

Parents experience of using ‘cold’ facilities at a children’s hospice after the death of  
their baby: A qualitative study

Elisabeth Anne Norton

Thesis submitted in partial fulfilment of the degree of Doctor of Clinical Psychology  
University of East Anglia

Faculty of Medicine and Health Sciences

Submission Date: 4<sup>th</sup> April 2018

Thesis portfolio word count: 25,129 (excluding appendices)

© This copy of the thesis has been supplied on condition that anyone who consults it is understood to recognise that its copyright rests with the author and that use of any information derived there from must be in accordance with current UK Copyright Law. In addition, any quotation or extract must include full attribution.

## **Thesis Portfolio Abstract**

**Background:** Movement in Children's hospices in the UK has seen the introduction of various 'cold' facilities, which allow families to spend time with their baby after they have died. To date, only two studies have explored the use of these facilities. This thesis aims to understand the experiences of parental grief and how this is expressed through a systematic review and explore the experiences of parents who have used 'cold' facilities within a paediatric hospice after the death of their infant.

**Methods:** A qualitative thematic synthesis of the literature was conducted using electronic databases and relevant reference sections of papers to evaluate parental grieving patterns. Alongside this, a qualitative study was conducted using semi-structured interviews with seven parents who had used 'cold' facilities at a regional children's hospice. Data were transcribed and analysed using thematic analysis.

**Results:** The systematic review found 7 studies which met the inclusion criteria. Quality was appraised, and data was analysed using thematic synthesis. Three themes identified: Affective vs. non-affective expression of grief; a reciprocal negotiation of grief; the pointlessness and importance of words. The thematic analysis of the qualitative study identified eight key themes.

**Conclusions:** The research highlighted the unique experiences of parental grief and the experience of using 'cold' facilities. It highlighted the need for education, discussion and openness about death and grief within the wider community. Limitations and directions for future research are considered.

## Table of Contents

<b>Acknowledgements.....</b>	<b>4</b>
<b>Introduction to thesis portfolio.....</b>	<b>6</b>
<b>Chapter 1: Systematic Review.....</b>	<b>7</b>
Title page and abstract.....	9
Introduction.....	10
Method.....	14
Findings.....	25
Discussion.....	31
References.....	35
<b>Chapter 2: Bridging Chapter.....</b>	<b>40</b>
<b>Chapter 3: Empirical paper.....</b>	<b>46</b>
Title page.....	47
Abstract.....	48
Introduction.....	49
Method.....	54
Results.....	59
Discussion.....	73
References.....	79

<b>Chapter 4: Extended Methodology</b> .....	<b>86</b>
Rationale for qualitative framework.....	86
Rationale for thematic analysis.....	87
Decisions regarding analysis.....	89
Ontological and epistemological.....	89
Reflective Journal.....	90
Researcher position: own position.....	90
Procedure.....	91
Ethical considerations.....	91
Interview topic guide.....	94
Thematic Analysis.....	95
<b>Chapter 5: Critical Analysis</b> .....	<b>97</b>
Overview of results.....	98
Strengths and limitations.....	99
Theoretical and clinical implications .....	100
<b>References</b> .....	<b>102</b>
<b>Appendixes</b> .....	<b>108</b>

## Acknowledgements

I would like to express my immense gratitude to the parents who have not only given their time and their story to this research, but who have helped me, personally and professionally, to think of others and appreciate the little things in life around us.

I hope that I can honour Archie, Alfie, Jude, Emma and Callum's memory and add to their legacy. I have held them in mind throughout and feel touched and blessed that I was able to hear about their journey in their short lives.

I would like to thank my primary research supervisor, Kiki Mastroyannopoulou, for her ongoing support throughout the research process. I have found you an inspiration from the beginning of my clinical journey and your guidance in researching such an emotive topic has been essential. To Imogen Rushworth, my advisor and secondary supervisor, without your above and beyond continued support I would not have made it through this process. Your words of encouragement at the most difficult times have always stayed with me and you have helped me to believe that I am capable, strong and resilient.

To my Mum, my constant inspiration to be a better person, to be caring and loving. I am so lucky and grateful that you have helped me to raise my children in the past four years. I can only say that without your love, praise, time, and for every cooked meal, load of washing, and for every school run I would not be where I am today.

To the man that became my Dad, you never failed to show me how proud you were of me and oh how I wish you were here today. I have fought a long battle

to be where I am today, you most certainly made that happen. Your presence is in the essence of this research, my determination to succeed for my family, my compassion, and my empathy for loss.

Last but by no means least, to my husband, you have stuck by me through the most challenging times and have been the one who has taken a lot of this on your shoulders as well.

### **Dedication**

This thesis is dedicated to my children who inspire my every move. You have allowed your mummy to follow her dream. I will do everything that I can to help you follow yours. You have all been the brightest of lights in the darkest times. As you would say Harry, there is no such thing as “I can’t do it” but “I can’t do it yet but I’ll try” ...and that I definitely have.

## **Introduction to the thesis portfolio**

**Chapter 1** is a qualitative thematic synthesis which reviews current literature exploring fathers' and mothers' grief response and patterns and how these may interact within a relationship. There is an extensive evidence base in quantitative research regarding parental bereavement. This review adds to the evidence base giving a more in-depth analysis of this. It is hoped that it can inform bereavement services' practice when considering appropriate support as well as wider social understanding of grief response.

**Chapter 2** is a bridging chapter linking the experiences of mothers' and fathers' expressions of grief to the empirical study of parents' experiences of 'cold' facilities used at a children's hospice following the death of a baby. Consideration for the context of societal views on death, gender and grief is included.

**Chapter 3** is an empirical paper exploring the experiences of parents who have used 'cold' facilities at a children's hospice following the death of their baby. The study explores how parents experienced spending time with their baby after death and their views of using this service. The results are described in terms of key themes. The findings are discussed in addition to clinical and research implications.

**Chapter 4** is an extended methodology section and outlines the qualitative methodology used for the empirical paper.

**Chapter 5** presents a critical analysis of the thesis portfolio, summarising combined results and considering strengths and limitations of the papers.

## **Chapter 1: Systematic Review**

Systematic review prepared for submission to Death Studies and formatted in accordance with their guidance (Appendix A). The systematic review is 6,017 words in length, there is no word limit for this journal but should be no more than 25 pages. This review is 23 pages in length excluding references. The abstract is 98 words in length (journal abstract word limit 100 words excluding keywords).

**How mothers and fathers grieve: A thematic synthesis.**

**Elisabeth Norton**

*Department of Clinical Psychology, University of East Anglia, UK*

[Elisabeth.norton@uea.ac.uk](mailto:Elisabeth.norton@uea.ac.uk)

**Kiki Mastroyannopoulou**

*Department of Clinical Psychology, University of East Anglia, UK*

**Dr Imogen Rushworth**

*Department of Clinical Psychology, University of East Anglia, UK*

### **Abstract**

Understanding parental grieving patterns and how these may interact within a spousal relationship is crucial to inform bereavement services. A review of qualitative data on parents' grief response was synthesized to identify grief patterns in mothers and fathers. Seven electronic databases were searched systematically, along with a manual search. Peer reviewed articles were included if they qualitatively explored experiences of parents' grief expression. All included studies were subjected to a quality assessment. Three themes were identified: Affective vs. non-affective expression of grief; a reciprocal negotiation of grief; the pointlessness and importance of words. Conclusions and service implications are discussed.

Keywords: parental grief, grieving patterns, thematic synthesis, death of a child

Word count: 98

## **Introduction**

There is an overwhelming volume of quantitative research into the complexity of parental grief and how it is experienced by mothers and fathers (Field & Filansky, 2010; Hawthorne, Youngblut & Brooten, 2016; Moriarty, Carroll, & Cotroneo, 1996; Riley, LaMontagne, Hepworth & Murphy, 2007; Vance, Boyle, Najman & Thearle, 1995). This includes systematic reviews (Albuquerque, Pereira, & Narciso, 2016; Burden, et al., 2016; Koopmans, Wilson, Cacciatore & Flenady, 2013), and theoretical literature reviews (Davies, 2003). Qualitative studies can help to explore and understand more refined areas of interest (Braun & Clarke, 2013) and the variety of different methods to synthesize qualitative research are emerging and developing (Barnett-Page & Thomas, 2009; Thomas & Harden, 2008). A thematic synthesis of qualitative research can be a beneficial starting point when trying to understand a phenomenon and bringing together a body of research (Thomas & Harden, 2008). Bearing in mind the complexity and uniqueness of parental grief and gender differences, this approach has been adopted to understand the literature thus far.

## **Background**

As discussed above, there is extensive literature concerning parental grief, an inimitable form of grief and one of the most devastating forms of bereavement (Arnold & Gemma, 2008; Arnold, Gemma & Cushman, 2005; Nordlund et al, 2012; Tugendhat, 2005). Some parents navigate their way through the depths of grief whilst being in a relationship. Co-experiencing grief as two parents who have lost a child could bring additional challenges (Bergstraesser, Inglin, Hornung & Landolt, 2015; Vance, Boyle, Najman & Thearle, 2002).

How a parent reacts and responds to grief is individual and the way in which this evolves within a relationship is of interest. It is important to consider what the current understanding is within the literature relating to different ways of grieving in order to inform bereavement practices. Martin and Doka (2000) addressed different ways that grief can be expressed and suggested that there are four main domains in which grief is experienced: physical, affective, cognitive and spiritual. These four domains were proposed to be expressed in varied behavioural experiences, for example, crying could be showing affective expression and illness-related behaviours could be expressing physical reactions. In this work and later work (Doka & Martin, 2010) the authors outline two different ways in which a person can grieve: instrumental and intuitive. Grieving can be seen on a continuum with what is known as an 'intuitive' pattern at one end and 'instrumental' at the other. Intuitive grievers experience and express through their affect, whereas instrumental grievers may do this in a physical or cognitive way. As the continuum would suggest, the two patterns to grieving are not absolute; the authors also termed a *blended pattern* of using both. Although the different types of grief patterns can be seen to favour certain genders, with men often exhibiting instrumental grief reactions and women often more intuitive emotive expression of grief, they state that "clearly, patterns are *influenced* by gender but not *determined* by it" (page 4). Fathers are more likely to avoid or repress difficulties than mothers (McGeal, Evans, & Burrows, 1997). Nevertheless, a spouse can show a greater understanding and acceptance for the different ways their partner could grieve (Toller & Braithwaite, 2009).

Furthermore, implications of these grieving patterns are that there is a bias towards an affective expression of grief in western culture, therapeutic professions and self-help literature (Martin & Doka, 2000). This indicates the need for more

understanding of these different forms of grief, including the advantages and disadvantages of the different forms.

Despite the literature on grieving patterns being extensive, the way in which such patterns might interact or be experienced within a relationship, particularly following parental bereavement, is limited. A recent systematic review of both quantitative and qualitative literature looked at changes in a couple's relationship after the death of their child (Albuquerque, Perira & Narcisco. 2016). Particularly of note, Albuquerque et al. referred to "incongruent grieving after the death of a child, where mothers and fathers often grieve differently, expressing and coping with the loss in different ways". However, the concept of incongruent grieving was not the focus of the systematic review and the literature reviewed both quantitative and qualitative studies. There appears to be a gap in the literature relating to incongruent grieving in parents. Furthermore, understanding an in-depth phenomenon such as this requires more insight which could be gained through qualitative research methods.

Previous reviews have been applied broadly to the area of experiencing the death of a child. A recent narrative review outlines the enduring impact of the life changing loss of a child (Price & Jones, 2015). It highlighted that there is a lack of support and a lack of insight into male bereavement needs. However, this review rather sparsely explored grieving patterns within a relationship following parental bereavement and a more detailed and refining exploration is needed.

## **Rationale for current research**

Gaining a deeper understanding of grief patterns of mothers and fathers after the loss of a child, as well as how grieving patterns may interact within a relationship would be beneficial for bereavement support services. In addition to this, it is hoped that sparking a wider social insight into different grieving styles may allow for extended empathy and consideration to those grieving. As discussed, existing research has given greater insight into the experiences of bereaved parents and the uniqueness of parental grief and possible effects on a couple's relationship (Cacciatore, Lacasse, Lietz & McPherson, 2013; Erlandsson, Saflund, Wredling & Radestad, 2011; Field & Filanosky, 2010; Hawthorne, Youngblut & Brooten, 2017; Riley, LaMontagne, Hepworth & Murphy, 2007). However, the majority of studies are quantitative, which does not allow for an in-depth investigation of the lived experiences of parental grief. A qualitative review of the literature would aim to gain a unique insight and understanding of the complex phenomenon of gender differences in parental grief (Stern, Jordan & McArthur, 2014).

## **Aims**

A thematic synthesis of qualitative data has been adopted. The aim of this review is to synthesise the best available evidence exploring the experiences of grief within genders on bereaved mothers and fathers after the loss of a child.

