the study.

#### Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

## How do I take part in the study?

Please ensure that you take adequate time to read this information sheet and consider your participation before expressing your interest in taking part. Should you wish to take part in the study, please contact the principal researcher, by email: *Contact details removed for submission*. The principal researcher will arrange an initial phone call with you to confirm that you meet criteria for taking part in the study. Following this you will receive a link to an online demographics and consent survey. The researcher will also organise with you a date and time for your interview. Should the interview take place over Microsoft Teams you will be sent a guide on how to use this platform.

## If I express interest, am I guaranteed to take part?

This study will involve only a small sample of fathers. Therefore, unfortunately it might be that not everyone who expresses interest will be able to take part. If you express interest at a time when it is not possible to take part, I will keep your name on a waiting list and contact you to take part should any participants withdraw from the study.

## Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

#### Contact details removed for submission

Alternatively, you can contact:

#### Contact details removed for submission

#### Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

#### Contact details removed for submission

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

#### Contact details removed for submission

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

# Appendix D: Consent form

Lancaster University	
Doctorate in Clinical Psychology	_
Please enter the unique participant code emailed to you by the principal researcher ( <i>if yo have not received this code, please get in touch with the principal researcher by email, a.burgess5@lancaster.ac.uk</i> )	ou -
experiences of stillbirth. In particular we would like to explore the relationships fathers' be with their baby in pregnancy, experiences of the stillbirth and the facilitation of relationships with the baby post-loss. We are also interested in the use of objects (soft toys, photographs, clothes) throughout this process.	
Before you consent to participating in the study we ask that you carefully read the participant information sheet that has been emailed to you. Once you have read this, please read each consent statement below and select 'agree' to confirm your agreemen with the statement.	nt
If you have any questions or queries before completing this consent form, please contact the principal researcher, Amy Burgess, by email: a.burgess5@lancaster.ac.uk.	ct
I confirm that I have read the information sheet and fully understand what is expected of me within this study.	ž
Agree	
Disagree	

I confirm that I have had the opportunity to ask any questions and to have them answered.

Agree

Disagree

I understand that my interview will be audio recorded and then made into an anonymised written transcript.

Agree Disagree

I understand that information from my interview will be pooled with other participants' responses, anonymised and may be published; all reasonable steps will be taken to protect the anonymity of the participants involved in this project.

Agree Disagree

I consent to information and quotations from my interview being used, in an anonymised form, in reports, conferences and training events.

Agree

Disagree

I understand that the researcher will discuss data with their supervisor as needed.

Agree

Disagree

I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with their research supervisor.

Agree

Disagree

I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has been completed.

Agree

Disagree

I consent to take part in the above study

Agree

Disagree

**Appendix E: Demographic Survey** 



Doctorate in Clinical Psychology

Thank you for consenting to take part in the study.

The following questions are intended to gather demographic information about the fathers participating in the study. The purpose of collecting such information is to report on the demographic 'make-up' of the fathers interviewed for the project. The research will not infer any differences in experience based on any of the information you give below, but reporting this information may help future researchers to target investigations at particular groups if this research is lacking. You are free to answer 'prefer not to say' for any of these questions, this will not affect your participation in the project in any way, all data collected through this survey will remain anonymous.

18-25	
26-35	
36-45	
46-55	
55+	
prefer not to say	

Please select the age group you fall into...

Which ethnic group do you identify with? *please chose one option that best describes your ethnic group and background. It is possible that none of the following options describe how you identify your ethnicity, if this is the case please select 'other' in the group which best describes you, or 'other, I would like to describe my ethnicity', please then describe this in question 22.* 

 White British

 White Traveller

 White American

 White other, please describe in question 22

 Black African

 Black Caribbean

 Black other, please describe in question 22

 Indian

 Pakistani

 Bangladeshi

#### Chinese

Asian other, please describe in question 22

White and Black Caribbean

White and Black African

White and Asian

Black Asian

Mixed other, please describe in question 22

I would like to describe my ethnicity (please do this in question 22).

If the boxes above do not capture your chosen ethnicity, please insert your own description:



Thank you for completing this survey and for volunteering to take part in the study.

You should have received a phone call form the principal researcher to schedule a date and time for your interview. If you have not yet received this or have any questions about the interview or this survey, please contact the principal researcher, by email: a.burgess5@lancaster.ac.uk.

#### **Appendix F: Debrief Information Sheet**



#### **Debrief Information Sheet**

#### Fathers' Relational Experiences of Stillbirth: Pre-natal Attachment, Loss and Continuing Bonds Through Use of Objects

Firstly, I want to take the time to thank you for taking part in the study and completing an interview about your experiences of stillbirth. The study aimed to investigate the ways fathers' experience building relationships with their baby in pregnancy, and how these continue following the loss. The study also looked at the ways in which fathers manage the emotional impact of stillbirth.

The data from your interview will be pooled with data from the other participants who took part. The data will be analysed to bring together themes of experience across a group of fathers' who have experienced stillbirth. It is hoped that findings can be used to inform the support offered to fathers with similar experiences.

The topics we discussed in the interview are sensitive and could have been distressing for you to talk about. You may have experienced emotional distress during the interview, it is also possible that you could experience emotional distress in the time following the interview. The interviewer should have asked you how you were feeling at the end of your interview and offered a follow up phone call to check in with you if this felt helpful. The following services are available to you should you wish to seek any further support:

- SANDS (Stillbirth and Neonatal Death Charity).
   Website:<u>https://www.sands.org.uk/?gclid=EAIaIQobChMI7dPUofvy6wIVWuJ3Ch3</u> <u>mHAe0EAAYASAAEgIvIvD\_BwE</u> Helpline: 0808 164 3332
- Mind (mental health charity)
   Website: <u>https://www.mind.org.uk/</u> Infoline: 0300 123 3393
- If you are worried about your emotional wellbeing and would like support for this, you can always book an appointment with your GP to discuss this. Your GP can refer you to a range of services for support with your mental health.

• If you are worried about keeping yourself safe, please seek support urgently by attending your nearest accident and emergency service.

You have the right to withdraw your data from the study, without giving any reason. Since your data will be pooled with other participants and analysed, you have 2 weeks from the date of your interview in which to request this. If you would like to withdraw your data from the study, please contact the research team with the contact details below.

You will be able to request a summary of the findings from the study as soon as they are available. It is estimated this will be available from August 2022. To request a summary, or to ask any further questions about the study, please contact:

#### Contact details removed for submission