## **Method**

A thematic synthesis of published studies was conducted which qualitatively evaluated the experiences of parents after the death of a child. Only previously

published studies were used, so there was no requirement for ethical review. Studies were included for full review if they adhered to the following criteria:

### **Inclusion Criteria**

- Adults aged 18 and over
- Mothers and/or fathers who had experienced the death of a child
- Studies exploring how grief is experienced by mothers and/or fathers
- Gender and relational aspects of parental grief are the focus of the study
- Exclusively qualitative methodology

### **Exclusion Criteria**

- They were not written in English.
- Parental grief and the couple's relationship were outlined, but the focus was on something other than the relationship (for example, experience of having another child).
- Mixed methods or quantitative design

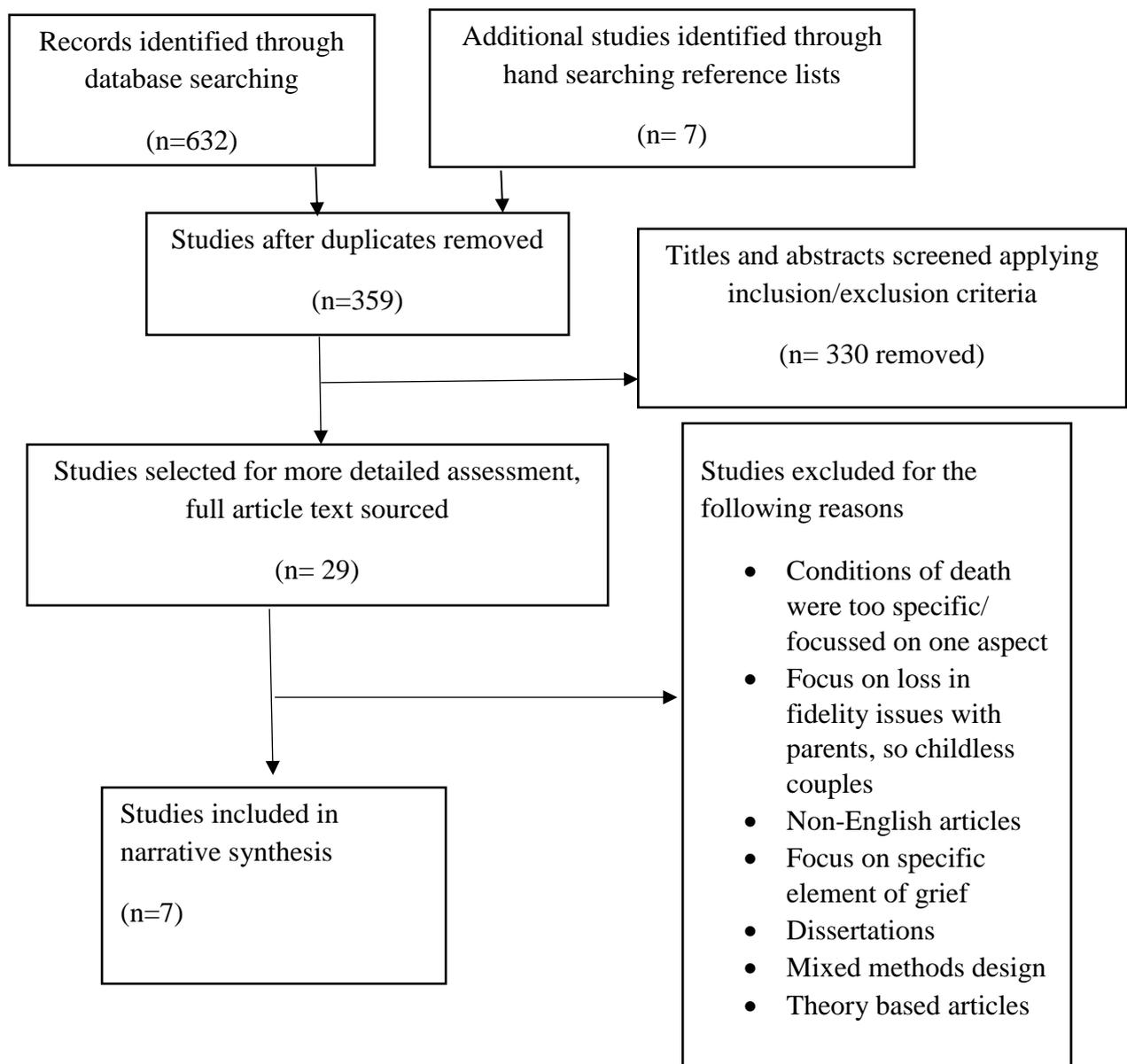
### **Search Strategy**

Studies were identified by searching seven electronic databases: Medline, PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Social Science Citation Index (SSCI), Embase, Applied Social Science Index and Abstracts (ASSIA), Applied and Complimentary Medicine Database (AMED) and the Cochrane Library. Searches were run in August 2017. The search terms used in each of the databases were as follows: (“parental grief” OR “bereavement” OR “grief” OR “parents experience”) AND (“relationship”) AND (“child death” OR “child loss”) AND (“qualitative”). Reference lists of relevant studies were then

scanned for additional studies of relevance to ensure that relevant papers were not overlooked. Initially titles were screened, followed by abstracts. For relevant studies, full texts were sourced.

A total of 7 papers were included in the review. All full papers retrieved had been published since 1996. Figure 1. Shows a consort diagram of the search process

Figure 1. Consort diagram of search methodology



## **Study selection**

The review limited the search to experience of parental grief and couple's relationship only and excluded studies if they focused on other specific aspects within a relationship (e.g. having another child). This was to ensure that the studies included in the review would comprise of accounts regarding grieving patterns within a relationship. To ensure that adequate descriptive detail was provided, mixed methods and quantitative studies were excluded. Studies were included of experience of parental bereavement, regardless of the amount of time passed since death and the age of child at death, as intensity of this unique form of grief is present throughout (Arnold & Gemma, 2008).

The extensive search items for parental bereavement were to ensure that key articles were found. After duplicates were removed, 359 search results required further screening.

This initial screening focused on removing studies that clearly did not meet criteria e.g. theses, book chapters, or non-human studies. The titles and abstracts were then screened to identify articles that met the eligibility criteria, resulting in 29 appropriate articles. The articles were read in full to assess their quality. Studies were excluded where the focus was not specifically on how parental bereavement was either experienced through the relationship, and/or if it did not outline a gendered account.

## **Data extraction**

In accordance with Butler, Hall and Copnell's (2016) guide to writing a qualitative systematic review the following data were extracted from the findings of

the final articles by the primary author: bibliographic information; study aims; study design: methodological underpinnings; sample: strategy, size, inclusion/exclusion criteria and participant characteristics; data collection methods; data analysis techniques; ethical considerations and issues; results: themes, quotes, author interpretations or explanations; and strengths and limitations. First order constructs (participant quotes) were considered and then second order constructs (researcher interpretation) by line by line coding.

### **Study characteristics**

Seven studies were qualitatively reviewed. These studies provided data on mothers and fathers experience of grief after the loss of a child. The following will describe characteristics of each study, which is given in more detail in Table 1.

The focus of these studies was mainly the effect of death of a child on their relationship and how the grief was experienced by mothers and fathers (Alam, Barrera, D'Agostino, Nicholas & Schneiderman, 2012; Cacciatore & Defrain, 2008; Hooghe, Rosenblatt & Rober, 2017; Hussin & Azman, 2016; Maritz, Poggenpoel & Myburg, 2008; Richies & Dawson, 1996), except one which focussed purely on the fathers' experience (Aho, Tarkka, Astedt-Kurki & Kaunone, 2009).

In Aho et al.'s (2009) study of fathers, participants' age ranged between 29 to 49, and all but one were married. In this study, the life span of the deceased child was 40 minutes to two years and three months old, 80% of the sample died before the age of four months old. The children had died for varying reasons including heart defect, kidney disease and cot death.

Table 1: Summary of included studies

First Author, year, country, reference	Interest	Participants/ Data collection method	Interviewed individually or dyads	Perspective/ Analysis	Main results
Aho et al, 2009, Finland	Fathers' experience of support after the death of a child	8 father whom had lost a child under the age of 3 All completed questionnaire 6 completed semi-structured interview	Individually	Inductive qualitative content analysis	Outlined themes around support: Positive & Negative Support from the spouse and other children in the family. Positive & negative support from close relatives and friends Positive & Negative support from professionals
Alam et al, 2012, Canada	Bereavement experiences of mothers and fathers over time	18 mothers, 13 fathers In depth interviews, total of 18 interviewed at time point 2	Individually	Content analysis	Following major themes and categories emerged: a) Employment attitudes and practices b) Grief expression c) Coping with grief and bereavement d) Relationship with surviving children e) Communication with spouse f) Relationship with other family members
Cacciato re et al, 2008, USA	Stillbirth and the couple: A gender-based exploration	Retrospective analysis of anonymous data, quotations from 74 bereaved family members Discussion group	N/A	Constant Comparative method Grounded theory	Findings: Cohesion Sense of control: internal and external loci Attachment Social Support

Hooghe et al, 2017, Belgium	Emotional responsive attunement in couples after the loss of a child	15 in-depth interviews with couples 26 parents participated (14 mothers, 12 fathers) who had lost a child to cancer	12 Dyads interviews 2 mothers individually (fathers did not want to take part) 1 couple interviewed separately	Social Constructivist Thematic coding	4 main meanings related to not talking 1) Not talking because of the inadequacy and pointlessness in grief 2) Not talking to create some distance from the pain of grief 3) Not talking as an expression of a personal, intimate process 4) Not talking because the partner has the same loss but a different grief process
Hussin et al, 2016, Malaysia	Parental grief & marital issues	3 bereaved mothers 3 bereaved fathers All bereaved parents were Muslim or Malay and had lost a child due to vehicle accidents Semi structured interviews	Not clear	Thematic Analysis	Themes identified Challenges in; communication; respect different coping styles; to maintain spousal relationship  Spousal relationship: As usual (no change); Pretend like nothing happened; Conflicts; Closer relationship
Maritz et al, 2008, South Africa	Couples relationship	9 in-depth semi structured interviews with 7 mothers & 2 fathers	Not clear, indicates individually	Descriptive method of open coding Autoethnography	Themes identified: Couples talk of their life "before" bereavement The extremity of this traumatic & shocking event hits like a tornado Even if death was expected it was a shock

---

					<p>Parents loss of, or attempt to control their internal as well as external environment is a continuous process</p> <p>Confusion impacts on the role expectations of the parent and results in role conflict</p> <p>Grief is highly individualized, as each parent is unique</p> <p>Feelings of anger, guilt and blame are experienced</p> <p>The effect on the couples' communication</p> <p>Realising the permanence of loss and the aftermath.</p>
Richies et al, 1996, UK	Communities & bereavement	<p>31 Narrative interviews with parents</p> <p>Overt observation of bereavement groups</p> <p>18 marital experiences sampled</p>	<p>7 couples interviewed individually</p> <p>5 couples together</p> <p>6 mother only individually</p>	Social constructivist perspective	<p><i>The gendering of grief work:</i> Women play a large role in bereavement support networks. Women more willing to express emotion in relation to the loss of their child/men more considered accounts. They are more prepared to express grief publicly whereas men would be very private.</p> <p><i>Marking the boundary:</i> sense of being avoided by society, distance from partner, absence of deceased child in everyday conversations, returning to work and 'normality'</p> <p><i>Shared ordeal:</i> Common experiences and shared distress, importance of reliving and retelling stories with grief groups.</p>

---

Furthermore, five of the reviewed articles included mothers and fathers aged between 27 and 65 years old (Alam et al., 2012; Hooghe et al., 2017; Hussin & Azman, 2016; Maritz et al., 2008; Richies & Dawson, 1996) and one of the reviewed studies reported very limited demographic information due to data collection method (Cacciatore & Defrain, 2008). Maritz et al. (2008) outlined that at least a year had passed since the death of the child, and couples were married at the time of child's death. The children in Richies and Dawson's study were aged between eight and up to 33 at the time of death as well as three stillbirths: and time passed since death ranged from three months to 23 years ago (average of two and a half years).

### **Assessment of Quality and Risk of Bias of Included Studies**

After relevant articles were identified and selected, included studies were appraised using the Critical Appraisal Skills Programme (CASP, 2014) for qualitative studies. This checklist provides a framework for systematically appraising the quality of qualitative research (see Appendix B). To address the quality of research, the CASP incorporates three main steps to assessing the research, these are: (1) Are the results of the study valid? (2) What are the results?; (3) Are the results useful?.

Ordered steps were carried out; firstly, by familiarisation to the CASP questions (outlined in Table 2.); secondly, reading the studies with the CASP questions in mind, and; thirdly, by re-reading the studies in detail and scoring the studies whether criteria were met on each individual quality question of the CASP. The CASP evaluated the selected qualitative studies by asking 10 questions. The initial two questions screened the studies to consider proceeding, these were "was there a clear statement of the aims of the research?" and "is a qualitative methodology

appropriate?”. The following eight questions appraised the studies, for example, “was the research design appropriate to address the aims of the research?”, “has the relationship between researcher and participants been adequately considered?” and “was the data analysis sufficiently rigorous?”

First author, year, country	clear statement?	qualitative method?	Research design	Recruitment	Data collection	Consideration of the relationship between researcher and participant	Ethical issues considered?	Rigor in data analysis	Clear statement of findings?	How valuable is the research?	Overall CASP score
Aho et al., 2009, Finland	Yes	Yes	Yes	Yes Fathers identified through closed internet group for bereaved parents	Yes Triangulation method	Not clear	Yes, but short time since death (2.5 months)	Yes	Yes	Important aspects for, service implications	8
Alan et al.	Yes	Yes	Yes	Yes Child had been treated at oncology/hematology unit	Yes	No clear description regarding this	Yes	Yes	Yes	Important understand what parents need	9
Cacciatore et al.	Yes	Yes	Yes	Yes but limited information about participants	Yes	No consideration	No not sufficiently discussed	Yes	Yes	Applicable to systemic therapy	7
Hooghe et al.	Yes	Yes	Yes	Yes	Yes	Yes, but limited	Yes	Yes	Yes	Yes	9
Hussin et al.	Yes	Yes	Yes	Yes	Yes	Yes, but limited	Not sufficiently	Yes	Yes	Yes	8
Maritz et al.	Yes	Yes	Yes	Yes	Yes	Yes ++	Yes	Yes	Yes	Yes	10
Richies et al.	Yes	Yes	Yes	Yes	Yes	Not clear	Not sufficiently discussed	Yes	Yes	Yes	8

## Critical Appraisal

The CASP tool was used to consider the quality of each study with scores varying between seven and ten on the ten criterion markers. Some criteria on the CASP were met by all the studies. For example, of the seven included studies, all had a clear statement of aims, outlining the relevance of the research and the goal of the study, with a qualitative methodology being viewed as appropriate for all included studies. None of the studies were excluded based upon quality grounds, but quality ratings are reported, and issues of quality are discussed.

Consideration of the relationship between participants and researcher (question six) was often not considered or written about sufficiently, this was considered alongside rigor in data analysis and as all of the seven studies met data analysis criteria, the studies were included.

Conducting research with a vulnerable population such as bereaved parents requires ethical consideration (question seven). Some of the articles reviewed in this systematic review described some of the ethical considerations that were made, for example, right to withdraw and informed consent (Aho et al, 2009; Alam et al 2012; Hooghe et al 2017; Maritz et al, 2008). However, three of the studies made no specific mention to ethical procedures or ethical approval (Cacciatore & Defrain, 2008; Hussin & Azman, 2016; Richies & Dawson, 1996).

### **Method of Synthesis**

Analysis of the extracted data were completed applying thematic analysis techniques: to collectively organise the findings of multiple qualitative data (Thomas & Harden, 2008). The thematic synthesis followed guidelines outlined by Thomas and Harden alongside the guidelines within the Cochrane Handbook for systematic reviews (Higgins & Green, 2011). Such guidance supports the researcher in maintaining a systematic structure to the review, however, allowing a synthesis of themes should be done with caution and efforts were taken by the primary researcher to avoid bias and enhance transparency in the systematic review.

The thematic synthesis of the data followed three stages as outlined by Thomas and Harden (2008): (1) line by line coding of the findings; (2) organisation of codes into related areas of construct (descriptive) themes; (3) development of analytical themes. Firstly, in stage one, data were extracted in order to synthesise the

study findings according to the review question of exploring the experiences of grief on bereaved mothers and fathers after the loss of a child. Line-by-line hand coding of the findings of each study was completed according to its meaning and content. Coding of direct quotes from participants from each study along with analysis of the study. Free coding involved researcher interpretation of participant quotes: an example of this process is shown below in Table 3.

**Table 3. Example of coding of data**

<b>First author, year</b>	<b>Direct quote</b>	<b>Codes</b>	<b>Descriptive themes</b>	<b>Analytical themes</b>
Alam et al. 2012	“I probably talk about it more (than husband)”	<ul style="list-style-type: none"> <li>• Mothers expression of grief</li> <li>• Talking about grief</li> <li>• Different coping style compared to fathers</li> </ul>	<ul style="list-style-type: none"> <li>• Affective Expression of Grief</li> <li>• Coping style</li> </ul>	Affective grieving pattern

## **Findings**

Based on the results of the thematic synthesis of reviewed studies: three themes were identified: Affective vs. non-affective expression of grief; a reciprocal negotiation of grief; and the pointlessness and importance of words.

## Themes

### *Affective vs. Non-Affective Expression of Grief*

In seven of the studies, fathers reported expressing grief differently from their partners (Aho et al., 2009; Alam et al., 2012; Cacciatore & Defrain, 2008; Hooghe et al., 2017; Hussin & Azman, 2016; Maritz et al, 2008; Richies & Dawson, 1996) either by repressing their own feelings “as long as the lid is on it, it’s ok. But if the lid goes off then it splashes out” (Hooghe et al., p. 5), by being the ‘strong’ one, or expressing them privately, or finding comfort from physical aspects of life such as ‘doing’ or returning to work “it’s easy to get involved in work...hide in work” (Alam et al, p.11) and “when he grieves he likes to you know get out of the house, into the garage and do his thing” (Maritz et al., p. 606). One father reflected on this difference:

I mean it’s the sort of standard thing you read...a lot...and...they talk about it at (bereavement support groups) as well...women weep and men get angry...and I’d say...we’re classic examples of that. I’ve been more angry and unaccepting of this. (Alam et al., p.9)

A mother reflected that “it was difficult to understand him (husband). He never cry. The only thing that he did was going out with his friends and neglected me.” (Hussin & Azman, p.21). These two quotes demonstrate the immense and complex journey of grieving together after the loss of a child and the layered impact of the effect of different grieving styles.

However, some studies showed that fathers did experience the affect but that this was just done in a private way: “we’ve this shed at work and there would be times I would lock myself in and just roar” (Richies & Dawson, 1996, p. 149). One

father in one of the studies described an affective expression of grief with his spouse “grieving together...talking, weeping” (Aho et al, 2009, p. 96).

In general, throughout all reviewed studies, bereaved mothers showed a more emotionally intense expression of grief, crying and talking about it “all mothers reported continued intense and prolonged grief reactions...compared to the majority of fathers, whose grieving was reported to be more private and less intense” (Alam et al., p.9). In two of the studies there was higher reporting of suicidal ideation in women (Alam et al., 2008; Hooghe et al., 2017) “you think about dying, all you want to do is die...want to go be with him...on the worst days (pause) where uh, even with (surviving child) here, I still want to die” (Alam et al., p. 9). Further, mothers would tend to seek support from extended family members, friends, or support groups for bereaved parents (Cacciatore & Defrain, 2008; Richies & Dawson, 1996).

To express grief privately was noted more for fathers than mothers: however, one of the analysed studies described that this was universal in both parents. One mother commented “And then, at night, when I’m in my bed, then I can let myself go. Then I cried, when nobody was around. I rather do that on my own, just like he (the father) does” (Hooghe et al., p.6).

The consequences of a lack of understanding for different grieving styles was noted throughout all of the studies and the implications for appropriate support “he had a hard time, he uhm...because we raise our sons and men with the idea that cowboys don’t cry; it was very difficult for him” (Maritz et al., p.606). Reflecting on support and amount of leave granted a father said, “the most important thing would have been for everybody to understand and accept that men, too, grieve for their children just as intensely as women” (Aho et al., p.100).

Although some of the studies suggest that fathers seek a more physical outlet for grief, having a meaningful role was important for both mothers and fathers. The importance of having a role in giving meaning and focus: parenting remaining siblings “we have two other living children we have to carry on for them...our (living children) are why we had to try hard to keep ourselves together” (Cacciatore & Defrain, 2008, p. 361); organising the funeral; providing support (emotional, physical and financial); and home keeper was important to both mothers and fathers (Aho et al., 2009; Alam et al., 2012; Cacciatore & Defrain; Hooghe et al., 2017; Maritz et al., 2008; Richies & Dawson, 1996). A father described possible therapeutic benefits of this “maybe I got a role in which I felt that I was useful and it did not seem to be all in vain” (Aho et al., p. 96). A meaningful role was also found in the ability to contribute to building a legacy for the deceased child “we are...helping out with the bikeathon...dedicating the whole Ontario portion to (daughter)...if someone was to...hand me a million bucks I would be gone out of (workplace) so fast...I’d just spend the rest of my life doing this stuff” (Alam et al., p. 8).

### ***A reciprocal negotiation of grief***

As discussed in the introduction, a previous systematic review reported “incongruent grieving” which may give rise to difficulties in a relationship and feeling confused (Albuquerque, Pereira & Narciso, 2016; Burden et al., 2016). Albuquerque et al. discuss the findings of studies that detail positive and negative effects on a couple’s relationship. However, the current systematic review found that there was an overarching common notion of acceptance, respect and a negotiation of grief within a relationship: allowing for different grieving styles. When this reciprocal understanding was present, couples spoke of experiencing a

strengthened relationship, going beyond existing bonds “we weathered it actually surprisingly well, actually, if anything it drew us together. We supported each other...it made our, it proved our bond was very strong” (Maritz et al., 2016, p.609).

Mothers and fathers reported recognising the needs of their spouse and either allowing them the time to grieve in the way that they required “I often sense what he is feeling, and then I’ll leave him to it” (Hooghe et al. 2017, p.7), or adjusting, accepting and negotiating a way through it together “he has tried to meet me half way...to talk about (daughter)...more” (Alam et al. 2012, p.10) and “putting the spouse’s grief before their own” (Aho et al. 2009, p. 96). Spouses showed respect for one another “I respect his need, he needs room and space to grieve” (Hussin & Azman, 2016, p. 21) and “we allow each other to grieve in our own way” (Cacciatore & Defrain, 2008, p. 259). Whether this was done as a couple or alone “we left each other on our own to cope” (Alam et al, p. 12) there was a sense that it allowed for a deeper connection. Although the dialogue of frustration and challenges in a relationship was not absent, there was another layer of bonding and intimacy reported in these studies (Alam et al., 2012; Cacciatore & Defrain, 2008; Hooghe et al., 2017; Hussin & Azman), “our relationship seems stronger now that it has weathered the storm” (Cacciatore & Defrain, p. 358).

### ***The pointlessness and importance of Words***

Hooghe et al. (2017) termed a theme “the uselessness of words” (p. 7) and the current review found a similar theme. This was a sense from mothers and fathers that sometimes what is not said is more important, or of the total inadequacy for words in being able to describe the magnitude of their feelings “I understand that it was difficult to have conversation after the loss. Therefore, instead of talking, the presence of my wife was more important. It gave me comfort and serene” (Hussin &

Azman, 2016, p. 21); along with a felt absence of words from others “parents sensing a lack of permission (from others) to talk about their child’s earlier life” (Richies & Dawson, 1996, p. 153); there was also a sense of protecting their partner from their grief and a feeling that words evoke grief and the pain associated with it (Alam et al., 2012; Cacciatore et al., 2008; Hussin & Azman; Maritz et al., 2008; Richies & Dawson).

Hooghe et al. (2017) described that parents in an intimate relationship did not need to communicate using words, that there were other ways of “reading” communication cues, such as facial expression, physical touch and nonverbal cues “We often understand each other without saying one word. Then we look at each other for just one moment, like, yes, again we are thinking about the same thing” (p.7). They found that this could be positive or negative; for some parents a nonverbal cue could indicate that they did not require their support at that time and might result in them grieving alone, whereas for others, a nonverbal cue could signal a need for comfort.

In several of the studies, both mothers and fathers reported the need to talk about their deceased child with friends and other family members and that doing so kept their memory alive, however, mothers would do this more frequently than fathers (Aho et al.; Alam et al.; Cacciatore & Defrain; Maritz et al.; Richies & Dawson).

Additionally, some studies suggest that there is an element of avoidance from fathers: avoiding speaking of the deceased (Aho et al.; Alam et al.) “If I am not thinking about my son, obviously I am not grieving” (Alam et al., p. 11). This avoidance could be a strategy to protect each other “You don’t want to hurt each other, you keep the pain to yourself, it is actually just better to keep it somewhere,

deep down inside, than confront it...remember it, in a way” (Maritz et al. 2014, p. 607). Words can signal and evoke feelings and emotions in someone else; therefore, experiencing grief as a couple, a couple of individuals, it is important to be mindful of the impact of words. Maritz described:

I think, it's, as a couple, there's that underlying...thing that each of you carry and you're never quite, maybe honest. You don't ever go there with each other because it's too painful...if you're feeling...down or if you're feeling sad for any reason and you see your partner's fine, there's no ways you're going to burden them, you're not going to want to bring them down as well, because they have their days when they're feeling...so you learn to be very respectful of each other. (Maritz et al., p.608)

### **Discussion**

This systematic review aimed to synthesise current literature on experiences of mothers' and fathers' grief after the loss of a child. In summary, the results indicate that mothers and fathers often grieve very differently but that this is not conclusively determined by gender. It was found, that, generally, fathers tend to express grief through non-affective means such as attending to physical activity and repressing feelings. All of the reviewed studies irrefutably described mothers grieving style more concordant with an affective expressive. However, there were exceptions to this rule and fathers expressed their grief through an intense outpouring of emotion (Aho et al., 2009; Alam et al., 2012; Richies & Dawson, 1996). Therefore, the current review concurs with Martin and Doka's (2000) findings that gender influences grieving style but that it does not determine it.

The themes in this review are similar to that of previous research demonstrating consistency in the literature on bereaved parents that differences in each parent's response are present but that a couple can be accepting of these in each other (McGreal et al., 1997; Toller et al., 2009). However, this review provides a more detailed synthesis on how bereavement is experienced between mothers and fathers and that the effects on a relationship are complex and can ultimately result in strengthening of one. Previous literature reviews in this area have considered the effects of a child's death on a couple's relationship and how severe or long-term the effects may be, e.g. divorce (Albuquerque et al., 2016; Schwab, 1998).

It is essential to consider the multiple factors that influence and determine how a parent grieves for their child for example, "individual coping styles, personality types, the type of death, religious and spiritual beliefs and the meaning the loss holds for each individual" (Maritz et al. 2008, p. 607). Indeed, the level of pain and trauma experienced by parents after the death of a child is highly individual and complex (Arnold et al., 2008).

In addition, there is evidence of multiple ways of communicating and reading nonverbal cues within a relationship in order to support one another. Furthermore, avoiding discussions about the deceased with one another could be a protective factor for themselves as well as their partner; not wanting to evoke or upset one another. Nonetheless, words from others were still valuable and parents found comfort in discussing their deceased child with other family members and friends.

As previous research shows, grief is not determined by gender but would appear to be significantly influenced by it (Doka et al., 2010). The current review would enhance the argument that advocates for mothers and fathers to grieve in their own way, regardless of gender; and that professionals can play a role in helping

acceptance of this. As a Western society, we favour more affective expression of grief; but, as shown above, grieving patterns are on a continuum. Encouraging society to develop a more coherent understanding of grief and bereavement could help to soften this stereotype of how a person should grieve, allowing for empathy, appropriate support and understanding from wider community.

The current review aims to enhance and deepen our understanding of parental bereavement and hopes to guide professionals/services in what/and how they provide them to both mothers and fathers. Whilst other reviews provide invaluable information regarding the matter, this review, from a qualitative stand point offers a more enriched window for developing a view on the experiences of mothers and fathers within the reviewed studies (Florczak, 2017).

### **Limitations and Strengths of the Reviewed Studies**

There are a number of limitations to the current review. The studies reviewed primarily reflect the views of those participating, therefore, conclusions should be drawn with caution, as with most qualitative research, sample size of the studies were small. However, the review does include studies from different countries, for example, Malaysia and South Africa, in the hope to give a broader representation of views.

In one of the studies, which used an internet-based method of recruitment, Cacciatore and Defrain (2008) provided very limited demographic information about their participants. Of that provided, the study did state that some of the parents had been bereaved very recently, whereas for others several years had passed. This limited information makes it difficult to draw conclusions with the other studies.

In addition, one of the reviewed studies reported concise accounts of data (Hussin & Azman, 2016), whereas providing more detail could have given deeper insight, albeit this may not have been appropriate for the data available.

### **Limitations and Strengths of the Current Review**

There are a number of methodological limitations to the current thematic synthesis. Firstly, publications were limited to those published in English, which may produce publication bias. Journals written in English are predominantly from developed countries and this could imply that Western countries are skewing expectations of what grief should look like. However, this review does not claim to provide absolute knowledge that is transferable to all but, as a qualitative review, provide knowledge of those studies reviewed in order to enhance our understanding.

The use of the CASP in this review has highlighted the importance for consideration of how best to use this tool when reviewing qualitative research. Regardless of some studies using the CASP as a measure to exclude studies, to date, there is no consensus on how to appraise qualitative papers for inclusion, using such tools (Dixon-Woods, Bonas, Booth, Jones, Miller, Sutton & ...Young, 2006; Dixon-Woods, Shaw, Agarwal & Smith, 2004). The varied reporting of data may reflect numerous aspects of a study e.g. word limit constraints, which suggests that using such a tool to evaluate quality should be done with caution. Therefore, using the CASP as a way of excluding studies rather than as a reflective tool to comment on the quality of studies included may risk discounting important studies. Certainly, the quality of studies by the CASP did not appear to influence the number of themes the studies contributed to, and the richness of data. Further consideration and debate regarding critical appraisal of qualitative studies is required.

## References

- Aho, A. L., Tarkka, M., Astedt-Kurki, P., & Kaunonen, M. (2009). Fathers' experience of social support after the death of a child. *American Journal Of Men's Health*, 3(2), 93-103.
- Alam, R., Barrera, M., D'Agostino, N., Nicholas, D. B., & Schneiderman, G. (2012). Bereavement experiences of mothers and fathers over time after the death of a child due to cancer. *Death Studies*, 36, 1-22. Doi: 10.1080/07481187.2011.553312
- Albuquerque, S., Pereira, M., & Narciso, I. (2016). Couple's relationship after the death of a child: a systematic review. *Journal of Child Family Studies*, 25, 30-53.
- Arnold, J. & Gemma, P.B, (2008). The continuing process of parental grief. *Death Studies*, 32, 658-673.
- Arnold, J., Gemma, P.B., & Cushman, L. (2005). Exploring parental grief: combining quantitative and qualitative measures. *Archives of Psychiatric Nursing*, 19(6), 245-255.
- Bergstraesser, E., Inglin, S., Hornung, R., & Landolt, M. A. (2015). Dyadic coping of parents after the death of a child. *Death Studies*, 39, 128-138.
- Braun, V. & Clarke, V. (2013). *Successful qualitative research: a practical guide for beginners*. London: Sage.
- Burden, C., Bradley, S., Storey, C., Ellis, A., Heazell, A. E. P., 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(9), 1-12.

Butler, A., Hall, H., & Copnell, B. (2016). A Guide to Writing a Qualitative Systematic Review Protocol to Enhance Evidence-Based Practice in Nursing and Health Care. *Worldviews On Evidence-Based Nursing*, 13(3), 241-249. doi:10.1111/wvn.12134

Cacciatore, J. & Defrain, J. (2008). Stillbirth and the couple: a gender-based exploration. *Journal Of Family Social Work*, 11(4), 351-372.

Cacciatore, J., Lacasse, J. F., Lietz, C. A., & McPherson, J. (2013). A parent's tears: primary results from the traumatic experiences and resiliency study. *Omega*, 68(3), 183-205.

Critical Appraisal Skills Programme; CASP. (2014). *CASP Checklists*, CASP: Oxford, available at: <http://www.casp-uk.net/checklists> (accessed 25 November 2017).

Dixon-Woods, M., Bonas, S., Booth, A., Jones, D., Miller, T., Sutton, A.,... Young, B. (2006). How can systematic reviews incorporate qualitative research? A critical perspective. *Qualitative Research*, 6, 27-44.

Dixon-Woods, M., Shaw, R. L., Agarwal, S., & Smith, J. A. (2004). The problem of appraising qualitative research. *BMJ Qualitative and Safety*, 13, 223-225.

Doka, K. J., & Martin, T. L. (2010). *Grieving beyond gender: understanding the ways men and women mourn*. New York: Routledge, c2010.

- Erlandsson, K., Saflund, K., Wredling, R., & Radestad, I. (2011). Support after stillbirth and its effect on parental grief after time. *Journal Of Social Work In End-of-Life and Palliative Care*, 7: 139-152.
- Field, N. P. & Filanosky, C. (2010). Continuing bonds, risk factors for complicated grief, and adjustment to bereavement. *Death Studies*, 34, 1-29.
- Florczak, K.L. (2016). Adding to the truth of the matter: the case for qualitative research. *Nursing Science Quarterly*, 30(4), 296-299.
- Hawthorne, D. M., Youngblut, J. M., & Brooten, D. (2017). Parent spirituality, grief, and mental health at 1 and 3 months after their infant's/child's death in an intensive care unit. *Journal Of Pediatric Nursing*, 31(1), 73-80.
- Hooghe, A., Rosenblatt, P.C., & Rober, P. (2017). "We hardly ever talk about it": emotional responsive attunement in couples after a child's death. *Family Process*, 1-15.
- Hussin, N. A. M. & Azman, A. (2016). Parental grief and marital issues aftermath: a pilot study. *Journal Of Arts And Humanities*, 17-25.
- Koopmans, L., Wilson, T., Cacciatore, J., & Flenady, V. (2013). Support for mothers, fathers and families after perinatal death. *Cochrane Database Of Systematic Reviews*, 6, 1-22.
- Martin, T. L., & Doka, K. J. (2000). *Men don't cry...women do: transcending gender stereotypes of grief*. Philadelphia: Bruner Mazel Publishers.

- Maritz, J., Poggenpoel, M., & Myburgh, C. (2008). A parent's experience of the couple relationship after child bereavement in south Africa. *Journal Of Psychology in Africa*, 18(4), 603-611.
- McGreal, D., Evans, B., & Burrows, G. (1997). Gender differences in coping following loss of a child through miscarriage or stillbirth: a pilot study. *Stress Medicine*, 13, 159-165.
- Moriarty, H. J., Carroll, R., & Cotroneo, M. (1996). Differences in bereavement reactions within couples following death of a child. *Research In Nursing & Health*, 19(6), 461. doi:10.1002/(SICI)1098-240X(199612)19:6<461::AID-NUR2>3.0.CO;2-M
- Norlund, E., Borjesson, A., Cacciatore, J., Pappas, C., Randers, I. & Radestad, I. (2012). When a baby dies: motherhood, psychosocial care and negative affect. *British Journal of Midwifery*, 20(11), 780-4.
- Price, J., & Jones, A. (2015). Living through the life-altering loss of a child: a narrative review. *Comprehensive Child And Adolescent Nursing*, 38(3), 222-240, doi:10.3109/01460862.2015.1045102
- Richies, G. & Dawson, P. (1996). Communities of feeling: the culture of bereaved parents. *Mortality*, 1(2), 143-161.
- Riley, L. P., LaMontagne, L.L, Hepworth, J. T., & Murphy, B.A. (2007). Parental grief responses and personal growth following the death of a child. *Death Studies*, 31, 277-299.
- Schwab, R. (1998). A child's death and divorce: dispelling the myth. *Death Studies*, 22(5), 445-468. doi:10.1080/074811898201452

- Stern, C., Jordan, Z., & McArthur, A. (2014). Developing the review question and inclusion criteria: The first steps in conducting a systematic review. *American Journal of Nursing, 114*(4), 53–56.
- Harden, A., & Thomas, J. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology, Vol 8, Iss 1, P 45* (2008), (1), 45. doi:10.1186/1471-2288-8-45
- Higgins, J. P., & Green, S. (2011). *Cochrane Handbook for Systematic Reviews of Interventions* Version 5.1.0, The Cochrane Collaboration, 2011.
- Tugendhat, J. (2005). *Living with loss and grief*. London: Sheldon Press.
- Toller, P. W. & Braithwaite, D. O. (2009). Grieving together and apart: bereaved parents' contradictions of marital interaction. *Journal Of Applied Communication Research, 37* (3), 257-277.
- Vance, J. C., Boyle, F. M., Najman, J. M., & Thearle, M. J. (1995). Gender differences in parental psychological distress following perinatal death or sudden infant death syndrome. *The British Journal Of Psychiatry, 167*, 806-811. Doi:10.1192/bjp.167.6.806
- Vance, J. C., Boyle, F. M., Najman, J. M., & Thearle, M. J. (2002). Couple distress after sudden infant or perinatal loss: a 30 month follow up. *Journal Of Paediatrics and Child Health, 38*(4), 368-372.

## **Chapter 2**

### **Bridging chapter**

## **Bridging Chapter**

This bridging chapter sets out to link the systematic review and the empirical paper. Firstly, an overview of the evidence reported in the systematic review and an introduction to the empirical paper will be outlined to give the reader context. Lastly, there is a discussion on societal views around death, gender and grief. Consideration and explanation of hospice care is detailed within this.

### **Overview of findings from the systematic review**

The systematic review aims to understand how grief is expressed by mothers and fathers after the death of a child, while the empirical paper explores the experiences of parents who have used ‘cold’ facilities at a hospice to spend time with their baby after death.

The results of the systematic review concur with previous research that mothers and fathers can often grieve differently but this is not solely determined by gender (Martin & Doka, 2000). In addition, it contributes to our understanding of the relational aspects of grief within a spousal relationship following the death of a child: couples who experience grief together and on their own, whilst accepting and being respectful of their spouse’s needs. It emerged that understanding the impact of words was essential. Words at a devastating traumatic time could be inconsequential due to the sheer grief felt. Nevertheless, for others comfort was sought through speaking of the deceased and this paid tribute to them and their legacy.

The systematic review highlighted the enormity and complexity of parental grief and how interventions should be tailored appropriately. There are a number of interventions offered for people experiencing grief with or without complications

(Hooyman, 2006), from Cognitive Behaviour Therapy for complicated grief (Rosner, Pfoh, & Kotoucova, 2010) to scrapbooking (King, Prout, Stuhl, & Nelson, 2016).

Giving families the use of 'cold' facilities within a hospice is an intervention for grief: to allow parents time with their baby after death.

### **Parenting in a Neonatal Intensive Care Unit (NICU)**

Parenting a baby that is under the care of a NICU can have vast a impact on parents: feelings of inadequacy and disconnection through loss of role (Spinelli, Frigerio, Montali, Fasolo, Simonetta Spada & Mangili, 2015). Parents can feel a sense of failure as they were unable to shield their baby from harm and did not fulfil the role of being a pregnant mother (Baum, Weidberg, Osher, & Kohelet, 2012). Baum et al. go on to describe the complications of parenting within a NICU and the various elements to blame of themselves and others, along with other complex emotional responses. There is extensive literature on the effects of a traumatic birth on mothers which is exemplified if the baby is cared for in NICU (Baum et al, 2016; Hynan, et al, 2015; Singer, Salvator, Guo, Collin, Lilien & Baley, 1999; Umberger, Canvasser, & Hall, 2018). A woman's identity as a mother is defined by the birth and allows for the transition of role (Wigert, Johansson, Berg & Hellstrom, 2006). Often parents have very limited involvement in the care of their baby and normal routine activities for parents of a new baby are restricted or not present such as dressing, washing and close contact. Admission on to a NICU can confine the normal attachment process, which can have long-lasting effects on both the mother and baby (Kearvell & Grant, 2010).

When neonatal death occurs the support offered by services are crucial for this vulnerable group. Palliative and bereavement care provided should be

appropriate and based on the unmet needs of parent-infant bonds and evidence based.

### **Context of societal views**

Recent decades have witnessed emerging change in palliative care and a shift in openness relating to communication about death: however, wider societal views about death are often dominant and more complex to address (Davis, 1991; Parkes, Laungani, & Young, 2015). Similarly, gender roles in the past 100 years have evolved and progressed in relation to equality (McClain & Grossman, 2009), but how we are as male and females is a result of centuries of cultural views and historical events which are imbedded within our development as human beings (Keverne, 2017). The fundamental underpinnings of human evolution and practices are crucial in how we respond to and express grief.

### **Views and practices about death**

Society prioritises a state of denial about death (Davis, 1991; Zimmerman, 2012) and conversations about death are considered taboo where the dying are segregated from society (Zimmermann & Rodin, 2004). However, confronting death can lead to a more satisfying inner fulfilment and expanding psychological capabilities as well as an enhanced meaning in life rather than avoidance (Cozzolino, Blackie, & Meyers, 2014). Increased communication could help with confronting death: research has shown that education and encouragement to talk about death increases confidence to do so in professionals (Coyle et al., 2015).

It is imperative to recognise that different cultures and religions partake in their own hugely varied beliefs and rituals regarding death (Parkes, et al., 2015). Bereavement services need to be mindful of this diversity. Many cultures and

religions encourage care of the dead at home. In Buddhist beliefs and practices, preparing for a peaceful death is essential and the body should not be touched for several days after death and left to rest at home, if that is where the person died (Gouin, 2015). In traditional Hindu families the body remains at home until the funeral and close friends and relatives, including children, visit and spend time with the deceased (Pittu & Laungani, 2015). Jewish traditions require burial to take place as soon after death as possible to allow for the mourning period to begin and family members should not care for, or prepare the body, as this is viewed as too painful (Levine, 2015).

Traditional western beliefs regarding death have changed over time along with practices; previously the dying were more likely to be cared for at home. Death was a prominent fixture of everyday life and unavoidable due to high mortality rates (Bovey, 2015). However, advances in medical care and science have enabled a cultural shift of denial and avoidance and changed these views over time (Filippo, 2006).

### **Gender roles and grief in society**

As outlined above, traditional gender roles are imbedded into our everyday lives and an individual's beliefs, values and way of being (Montgomery, Caviano, Rayburn & McWey, 2017; Keverne, 2017). In Western cultures, 'Big boys don't cry' mentality encourages men to 'be strong' and 'non emotional' in adversity (Goodey, 1997; McNess, 2008; Oliffe, Kelly, Bottorff, Johnson & Wong, 2011). Whereas in grief, women are given free rein to express intense emotion and encouraged to process this through talking and sharing with others; in contrast men are encouraged to repress intense emotions (Martin & Doka, 2011). Views around

how an individual should grieve are endless, Wortman and Silver (1989) documented that individuals tend to hold very firm and rigid beliefs of how others should grieve a loved one.

### **Hospice care**

Hospices aim to support families and individuals with life-limiting conditions to live a fulfilling and meaningful end of life and a good death experience (Isler, 2017; Matthews, 2018; Taylor & Aldridge, 2017). Staff working in hospices are able to provide valuable care for the dying in an emotionally fuelled environment and, in turn, often find the work rewarding (Taylor & Aldridge, 2017).

### **Hospice care and ‘cold’ facilities**

The ‘Together for short lives’ document (Bennett, 2012) outlines best practice for end of life care for children and young people, enabling families the highest possible quality of life. Offering families a choice on where their child will be cared for after death is paramount; and cold facilities within a hospice should be one of the options. These have been defined as:

A ‘children’s hospice cool room’ is a designated, quiet room where children and young people may be placed after they die for a few days or until their funeral, and where the family can spend time with their child.

A ‘cool room facility’ refers to the use of a portable air conditioning unit that can be installed in a room either in the hospice or within the family’s own home, where the child may stay for a few days following death. (Bennet, 2012, p. 20).

The empirical paper recruited participants from a hospice which provided both a cool room and cool room facility. More recent years have seen an increase of the use of a refrigerated cot or portable cooling mattress for an infant. This new equipment has provided families opportunity to be with their infant after death in more comfortable conditions. The flexibility provided by the portable mattress means that the infant can be moved around a room. Throughout this thesis portfolio these will be referred to as 'cold' facilities. To date, only two studies have investigated the use of 'cold' facilities for children but these were both studies with older children and in the 'cold room' facility. No study to date has investigated the use of portable cold cots and mats. These 'cold' facilities are an intervention for families which, may, challenge current societal views of death and dying.

Families' abilities to cope with and face the reality of death vary immensely (Connor, 2009). Connor argues that whilst denying the existence of death can be problematic for society, as discussed above, denial plays an important role for individuals when faced with adversity and is a normal and natural response. Movement continues to promote hospice care (Connor, 2009; Haraldsdottir, 2017), however, diminutive awareness of what the services have to offer is prevalent within wider communities (Connor, 2009; Shalev, 2018).

### **Chapter 3.**

#### **Empirical paper**

Prepared for submission to Death Studies and formatted in accordance with their guidance (Appendix A). The empirical paper is 8,286 words in length; there is no word limit for this journal. The abstract is 99 words in length (journal abstract word limit 100 words excluding keywords).

**Parents experience of using ‘cold’ facilities at a children’s hospice after the death of their baby: a qualitative study**

Elisabeth A. Norton, Kiki Mastroyannopoulou, and Imogen Rushworth

*Department of Clinical Psychology, University of East Anglia, Norwich, United Kingdom*

### Abstract

Several children's hospices offer families the opportunity to be with their baby after death through use of a 'cold cot'. Seven parents were interviewed. Thematic analysis identified eight key themes: being able to care for their baby in a way that they never had, space and time to adjust to the loss, time as a family, having their baby close and knowing where they are, nurturing care for the whole family, importance of mementoes, building a relationship with hospice staff, and external perceptions of the use of the 'cold facilities'. Directions for further research and practical implications are discussed.

Word count: 99

## **Introduction**

There is extensive literature concerning parental grief, which is thought to be a unique form of grief and one of the most severe forms of bereavement (Arnold & Gemma, 2008; Arnold, Gemma & Cushman, 2005; Nordlund et al, 2012; Tugendhat, 2005). Tugendhat states that parents are programmed to want to bond and protect a child and that the loss of a child can have profound and devastating effects and can result in ruined dreams, hopes and expectations (Laakso & Paunonen-Ilmonen, 2001). Parents may also experience guilt for feeling unable to stop what has happened (Hollins-Martin & Forrest, 2013). Strong bonds are thought to have already developed between a mother and new born baby (McGuinness, Coughlan & Power, 2014). New mothers who have lost their baby also face additional physical difficulties, reminders and complications, such as, suppression of lactation of milk, after birth pains, and loss of blood (Broderick & Cochrane, 2013; McGuinness, Coughlan & Butler, 2014).

### **Theories of grief**

Early perspectives on grief were shaped by Freud (1917) who regarded grief as a process whereby the bereft gradually detaches from the deceased, in a solitary way. This process would focus on letting go of the deceased, which would in turn, alleviate the pain caused by grief and enable the grief to be overcome.

There is no typical response to loss; grief is an individual process and although some models of grief propose specific stages, not everyone goes through each one and not in a predefined order (Hollins-Martin & Forrest, 2013; Kubler-Ross & Kessler, 2005). Kubler-Ross (2009) described five stages of grief; denial, anger, bargaining, depression and acceptance. The accepting stage is characterised by the

bereaved person being able to start to live with their new reality and where the final stages of healing take place. With this healing, people can feel closer to the one they have lost, not detached from them, as earlier theorists, such as Freud, implied. Worden (1991) outlined the ‘tasks of mourning’ which provides a framework to guide grief work, for the bereft to accept the reality of loss, to work through the pain of grief, to adjust to an environment in which the deceased is missing, and to emotionally relocate the deceased and move on with life. Worden stresses that these tasks of mourning are essential and necessary, albeit a painful process. In both Kubler-Ross and Worden’s work there are themes that acceptance and moving on is important.

More recent years have seen a focus on the importance of cherishing and developing continuing bonds with the deceased (Broderick & Cochrane, 2013; Davies, 2004; Klass, 1993). A continuing bond has been described as “the presence of an ongoing inner relationship with the deceased person by the bereaved individual” (Stroebe & Schut, 2005, p.477). Arnold and Gemma (2008) report the findings of a survey completed by 74 parents who had lost a child, using both quantitative and qualitative methods to collect data about the life long effects of grief on parents after losing a child. One of the themes drawn out from this study was that parents find numerous ways to remain connected to their dead child and that memories and sharing are very important to them. They also found that parents found strength and support in talking about their loss.

### **Attachment**

Attachment bonds develop between a mother and a baby whilst the child is growing inside the womb and parents who have lost a child very early on, either

through stillbirth or within a month or so after birth, can experience the same level of grief to those who are widowed (Bowlby, 1998; Gaudet, 2010; Klaus & Kennell, 1976). Bowlby describes that parents who have lost a baby in their early days of life will experience feeling numb, stunned and that nothing feels real. After this initial phase, parents could then go on to experience distress, anger and depression.

Bowlby (1991) also states that many mothers have a strong yearning to hold their dead baby. Although it was not common practice at the time, Bowlby and colleagues believed that parents should be encouraged to hold and spend time with their baby after death and without this, emotional distress would be greatly increased (Klaus & Kennell, 1976). More recently, Cacciatore and Flint (2012) interviewed parents after the death of their child and reported that some described an intense yearning to hold and care for them and regretted not having asked to spend more time with their child. They proposed that through the development of their attachment they anticipated caring and looking after their baby and being able to respond to their every need. When the baby died this was taken away, therefore not being able to spend time with their baby could have devastating effects (Cacciatore & Flint, 2012; Root & Exline, 2014).

Considering the importance of attachment and bonding on grief literature and theory detailed above. Parenting whilst your baby is critically ill and under constant medical care can be debilitating for parents, introducing multiple emotional, physical and cognitive complications into their attachment and grief process (Baum, Weidberg, Osher, & Kohelet, 2012; Hynan, et al, 2015; Kearvell & Grant, 2010; Singer, Salvator, Guo, Collin, Lilien & Baley, 1999; Spinelli, Frigerio, Montali, Fasolo, Simonetta Spada & Mangili, 2015; Umberger, Canvasser, & Hall, 2018).

### **When a baby dies: Hospital Care**

When a baby dies in hospital, support for bereaved parents is provided in various ways. Staff initially encourage parents to hold or cuddle their baby, give them choice in how they are dressed and assist in memory keep sakes. Where possible, parents are given a choice of where their baby will be after death i.e. hospital morgue, taking them home or transfer to a children's hospice and to arrange any religious ceremonies they may want to carry out (Cawston, 2012; Roy & Shirtliffe, 2014).

### **Description of 'cold facilities'**

In the present study, parents who choose to use the hospice facilities after their baby's death are given use of accommodation in the hospice which includes a small lounge with sofas and television, two en suite double bedrooms for families to use and the separate cold bedroom. This room is cooled to the needed temperature (10 degrees Celsius) by a ceiling cooling unit; however, this is not ideal as it is uncomfortable for families to stay in. For neonatal/infant use of the facilities families can use a 'flexi-mort', known as a "cuddle cot", which looks like a typical cot but the mattress is kept at a very low temperature to allow the baby's body to be preserved for several days. This can either be kept in a separate bedroom from the parents, or the parents can choose to have the cot in their bedroom for families to have unrestricted access to their baby. The hospice offer support services for families including counselling, bereavement support, and support for siblings and other family members. These services support the idea that time, privacy and choice for families is crucial after the death of a child (Davies, 2009). However, wider

communities are often seemingly unaware of the services hospices' have to offer (Connor, 2009).

### **Rationale for Current Research**

There is limited research into the experience of using cold room facilities for families in a hospice. Forrester (2008) looked at the use of 'cold bedrooms' following the death of an older child and reported that parents found knowing who and where their child was being cared for as very comforting. Forrester identified the following themes: that their general care was looked after for their whole family, being involved in the funeral arrangements, and the importance of their religious/spiritual needs being considered. This gives insight into the experience of parents who have used cold room facilities with an older child but not how the facilities can be beneficial after the loss of a neonatal or new born baby. Jones, Holmes and Heazell (2017) provided data showing that not all parents are offered this bereavement service for perinatal death but that 93% of Healthcare Trusts reported that parents have access to facilities to take their baby out of hospital should they wish to. They advocate for an increased awareness that this service is available. However, their findings were somewhat sparse and much more detail about the benefits of this service is required in order to increase awareness.

Bereaved parents do not lose their sense of being a parent when their child dies, their parental instincts continue (Thomas & Chalmers, 2009). Davies (2005) interviewed mothers after the loss of a child and identified the following themes as important: time to be with their dying child, space and privacy, and time to be with their child's body after death. This supports new theoretical considerations of grief in that remaining connected to the deceased and 'continuing bonds' is important.

However, only the experiences of mothers were reported as fathers were not interviewed.

In a literature review, Harvey, Snowdon and Elbourne (2008) suggest that empirical evidence of bereavement services in both Neonatal Intensive Care Unit (NICU) and hospices is limited, and that effectiveness of such services is often assumed. They also suggest that in order to gain a true understanding of the effectiveness of bereavement services for parents, qualitative research might be used to further explore this.

### **Aim**

This study intends to understand lived experiences of parents who have chosen to use facilities which allow them to be with their baby after death in specially developed accommodation, either on their own with their baby or with other family members present. The study examined the experiences of parents to increase understanding of how these experiences shaped their grieving process and attachment with their deceased baby.

### **Research Questions**

This is a qualitative study; it is naturalistic and aims to understand the experience of those being interviewed. The main question to extract themes was:

1. What are the experiences of parents who opt to use post death facilities at a hospice i.e. cold cot or cold room facilitates?

The main research question is broad to allow scope for the interviews to develop themes relevant to what was important to the parents. In addition, the study aimed to find out further information about the following:

2. How can learning about these experiences help shape pathways to services for parents who have lost a baby?
3. Is there any additional support needed for people whilst using these services? (to what is already offered)

### **Method**

A qualitative study conducted through individual in depth semi structured interviews. The use of this method allowed for exploration of a sensitive topic, and flexibility and responsiveness to participants' issues as they arose, enabling them to focus on what was most important to them. The interviews were analysed using thematic analysis to identify themes and patterns of meaning from them.

### **Recruitment and Participants**

To address the research questions, participants were approached who had lived experience of the facilities in question, hence purposive sampling was used. Using purposive sampling supports the study's aim of generating a deeper understanding of the experiences of families. A total of seven participants were recruited from a children's hospice in the UK. This sample size is in keeping with recommendations for using thematic analysis (Braun & Clarke, 2013).

The participants were identified through the hospice, which had been given the inclusion/exclusion criteria. The criteria were that families had: (a) lost a baby under one-year-old at the time of death who died from six months up to three years ago (at the time of interview) and had used cold room and/or cold cot facilities at a children's hospice, (b) a good degree of spoken English due to the interview nature of the design. Families who had experienced more than one loss of a baby were

excluded, since their experience of using the hospice facilities could be somewhat different from families who have experienced loss on one occasion.

In order to minimise the possibility of over recruitment, an initial batch of ten letters were sent by the hospice on behalf of the research team (appendix C) including a detailed information sheet (appendix D) and included a consent to contact form (appendix E) which participants were required to return by post to the research team. Once this was received the primary researcher contacted parents to discuss the study further and arrange a time to meet to conduct the interview. From the initial batch of ten, four responses were received. After a month, a following ten letters were sent out to families meeting the inclusion criteria. An additional three responses were received from this. No further batches were sent out due to recruitment deadlines.

At the time of interview, demographic information (appendix F) including age, gender, length of time resident at the hospice following the death of their baby, and number of any other children was gathered. To maintain participants' confidentiality, demographics are reported broadly. Parents were given the option to choose the location of their interview, the interviews were between 45 to 75 minutes long. Seven semi-structured interviews were carried out; five within families' homes and two at the University of East Anglia. The interviews were conducted by the primary researcher (E.N.), a female with no prior relationship to the participants. A total of five different families participated: in two families both the mother and father were interviewed; in two families the mother was interviewed; in one family the father was interviewed. Both mothers and fathers were asked if they would like to participate in the study but were interviewed separately. The rationale for interviewing parents separately is twofold: (a) Firstly, it allows for them to be heard

as individuals, (b) Secondly, literature suggests that grieving patterns are individualised and the impact of different grieving patterns within family systems (Doka & Martin, 2010) would influence the narrative given (Feeley & Gottlieb, 1988; Jenkins & Merry, 2005; Vance, Najman, Thearle, Embelton, Foster, & Boyle, 1995), none of the participants objected to being interviewed separately.

The five babies were aged between a few weeks old and eight months at the time of death; reason for death included heart defects, genetic disorders, neonatal leukaemia, and serious illness resulting from premature birth. The families had all used the cold facilities at the hospice; three of the babies died at the hospice and two had died in hospital and then been transferred to the hospice via a private ambulance. Only one of the babies had been home prior to death; the remainder had always been under specialist care in a hospital. The length of time the cold facilities were used at the hospice varied from one day to three weeks; all but one of the families stayed overnight with their baby in the facilities.

The interview questions aimed to explore the complexity of the experience of grieving for their deceased child whilst in close proximity with their body, and the emotional impact of spending this time with them. A topic guide (Appendix G) initially developed from meetings with the hospice and consultation within the research team was peer reviewed by the Stillbirth & Neonatal Death Society (SANDS) prior to beginning recruitment. The interview schedule was a guide and only a small number of questions were used as the dialogue with participants shaped the interview to what was important about the experience for them.

## **Ethical considerations**

Ethical approval was granted from University of East Anglia's Faculty of Medicine & Health Sciences Research & Ethics Committee (Appendix H).

Approval was sought and granted from the study Hospice Board of Trustees to carry out research within the organisation (Appendix I). All participants gave written, informed consent (Appendix J).

The research proposal outlined that due to the sensitive nature of the topic careful consideration was given to the naming of the deceased child. Participants requested the use of the real name for their baby in both transcripts and published documents; an amendment (Appendix K) was submitted and ethical approval was granted for this (appendix L) on the grounds that going against parents' wishes would be detrimental and could cause unnecessary distress to them. Participants were informed of the implications of this and the impact of having their stories in the public domain, particularly, the process of assessment and publication. Additional written consent was sought for the use of their baby's name and the primary researcher will contact participants prior to publication to go through what information is included and if this is still preferred. This is in addition to member checking and theme consultation. All other identifiable information has been anonymised in the data.

The wellbeing of participants was paramount; and careful consideration needs to be given when conducting research with bereaved parents. There is no doubt that participating in in-depth interviews could evoke difficult memories and emotions, though attempts were made to minimise distress by allowing participants to take breaks or stop the interview if they wished. Participants were also given open

access to the study hospice's support services. The primary researcher would liaise with families if a referral needed to be made, families could either self-refer or a referral could be made on their behalf.

### **Data Analysis**

Interviews were audio recorded and transcribed verbatim by the primary researcher and reviewed to ensure accuracy. Thematic analysis was used to analyse the data generated: this allowed for themes to emerge from the data to better understand the experience using such facilities on grieving parents/family. This methodology was chosen for its flexibility in terms of its theoretical framework, as well as appropriateness for an under researched group. To generate meaning, thematic analysis is done in seven stages; transcription, reading and familiarising, coding, searching for themes, reviewing themes, defining and naming themes, and writing the final report (Braun & Clarke, 2013).

To avoid rigidity, an inductive approach was used, this involved coding and theme development drawn from the data content itself in a 'bottom up' approach rather than theoretical assumptions (i.e. 'top down') (Braun & Clarke, 2006). Themes emerge from, and are grounded, in the data.

Transcripts were coded line by line for relevance to the research questions, and codes were arranged into themes and subthemes by E.N. Transcripts were randomly selected and checked by K.M., codes, themes and subthemes were deliberated, and agreement was reached for corroborated themes (Appendix M: Example of table used for codes and themes deliberated). The initial thematic analysis was reviewed by one of the participants.

E.N.'s epistemological stance is largely social constructionist which assumes that the way we make sense of the world is built through the social processes we are a part of; it is culturally and historically dependent. This stance acknowledges my position as the researcher, as a mother, who views the services offered as of possible benefit to families, enabling parents' precious time with their deceased baby. It is important to acknowledge the primary researcher's role in obtaining the data, to reflect on questioning and conversational style. A reflective research journal was kept throughout to record thoughts, feelings and reflections about the progress and process, and decisions made.

## **Results**

Based on the results of the thematic analysis, eight themes were identified: being able to care for their baby in a way that they never had, space and time to adjust to the loss, time as a family, having my baby close and knowing where they are, nurturing care for the whole family, importance of mementoes, building a relationship with hospice staff, and external perceptions of the use of the 'cold facilities'. In addition, a summary of what parents noticed about the pathway into the service is reported.

### **Theme 1: Being able to care for my baby in a way that I never had**

All seven of the parents talked of the benefits of being able to dress, bath, cuddle and care for their baby, six of the parents had never been able to do this: whether this was due to constraints of being in hospital and/or due to medical grounds. There is a sense that being in the hospice and being able to fulfil some of those roles, of attachment and bonding that is instinctive in parents, even after death, helped in some way with their loss. Parents love their baby as much then as they

had before, the love they felt was profound and were able to “be in the moment” and embrace their baby.

*“We then gave her, her first bath because we hadn’t given her a bath before because of her condition, she was just so weak that a bath would have been too much stress for her so we’ve given her, her first ever bath and put fresh clothes on” (Participant 4, mother)*

*“Like have a...that extra cuddle, say goodnight do all the stuff that you were supposed to be doing” (Participant 2, mother)*

Parents gained a sense of ownership of their lives, previously inhibited by medical constraints. Making decisions and having choice enhanced feelings of parenthood that had not been fulfilled as well as a level of closeness with their baby. The parents described moments whilst using the cold mattress that were fundamental: cherishing the time they had.

*“When I was there I didn’t keep him in his cot because the cold facility is like a mat...um and so I put it like next to me on the bed and stuff...wherever I wanted him...I guess it was still like that mummy thing like I took clothes with me and changed him...because that’s like what I wanted to do...I think it’s just that mummy instinct...I knew I didn’t have a lot of time left with him so I wanted to make the most...my time was dedicated to him and I guess it was just that, you know making the most of the time with him, changing him.” (Participant 1, mother)*

*“It was quite nice to have that time ‘cause we couldn’t pick him up at all, I think it was nice for (wife) to pick him up and...Jude never wore clothes so*

*(wife) changed him every day...but he'd never needed, he didn't need clothes before" (Participant 3, father)*

*"I remember going in to the room and it was just like being at home and with that I felt really like ah this is, this is nice you know, we could lay him on a bed, we could cuddle him, we could take his clothes off, we could just have that contact with him"(Participant 7, mother)*

*"Just the possibility to be able to still hold her" (Participant 4, mother)*

The hospice provided space for parents to have intimate moments with their baby that would not be possible in hospital: creating memories and narratives for a family.

*"If they weren't there and hadn't done that for us, we'd have just been...in the neonatal ward...with all the other babies, all the other machines, all the other families and...it would have been horrible...because we got back to (hospice) and we've got some photos and pictures...he went from this little baby who was very pale and looked like he was about to pass away in hospital to waking up and had his eyes open and was squeezing a finger on the (hospice) bed...that might have been a little miracle in the same way" (Participant 6, father)*

*"I got to take him out of that hospital just for even just for a few hours and I got to do that, and I got to cuddle him and it wasn't clinical and you know it was a nice" (Participant 7, mother)*

## Theme 2: Space and time to adjust to the loss

The parents' narratives highlighted that neonatal death is a unique and complicated form of loss and grief. Alongside coming to terms with the death of their baby, this loss can often be a sudden shock and is accompanied by a loss of role and hopes and dreams. Parents felt traumatised and dazed by the death of their baby. All of the parents reported that the hospice provided essential time to process intense emotions and adjust to the loss of role.

*"I feel very lucky to have that time with him...and I think that helped me to say goodbye in a slow way instead of like a fast way...I guess it has helped me because I did get to say goodbye and I had my family there" (Participant 7, mother)*

There was a sense that being in a protected, neutral environment as opposed to home was crucial to this time to adjust, the space signified much more than what it represents: it gave parents a stopwatch to the challenges and interference of "reality" alongside having family around them to begin the grieving process. This time meant they could focus on each other, on their last moments with their baby and saying goodbye.

*"It was the cold room...I think it was just having that proximity...we could um, hold on to each other I suppose and hold on to Emma for just that bit longer" (Participant 5, father)*

*"the (hospice) and...the cold room...meant we could um, come to terms I suppose in a way with Emma being dead, um, she was there, could see her,*

*say goodbye...it offered us a space to grieve in, it offered us support"*

*(Participant 5, father)*

*"It was lovely going there every day and it gave us time to say goodbye to*

*him" (Participant 3, father)*

In addition to this, the hospice provided a space and time to adjust to the very physical process of the death of their baby, observing changes in them and being in a supportive environment at the time.

*"I wanted to change her in to different clothes after a few days...but I didn't*

*feel able to do it, so I asked a member of staff to do it for me because I was*

*worried about the changes her body might have gone through already, so I*

*thought no I wanted to keep her, those images I had" (Participant 4, mother)*

### **Theme 3: Time as a family**

All but one of the families had never taken their baby home, all had spent a period in hospital and had suffered tremendously, having not only a vast emotional impact on them as individuals but one on social functioning and relationships. Three of the families had other children at the time of their baby's death; not being able to take their baby home meant that they had never felt like a family unit. All seven of the parents described how the hospice allowed them precious time to come together as a family, whether this was through all being in one room, being able to play with their other children, have visitors or being in a homely private environment.

*"That was the first and the one and only night that we had really spent*

*together as a family yeah... it means a lot to us and still does mean a lot to us*

*that we had that, that night" (Participant 6, father)*

*“We kept her with us which was lovely to just spend one night the four of us together” (Participant 5, father)*

*“You could just be there as a family and you could still have your baby” (Participant 2, mother)*

*“So, we went back every day and spent every day with her, which was really lovely to spend the day with her and to be together as a family, for (son) to be there and not to be separated from one of my children” (Participant 4, mother)*

It enabled siblings to be a part of the process, the parents spoke of the resilience of siblings when seeing their dead brother or sister and how they coped and gave strength to their parents. There was a sense that this was therapeutic for siblings that were old enough to process the death.

*“Well at first as a parent you don’t want (son) to see Jude whose dead now... and in the end we were like yeah and he was actually fine, he came in the room stroked Jude’s head and said oh he’s cold and off he went and he was fine...that was really good as well that we included (son) into the journey...he was really gentle with Jude” (Participant 3, father)*

**Theme 4: having my baby close and knowing where they are - “A baby belongs with their parents”**

Mothers carried their baby in their womb, laboured them and then the majority of families spent extended length of time by their bedside, the unconditional love and need to protect is no different after death. All of the parents interviewed spoke of the importance of being with and knowing where their baby was, the

thought or the experience of having their baby in a morgue was very difficult to process and parents felt the need to still protect their baby after death. The hospice provided reassurance and relief to parents. Parents want to care for their baby after death and maintain responsibility for them, for example, many parents spoke of asking hospice staff to check on their baby if they were leaving their baby in the cold facilities for a short length of time. This brought comfort and a sense of competence contrasting the hopelessness and failure that parents can often feel.

*“I think...if he'd have passed away in hospital then he's taken away from you straight away, you're empty 'cause...we were spending 24 hours a day at his bedside...so if he'd of passed away in the hospital and then he got took away from us, we're sort of grieving straight away and then he's also been taken away whereas at (hospice) we did have that, the last final hours, and then he did sleep with us at the foot of our bed that night” (Participant 6, father)*

*“It was that whole being there with him, knowing that I didn't have to say goodbye to him, that he was being looked after because he wasn't on his own at night even...I guess it's just that mummy instinct” (Participant 1, mother)*

*“I think for me to just have her round me still and not having to have her in the morgue, I think that was...worth so much...I think it's because you are still...around caring for her rather than...having people around her rather than being alone” (Participant 4, mother)*

*“I remember going back to hospital with him and that's when like you had to let go of him and that's when it you know, it's just a funny feeling again you're just like empty but in the hospice you didn't feel so empty you had him there even when he passed away you had him” (Participant 6, father)*

### **Theme 5: Nurturing care for the whole family**

The nuances in narratives about time spent at the hospice bared the essence of care they received. Throughout each family's journey they came back to the "above and beyond" care that the hospice provides, minute aspects to widespread values that made a difference to their time there, that helped them to have time to grieve in a way that they would not have if the hospice was not involved.

*"They literally like waited on me, like anything I wanted or needed or wanted to do, whether I wanted to be left alone they respected that...if I wanted my dinner in my bedroom I could have that" (Participant 1, mother)*

The hospice staff provided relief from the day-to-day necessities, which enabled parents to focus on their baby and other family members.

*"It's like a home environment that you can be with your family...you can have who you want there...they've got stuff there for the kids, like for (younger son) they had toys...he was allowed to go up to the sensory room we were allowed to use their bathroom upstairs which had the sensory lights...that made it nice...you could just walk round as you wanted to, you could go out in the grounds uh...you still kind of away from the world if you like...out of reality type thing I don't know, uh you haven't got to get home and rush about and worry about feeding everybody and cleaning and getting, you can just have a bit of time to sort, you know they are there to help and they were" (Participant 2, mother)*

*"It was a little bit like a...like a bubble which was nice and that helped and I...I think I wrote loads and drew which helped, so I had the time and the*

*possibility to do that because there were staff looking after (older son)...and we didn't have...of course we got meals, breakfast, lunch and dinner every day which was beautiful not having to cook" (Participant 4, mother)*

Some parents reported the value in having other family members and friends to stay, the hospice staff recognised the importance of external support for the family as well as their grieving needs. Hospice staff arranged and organised things for the parents to minimise additional stress or worry.

*"I think it's helped a lot because...everything was done so well, there was nothing there...that upset us...everything was just as good as could be...even by them putting our parents up like that night, we weren't expecting it, they weren't expecting to be put up that night but it was all done, so everything that needed to be done to make everything as easy as possible or as painless as possible for us was, was done" (Participant 6, father)*

### **Theme 6: Creating mementoes**

Creating and making nice memories with their baby was a crucial part of their experience. These could be moments such as taking their baby for a walk using the cold mattress or photos, scrapbooks, and imprints handprints and/or footprints. All of the parents expressed value in having physical reminders of the time spent with their baby at the hospice after death. Hospice staff provided parents with a depth of insight and knowledge into how these things would help at a time when it is the last thing on their minds. Having made mementoes reminds parents that their baby will always be with them.

*“We done...hand prints, finger prints, imprint of the thumb, Oh the moulds...definitely helps...you try and grab hold of anything you really need you just need to hold on to things when you’ve lost someone.”(Participant 2, mother)*

*“We’d like done a canvas of Jude’s footprints and we put our handprints on it, that was really nice and then they told us about a website called that day, so a photographer goes out every morning at 5 o clock when the sunrises in Cornwall and takes pictures and you go on the website and pick what day you want, so (date) so we have two nice pictures of the sunrise coming up and for us it’s amazing um and we got hand carves and feet carves and we just went there every day it was lovely actually”(Participant 3, father)*

*“Handprints and the footprints and we done lots and that was really good that was really helpful because now they’re like my memories so like when I see those you know I don’t look at them like sad, they’re like part of Callum...so that was really helpful” (Participant 7, mother)*

### **Theme 7: Building a relationship with hospice staff**

All the families had built up supportive relationships with hospice staff. These relationships provided essential support in their grief, from a neutral and informed person. Most of the parents reported continuity in the member of hospice staff who provided support: often from the initial contact when their baby was still alive to counselling after the death. This meant that they had gone through part of their journey with them and this brought a great deal of comfort. Parents were able to confide in hospice staff with their most difficult thoughts and feelings. Having

this support so readily available, enabled parents an outlet of which they might not normally have, being able to talk to a neutral, skilled professional.

*“I could tell (hospice) anything and I felt better do you know what I mean...and I could tell ‘em when someone really annoyed me...and that was just nice because I could be so honest with ‘em” (Participant 7, mother)*

*“I think it was just having that neutral person to talk to, you know like sometimes with your family and your friends’ um it’s not the same, just having somebody that’s from the outside that’s not involved with it, you know, just being able to talk about how I was feeling and how Archie was and how that was affecting me I found that really helpful” (Participant 1, mother)*

*“I think just talking about the feelings and to be able to work the feelings and see that it’s normal to feel angry”(Participant 4, mother)*

Parents were able to continue counselling after they had left the hospice and one parent reflected on the relationship ending and the consequences of this.

*“Then it was time to stop the counselling and I found that quite hard...it was really hard like breaking away from (hospice worker) ...I felt like I was losing her because I felt like she was a bit of Callum because I had her straight after Callum kind of thing” (Participant 7, mother)*

### **Theme 8: External perceptions of the use of the ‘cold facilities’**

Not only did parents comment on their own preconceptions of the use of such a service but of others views on this as well. Our perceptions of a hospice our embedded by cultural experiences and perceptions. All of parents spoke of being

aware of a dominant view in society that questions spending time with a child after death. They described peoples' reactions and at times there was a sense that parents felt the need to justify why they had used the service.

*"I think until you're in that situation...you know...somebody might say to me oh I could never do that but if they were in that situation, they would probably change their mind and I think, to have that kind of service is so nice compared to a hospital environment." (Participant 1, mother)*

*"Until you're in that situation you haven't got a clue how you'll feel, I mean, if somebody had of said to me they'd kept their baby with them for all that while I'd have been like, really, how...yeah, you'd think, what on earth, why would you do that but until you're there you just don't know" (Participant 2, mother)*

*"It's weird, I mean it sounds a bit strange to want to be in a room next to where your dead daughter is lying in a cold room but that's...it was reassuring, I believe it helped (wife's name) to transfer from one to the other" (Participant 5, father)*

*"It was just nice and to have nice memories, it isn't everyone's cup of tea, but it was my cup of tea because I wanted to make those last memories and remember (hospice) as like a nice place" (Participant 1, mother)*

### **Summary of what parents noticed about the pathway into the service**

Many parents mentioned preconceptions about the hospice with their initial thoughts being very negative. They described hours or days of worry about the implications of using a hospice:

*“When you hear the word hospice you automatically think the worst I think but actually, going there and you know, and the services they provide, it isn’t just about nursing your child until they die, it’s not that at all, it’s actually all these other really positive things which I think, I don’t know, perhaps they can promote that more...I think as well, probably nothing to do with (hospice), but actually people that are having premmy babies or...actually having that chance to go round a neonatal unit, because it’s really scary, you know, you think the worst again, like your baby is being born early and going into intensive care, and you’re just kind of like plonked there... and I think making (hospice) more positive, not in what they do but actually people’s perception of (hospice) and what they do” (Participant 1, mother)*

Other parents spoke of being able to look around the hospice prior to the birth or transfer to hospice and how this helped in their journey:

*“We went there for tea and it was lovely, it was amazing and erm we met the um care team and one of the managers and we had tea there it was fish and chips actually it was really nice and (son) came as well and he loved it there and then one of the (hospice worker) would come and visit us every few weeks it was lovely actually so we knew (hospice) straight away”*  
*(Participant 3, father)*

*“I think it made it easier because I think it’s good to know where you’re going, especially if you’ve got a child like that, you don’t know where you are going...I think that would have been, I think it would have made that more difficult, I don’t know that I would have made that decision”*  
*(Participant 4, mother)*

All of the parents interviewed commented on their initial introduction to the service; the benefits of continuity of care and having someone knowledgeable and available to support them and ask questions.

*“Having (hospice) step in, just knowing that I could you know call them or they would call me” (Participant 1, mother)*

*“(hospice) really did hurry it up and they were getting like, we didn’t have a car seat and (hospice) said well it doesn’t matter, just carry him, just hold him do you know what I mean, so they were brilliant” (Participant 7, mother)*

### **Additional support needed**

One of the aims of the study was to establish is there any additional support needed for people whilst using these services. All the participants reported that their needs were taken care of and that they would not have required any additional support.

## **Discussion**

The findings of this study emphasise the inimitable experience of neonatal death and the use of cold facilities at a hospice. The study corroborates recent movement in understanding of grief, in that continuing bonds is an important aspect (Broderick et al., 2013; Davies, 2004; Gaudet, 2010; Klass, 1993; Klaus et al., 1976) and provides additional evidence that parents yearn to hold and care for their baby (Cacciatore et al., 2012). It is hoped that the findings of theme one demonstrates that cold facilities can often bring families opportunities to enhance and develop these bonds which had not had the chance to flourish to their full potential in other environments, particularly pertinent for parents of a neonatal death. The results

indicate that using cold facilities provides a therapeutic component for parents in adjusting and coming to terms with their loss which mirrors research findings in other studies (Davies, 2005; Forrester, 2008). Using the cold facilities allowed them time to say goodbye. The results showed that parents continued to want to protect and look after their baby by knowing where they were and wanting to spend time as a family: this corroborates the idea that parental instincts continue after death (Thomas et al., 2009). It also offers evidence to support the idea that creating new and positive memories is an essential component to bereavement care (Arnold et al., 2008). The importance of continuity of care which mirrors research findings from other studies (Tan, Docherty, Barfield, & Brandon, 2012) was also highlighted.

All of the above correspond with theories of grief and attachment.

Interestingly, as well as the importance of cherishing and developing continued bonds with the deceased there is an element of acceptance and moving on that parents described which mirrors Worden's (1991) and Kubler-Ross's (2009) theoretical outlook. The grief intervention within this study allowed parents to develop bonds and accept and adjust to the death of their baby.

Parents described valuing the emotional support they received from the professionals at the time of death and the weeks and months following. They found the professionals' timely insights into bereavement and grief salvaging through a lonely and painful ordeal. Parents talked about struggling with the ending of counselling and the relationship they had built up with the member of staff.

In addition, it was noted, that parents were often unaware of the services offered by a hospice and this corresponds to literature that, despite efforts to educate the wider community, people remain unaware (Connor, 2009; Shalev, 2018).

Furthermore, mirroring Connor's literature, the results showed that parents were often astonished by what the hospice had to offer once they had received care from them.

Growing literature on stillbirths and the importance of holding and having proximity to their deceased baby and the possible negative effects of separation (Hennegan, Henderson & Redshaw, 2015; Lindgren, Malm, & Radestad, 2014) suggest comparisons could be made with the findings of this study that holding and spending time with their baby after death is an important and therapeutic for parents. However, literature in this area is inconclusive (Koopmans, Wilson & Cacciatore, 2013; Redshaw, Hennegan & Henderson, 2016) and further consideration needs to be given to the effects of this time for mothers and fathers, and, if particular interventions are appropriate for the type of loss, for example, stillbirth and neonatal death.

The results show that parents' ability to be in the moment with their baby and appreciate and value those moments were crucial in their grief process, creating new and treasured memories. The primary researcher reflected on the use of the words such as 'nice' and 'amazing' throughout the data to describe their time with their baby after death. These narratives could be an indication of the therapeutic benefits; in that spending time with their baby allowed them to reframe their experience and create a new narrative supporting evidence that this can be of benefit to families (Bogensperger & Lueger-Schuster, 2014; Hedtke, 2014).

It helped in some way to be able to fulfil destined and lost roles of parenting and caring for their baby, as well as adjusting to the death of their baby. The use of cooling facilities to preserve a deceased infant's body to enable families to spend

time with them, is increasing within services and equipment is becoming more advanced and user friendly (Rothwell, 2013). This research gives a valuable insight into the experience and the potential therapeutic benefits this intervention may offer. This is particularly as the unique experience of neonatal death means that the service enables parents to be with their baby and care for them in a way that they may never otherwise have been able to.

### **Clinical implications and future research**

Parents in this study spoke of external or perceived perceptions on their choice to spend time with their deceased baby, there was an element that parents felt the need to justify why they had chosen to do this. There has been some movement in social understanding of spending time with a deceased baby (Davis, 2014; Morley, 2017). In addition, pioneers for a deeper understanding of the fundamental values of the dying and how we perceive death helped shape how hospice care is provided in Western societies (Kubler-Ross, 2011) and change has been noted within Western culture for increasing open communication about death in palliative care (Parks, Laungani, & Young, 2015). However, change within wider societal views regarding the care for the dead could reflect instinctive drives and conflicts regarding mortality, that denying the existence of death is a defence mechanism against the knowledge of our mortality (Becker, 1973).

Traditional mourning customs have been largely abandoned and the rituals of cremation or burial of the dead have lost much of the emotional significance which, in the past, often made them a source of support for the bereaved rather than an ordeal. (Parks et al., 2015, p. 4)

It would be fallacious not to recognise that many current religious practices encourage the care of the dead body at home (Gouin, 2015; Pittu & Laungani, 2015), and historically, in Western cultures it would be standard practice (Kerrigan, 2007; Parks et al., 2015). Modern western cultures and practices in death of separation from the deceased as soon as possible could potentially breed denial (Meladze, 2012) and non-acceptance in grief by not allowing an individual time to adjust and accept (Stroebe, 2008). However, there is some shift in practices and media coverage of parents speaking out about spending time with their deceased baby and the comfort this brought could help somewhat (Davis; Morley). The parents who gave their time to this study have helped to give further insight into the reasons why this service could be offered. None of the parents reported any negative experiences of using 'cold' facilities. The findings of the current study suggest that spending time with your baby after death is a choice parents should have and that it was beneficial to those that were interviewed. Furthermore, educating others about the benefits may continue to shift views and perceptions, which, in turn, may help a family that would not ordinarily have sought help to do so.

Parents demonstrated the use of reframing their loss and creating a new narrative of memories with their baby by using the cold facilities. Further research developing an understanding of the therapeutic benefits of this, gathered from multiple hospices could make the findings more applicable to a wider community.

It is important to consider the impact of endings within a therapeutic relationship, giving thought and planning to endings, maybe through a phased/gradual decline and/or preparation early on to difficulties they may experience.

Increasing public awareness of cold facilities and the benefits is crucial to widening access. Gaining a deeper understanding of dominant public views of spending time with a baby after death may enable services to overcome barriers as these may inhibit others from accessing a service which may be of therapeutic benefit to them.

### **Limitations**

The results should be considered with caution and are not necessarily transferable to other bereaved parents and hospice practices as this was taken from a small subsample of families, about the practices of one small hospice. The positive experience of using these facilities from the participants alongside the primary researcher's view that the hospice offers a valuable service inexorably bias the interpretation and this is a significant limitation of the study. However, the findings from this study correspond with key literature in this area showing that time, space, opportunity for slow separation, the importance of not being parted from their child, giving precious time as a family, and the importance of support for siblings (Davies, 2005; Forrester, 2008).

The parents that agreed to take part in the research gave positive accounts of how much they valued the service and the opportunity that it gave them to spend prolonged time with their baby, however, it could be that those with more negative experiences chose not to participate, but the reasons for this were not explored to avoid coercion.

## **Conclusion**

There is no doubt that the profound effect of neonatal death on parents is overwhelming and intense, this research has shown that the use of cold facilities at a hospice was beneficial to the parents in question, having spent more time in an environment that allowed for continued bonds to be attended to and adjusting to the loss of their baby granted some peace during a tumultuous time.

## References

- Arnold, J., & Gemma, P.B, (2008). The continuing process of parental grief. *Death Studies*, 32, 658-673.
- Arnold, J., Gemma, P. B., & Cushman, L. (2005). Exploring parental grief: combining quantitative and qualitative measures. *Archives of Psychiatric Nursing*, 19(6), 245-255.
- Bogensperger, J. & Lueger-Schuster, B. (2014). Losing a child: finding meaning in bereavement. *European Journal Of Psychotraumatology*, 5, 1-9.
- Bowlby, J. (1998). *Loss: sadness and depression* (Vol. 3). London: Pimlico.
- Bowlby, J. (2005). *A secure base: clinical applications of attachment theory*. Abingdon: Routledge, 2005, c1988.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Braun, V. & Clarke, V. (2013). *Successful qualitative research: a practical guide for beginners*. London: Sage.
- Broderick, S. & Cochrane, R. (2013). *Perinatal loss: a handbook for working women and their families*. London: Radcliffe Publishing Ltd.
- Cacciatore, J. & Flint, M. (2012). Mediating grief: post-mortem ritualization after child death. *Journal of Loss and Trauma*, 17, 158-172.
- Cawston, G. (2012). *Trust Guidelines for the management of bereavement and last offices for neonates*. Norfolk & Norwich University Hospital NHS Foundation Trust.

- Chichester, M. (2005). Multicultural issues in perinatal loss. *Association of Women's Health, Obstetric and Neonatal Nurses Lifelines*, 9, 312-320.
- Connor, S.R. (2009). *Hospice and Palliative Care: The Essential Guide*. Oxford, UK: Taylor & Francis.
- Davies, R. (2004). New Understandings of parental grief: literature review. *Journal of Advanced Nursing*, 46(5), 506-513.
- Davies, R. (2005). Mothers' stories of loss: their need to be with their dying child and their child's body after death. *Journal of Child Health Care*, 9(4), 288-300.
- Davies, R. (2009). Caring for the child at the end of life. In J. Price, & P. McNeilly (Eds.), *Palliative care for children and families*. (pp. 172-191). Hampshire: Palgrave Macmillan.
- Davis, D. (2014). Providing after-death care at home when a baby dies. *Psychology Today*. <https://www.psychologytoday.com/blog/laugh-cry-live/201403/providing-after-death-care-home-when-baby-dies>
- Doka, K. J., & Martin, T. L. (2010). *Grieving beyond gender: understanding the ways men and women mourn*. New York: Routledge, c2010.
- Feeley, N. & Gottlieb, L. N. (1988). Parent's communication and coping following their infants death. *Omega*, 19(1), 51-67.
- Forrester, L. (2008). Bereaved parents' experiences of the use of 'cold bedrooms' following the death of their child. *International Journal Palliative Nursing*, 14(12), 578-585.

- Freud, S. (1917). *Mourning and melancholia Vol. XiV the standard edition of the complete works of Sigmund Freud*. London: The Hogarth Press.
- Gaudet, C. (2010). Pregnancy after perinatal loss: association of grief, anxiety and attachment. *Journal of Reproductive Infant Psychology*, 28(3), 240-251.
- Gouin, M. (2015). The Buddhist way of death. In C. Parks, P. Laungani, & B. Young, B (Eds). *Death and Bereavement across cultures* (2<sup>nd</sup> ed). East Sussex: Routledge.
- Hall, C. (2014). Bereavement theory: recent developments in our understanding of grief and bereavement. *Bereavement Care*, 33(1), 7-12.
- Harvey, S., Snowdon, C., & Elbourne, D. (2008). Effectiveness of bereavement interventions in neonatal intensive care: A review of the evidence. *Seminars in Fetal & Neonatal Medicine*, 13, 341-356.
- Hedtke, L. (2014). Creating stories of hope: a narrative approach to illness, death and grief. *Australian & New Zealand Journal Of Family Therapy*, 35(1), 4-19.  
doi:10.1002/anzf.1040
- Hennegan, J. M., Henderson, J., & Redshaw, M. (2015). Contact with the baby following stillbirth and parental mental health and well-being: a systematic review. *BMJ Open*, 5(11), e008616. doi:10.1136/bmjopen-2015-008616
- Hollins-Martin, C. & Forrest, E. (2013). *Bereavement care for childbearing women and their families*. Oxon: Routledge.
- Jenkins, C. & Merry, J. (2005). *Relative care: parents and children, sisters and brothers, husbands, wives and partners, grandparents and grandchildren talk*

*about their experiences of death and grieving.* London: Jessica Kingsley Publications.

Kearvell, H., & Grant, J. (2010). Getting connected: how nurses can support mother/infant attachment in the neonatal intensive care unit. *Australian Journal Of Advanced Nursing*, 27(3), 75-82.

Kerrigan, M. (2007). *The history of death: burial customs and funeral rites, from the ancient world to modern times.*

Klass, D. (1993). Solace and Immortality: bereaved parents 'continuing bond with their children. *Death Studies*, 17, 343-368.

Klaus, M. H. & Kennell, J. H. (1976). *Maternal-infant bonding.* St Louis: C. V. Mosby.

Kohner, N. & Henley, A. (2001). *When a baby dies: the experience of late miscarriage, stillbirth and neonatal death.* (Revised ed). London: Routledge.

Koopman, L., Wilson, T., Cacciatore, J. & Flenady, V. (2013). Support for mothers, fathers and families after perinatal death. *Cochrane Database Systematic Review*, (6).

Kubler-Ross, E. (2009). *On death and dying: what the dying have to teach doctors, nurses, clergy and their own families.* London: Routledge.

Kubler-Ross, E. & Kessler, D. (2005). *On grief and grieving: finding the meaning of grief through the five stages of loss.* London: Simon & Schuster UK.

Laakso, H. & Paunonen-Ilmonen, M. (2001). Mothers' experience of social support following the death of a child. *Journal of Clinical Nursing*, 11, 176-85.

- McGuinness, D., Coughlan, B. & Butler, M. (2014). An exploration of the experiences of mothers as they suppress lactation following late miscarriage, stillbirth or neonatal death. *Evidence Based Midwifery*, 12(2), 65-70.
- McGuinness, D., Coughlan, B. & Power, S. (2014). Empty Arms:supporting bereaved mothers during the immediate postnatal period. *British Journal of Midwifery*, 22(4), 246-252.
- Meladze, V. (2012). Denial of death: America in decline. *The journal Of Psychohistory*, 39(3), 180-202.
- Morley, N. (2017, February 11). Parents document living with their dead baby for 16 days. Metro. Retrieved from <http://metro.co.uk/2017/02/01/parents-who-spent-16-days-with-their-dead-baby-girl-share-photos-of-the-experience-6420639/>
- Norlund, E., Borjesson, A., Cacciatore, J., Pappas, C., Randers, I. & Radestad, I. (2012). When a baby dies: motherhood, psychosocial care and negative affect. *British Journal of Midwifery*, 20(11), 780-4.
- Parkes, C., Laungani, P., & Young, B. (2015). *Death and Bereavement across cultures* (2<sup>nd</sup> ed). East Sussex: Routledge.
- Pittu & Laungani, A. (2015). Death in a Hindu family. In C. Parkes, P. Laungani, & B. Young, B (Eds). *Death and Bereavement across cultures* (2<sup>nd</sup> ed). East Sussex: Routledge.

- Redshaw, M., Hennegan, J. M., Henderson, J. (2016). Impact of holding the baby following stillbirth on maternal mental health and wellbeing: findings from a national survey. *BMJ Open*, 6 (8).
- Root, B. & Exline, J. (2014). The role of continuing bonds in coping with grief: overview and future directions. *Death Studies*, 38, 1-8.
- Rothwell, S. (2013). After death care in the hospital, home, and hospice – cooling the deceased. eHospice. Retrieved from <http://www.ehospice.com/ArticleView/tabid/10697/ArticleId/7844/View.aspx>
- Roy, R. & Shirtliffe, J. (2014). Guideline for management of a dying baby and his/her family. Norfolk & Norwich University Hospital NHS Foundation Trust.
- Shalev, A., Phongtankuel, V., Kozlov, E., Shen, M. J., Adelman, R. D., & Reid, M. C. (2018). Awareness and misperceptions of hospice and palliative care: a population-based survey study. *American Journal Of Hospice & Palliative Medicine*, 35(3), 431-439.
- Stroebe, M. S. (2008). *Handbook of bereavement research and practice: advances in theory and intervention*. Washington, DC: American Psychological Association, c2008.
- Stroebe, M. & Schut, H. (2005). To continue or relinquish bonds: A review of consequences for the bereaved. *Death Studies*, 29, 477-494.

Thomas, J. & Chalmers, A. (2009). Bereavement care. In J. Price, & P. McNeilly (Eds.), *Palliative care for children and families*. (pp. 192-212). Hampshire: Palgrave Macmillan.

Tugendhat, J. (2005). *Living with loss and grief*. London: Sheldon Press.

Vance, J. C., Boyle, F. M., Najman, J. M., & Thearle, M. J. (2002). Couple distress after sudden infant or perinatal loss: a 30 month follow up. *Journal Of Paediatrics and Child Health*, 38(4), 368-372.

Worden, J. W. (1991). *Grief counselling and grief therapy* (2<sup>nd</sup> ed). London: Routledge.

## **Extended Methodology**

The purpose of this additional chapter is to supplement the methodology section of the empirical paper. To provide a justification and greater level of detail regarding qualitative research analysis chosen. The ontology, epistemology, researcher position, and rigour will be discussed.

### **Rationale for qualitative framework**

Research looking at parental grief and grief interventions has been conducted using both quantitative and qualitative methodology. Both methodologies have advantages and disadvantages. Quantitative methodology can often allow collection of data from larger samples, comparison of groups, giving a comprehensive and generalized set of findings (Yilmaz, 2013). However, this requires adequate prior research and literature understanding to develop hypotheses for testing. It also restricts data collection methods.

In contrast, qualitative methods allow for rich and complex insights, meaning and understanding of individuals experience (Braun & Clarke, 2006; Lyons & Rohleder, 2015). It enables a greater understanding of the phenomenon which may or may not have been previously researched. Qualitative research methods, such as interviews, permit the study of issues that may be too complex or sensitive to investigate through other means, as well as being flexible and responsive to what interviewees raise, being the expert of their own experience (Burman, 1994). Rohleder & Lyons (2015) argue the value of using qualitative research methods in health and clinical psychology.

The unique experience of using cold facilities after the death of an infant baby has not been explored in any depth to date and, as discussed in the introduction of the empirical paper, it is important to explore the experiences of bereaved parents who have used this service. The experience of the use of cold facilities has been reported within two known studies (Davies, 2005; Forrester, 2008). There is a small body of literature concerning stillbirth and parents holding their baby, although extremely insightful to this group of individuals, it may be a very different experience and comparisons should be made with caution. The use of cold facilities for longer periods of time and often after parents have cared for their baby in hospital for a length of time requires investigation. As the phenomenon in question has not been researched before, this method gives a good starting point to develop future research.

### **Rationale for Thematic Analysis**

Thematic analysis is a method in which data is organized by identifying patterns, analyzing and reporting themes. It is accessible and theoretically flexible and can be particularly pertinent for researchers early on in their qualitative research journey (Braun & Clarke, 2006).

Thematic analysis was chosen as a sound starting point for an area which is under-researched and its ability to answer the research questions. It was also chosen for its suitable fit with the epistemological stance of the primary researcher. It allows for data to be viewed from the parents' experiences rather than from theoretical assumptions. An inductive approach allows for generation of new theory emerging from the data (Braun & Clarke, 2006; Thomas, 2003).

## **Decisions regarding analysis**

Braun and Clarke (2006) advocate that prior to research commencing certain decisions need to be made with regards to the analysis, and that giving consideration to these enhances the data. Firstly, as described above, a decision was made that the thematic analysis would be inductive, namely, due to the lack of research within this specified area as well as answering the research questions.

Secondly, it was decided within the research team that themes would be identified semantically, allowing for explicit connection with the data rather than interpretation, again, as this area is under-researched it will hope to provide a starting point for future research. This is done as opposed to analysing latently, which would give more depth to the analysis as it allows for interpretation and specific focus on certain areas. The research team felt that reporting semantically, showing a description of what the participants had reported would be more beneficial.

Thirdly, it was decided that data which directly answered the research questions would be included in the data. Finally, it was discussed within the research team as to what counts as a theme, in accordance with Braun and Clarke's (2006) guidelines, a theme is representative of something imperative in the data in relation to the research questions and henceforth was considered if it was highly prevalent within the data and reported by numerous if not all the participants.

## **Ontological and epistemological**

In general, there is an assumption that qualitative researchers cannot be objective. Therefore, the researcher's ontological and epistemological stance are central and worthy of consideration (Coyle, 2016).

Ontology refers to “assumptions about the nature of the world” (Chamberlain, 2015, p. 10) and concerns whether there is an objective reality (positivism) or reality is subjective and socially constructed (Interpretivism). The ontology of this research was interpretivism, as it focussed on parents’ accounts of their experience of using ‘cold’ facilities.

Epistemology refers to “assumptions about how the world can be investigated” (Chamberlain, 2015, p. 10). This thesis portfolio was approached from a largely social constructionist which assumes that the way we make sense of the world is built through the social processes we’re a part of; it is culturally and historically dependent. This stance acknowledges the researcher’s position.

### **Reflective Journal**

I kept a research journal throughout the research process (Appendix M), to facilitate reflexivity, enhance transparency by making my thoughts and feelings discernible in the research process (Ortlipp, 2008). Reflective research journals should be central to the methodology of a study (Jasper, 2005). The reflective journal was used during recruitment, interviews and the analysis process.

### **Researcher position: own position**

I am a 34-year-old woman in my third year studying to become a clinical psychologist. I have a bachelor’s degree in psychology from University of Westminster, when I was first ignited with qualitative research positions, taking an interest in feminist literature and critical psychology. My undergraduate dissertation was of mixed methods design investigating the pragmatics of children’s language in different social settings. In my working life, I worked on two major national

randomized controlled trials and expanded my research knowledge, particularly gaining insight into the mechanics of completing a large study and some of the limitations. This has led to an interest and thirst for knowledge and understanding of qualitative research. I delight in the idea that researchers do research 'with' not 'on' the participants.

My degree afforded me the experience of working within three different medium secure forensic units, as a support worker, assistant psychologist and then as a trainee psychologist. These combined harnessed a development of skills of resilience, compassion, and understanding of some very challenging and sensitive stories. It gave me a great sense of pain from different angles, from perpetrators and victims which enabled me to hear respect and respond to individuals. I have heard awful lived experience of grief and talking about death and severe abuse became a part of every day. I believe that having developed these skills early on in my career allowed me to talk to parents about such unspeakable pain without becoming emotionally immersed in it.

I am a mother of three young children, taking maternity leave from my Clinical Psychology training to have my third child. Prior to having my three children, I had a miscarriage and a subsequent ectopic pregnancy. At the time of these, I suffered immensely and longed for a connection with the loss I felt. The hope of becoming a mother was something that I always felt destined for and my brief and minimal experience of loss, in comparison to those within my research, gave me insight into having a loss of hopes and dreams for the future, also for the immense connection that a mother can feel for a fetus long before it is born. Having these experiences lend themselves towards my position of the use of cold facilities for infants and children, in that I can view them to potentially give incredible value

of precious time with their child. There is potential bias here, in that my own experiences as well as views of the service could lead me to selectively attend to the benefits of service and be less attuned to the negative experiences reported. I tried to be mindful and curious of my own assumptions and kept a reflective journal throughout.

Therefore, I accept that I bring the above with me throughout this research process and that self-reflection and being transparent about my views allow for an awareness of this within the data. I believe that the relationship formed between myself and the parents interviewed gave way for a co-constructed meaning about their experience but that I am central to the sense that is made.

### **Critical Reflection on the Quality and Rigour of the Research**

Both the reflective diary and acknowledgment of the researchers own position were attempts to improve the rigour of the research. It was paramount to the primary researcher to be faithful to the participants experience and that the results reflected this. Codes and themes were cross checked and deliberated by the research team. On reflection, multiple coding of the entire data set would improve the rigour of this research. Particularly, if different coders were from different disciplinary backgrounds. However, due to budget and time restraints this was not possible. Triangulation within data can no doubt improve the rigour, and it could be that other data collection methods could have encouraged others to volunteer such as a focus group. It may be that future research can consider these different options.

## Procedure

### **Ethical Considerations**

**Ethical approval.** The proposal for this project was submitted for review by staff within the Clinical Psychology Department at UEA and was approved. Feedback on the methodological procedure was attended to prior to submission for ethical review from University of East Anglia's Faculty of Medicine & Health Sciences Research & Ethics Committee, small amendments were required and attended to and ethical approval was granted on 24<sup>th</sup> March 2017 (Appendix H: Approval from FMH Ethics). The research was carried out within a private charity therefore approval was sought from the organization's board of Trustees and was granted in March 2017. Recruitment began in April 2017 and the first participant was interviewed on Tuesday 9<sup>th</sup> May 2017.

**Data handling.** To respect the privacy, autonomy and dignity of participants, all data were kept confidential in accordance with the Data Protection Act 1998. A discussion took place prior to the commencement of the interview regarding confidentiality and that if the participant disclosed anything that concerned me for their safety or the safety of others I had a professional obligation to pass this information on. This would have been done, where possible, with their knowledge and consent. None of the participants showed any cause for concern regarding these matters.

The interviews were recorded on a Sony ICD-PX333 Dictaphone, then immediately transferred to an encrypted USB via a personal laptop bought to each interview and were stored in a password protected encrypted manner. The data were not stored on this laptop, merely used to transfer to a secure means. Once the data

were successfully transferred, it was deleted from the Dictaphone in order to protect the participants' confidentiality. Data were anonymized by giving a study number and labelling the recording at the beginning of each interview. Anonymized printed paper transcripts and consent forms will be stored separately in locked filing cabinets at the UEA and will be destroyed after ten years. This will be facilitated through Helen Sayer (Administration Assistant, ClinPsyD Programme). Both the electronic and paper data will be kept in accordance with UEA's data management policy. Participants were given the option to receive a copy of their transcript should they wish to. If participants chose to receive their transcript then it would be sent to their preferred method including a second sheet requiring confirmation that it is an accurate presentation of their words. If there was any discrepancy with the content of the transcript then the primary researcher would arrange to meet with the participants to discuss this, following the same procedure outlined for original interviews. If this cannot be resolved then we will collaboratively decide which segments will be removed.

**Confidentiality.** Due to the sensitive nature of the topic careful consideration has been given to the naming of the deceased child during the interview. The chief investigator will have a discussion with the interviewees prior to the commencement of the interview to establish how they would like to go about this. For example, participants' may decide to use their child's first name rather than a pseudonym, both options will be given to the participants explaining the rationale for a pseudonym that it allow for data to be anonymized.

As discussed in the empirical paper following interviews and informal discussions participants requested the use of the real name for their baby. Careful thought and consideration was given to this and the views of parents were

paramount. The primary researcher discussed the implications of their stories being in the public domain without anonymity; parents came to the conclusion that they wanted real names to be used in both transcripts and published documents. Ethical approval was sought which included emails from parents (appendix K) detailing their views and standpoint, approval was granted for this on the grounds that going against parents' wishes would be detrimental and could cause undue distress to them. Additional written consent was sought for the use of their baby's name and the primary researcher will contact participants prior to publication to go through what information is included and if this is still preferred. All other identifiable information has been anonymized in the data.

**Supervision.** Conducting research with people who have gone through bereavement of a child will inevitably be an emotionally demanding experience for both the participants and the researcher conducting the interviews. It was essential the primary researcher had monthly supervision, provided by the primary research supervisor to cover the emotional impact of the interviews, in addition to normal research supervision. The primary researcher returned from maternity leave in August 2016 and has three young children, their welfare and wellbeing will be closely monitored, and regular risk assessments took place in advisor meetings at the UEA with the secondary supervisor alongside regular supervision. In the risk assessment meetings to date, the primary researcher has identified strategies to protect their wellbeing as much as possible, for example, being aware of times interviews take place, activities following the interview and having a 'buddy' system with the primary or secondary supervisor where they can contact to talk through any issues that arose.

**Home Visits.** Where a convenient location could not be agreed, for example, other than UEA or E.A.C.H premises, interviews were carried out in the participants home. In order to maintain the safety of the chief investigator, lone working policy was followed and the primary supervisor has agreed to act as a 'buddy'. This involved a text messaging system pre and post interviews. Should the primary researcher not contact the primary supervisor within the specified time frame then action will be required by the primary investigator.

### **Interview Topic guide**

The interview questions will aim to explore the complexity of the experience of grieving for their deceased child whilst in close proximity with their body, and the emotional impact of spending this time with them. A preliminary plan for the route of questioning was developed and reviewed by Stillbirth & Neonatal Death Society (SANDS) prior to beginning recruitment. The interview schedule was a guide and only a small number were used in order to allow for participants to shape the interview to what was important about the experience for them.

### **Thematic Analysis**

The primary researcher followed Braun and Clarke's stages of thematic analysis and are detailed below.

**Transcription.** Following interviews each interview was listened to prior to transcription, paying attention to thoughts, feelings and patterns in the data then reporting these in the reflective journal. The primary researcher transcribed all seven interviews verbatim. Following transcription, interviews were listened to, to cross reference the transcript with the audio recording, minor changes were made and

some sections were listened to several times to ascertain more inaudible sections of the data. All identifiable information was removed and replaced with a description e.g. (husband's name) or (Hospital A). The entire data set was read before and after coding in line with Braun & Clarke's (2006) advice. This process allowed for an in-depth familiarization with the data and to become truly immersed.

**Coding and Searching for Themes.** Line by line coding of the data were conducted, this was done in two phases. Firstly, after consultation within a qualitative research forum made up of both Clinical Psychology department staff and Clinical Psychology Trainees of the UEA, advice was given regarding methods of coding. The primary researcher had tried using NVivo, computer software which can assist with qualitative research but had found this problematic. Advice was given to use excel to assist in this process, Data were organized using the headings displayed in table 1. The research team are aware that there are a number of ways that this phase of analysis can be done, careful consideration was given to which method to use.

---

Table 1. Organisation of Data in excel

---

Id	Line	Large extract of	Short	Initial	Possible	Possible
number	number	text	extract of text	codes	category	theme

---

If the data were relevant or answered one of the research questions, then an initial segment of text was highlight (Appendix N: Example of transcript) and then transferred to excel and codes derived were kept as close to the original wording of participants as possible (Appendix O: Example Transcript and Codes). Coding was

done by a process of identifying interesting segments of data and then patterns within the data corpus and sorted into possible themes. The patterns identified were then grouped into initial categories and then cross referenced with other segments in this category.

## **Chapter 5: Critical Analysis**

## **Critical Analysis**

### **Overview of results**

Consistent with the small evidence base for the use of ‘cold’ facilities to care for a dying child (Davies, 2005; Forrester, 2008), the empirical paper results suggest that the service provide comfort and meaning to parents. The unique experience of neonatal death is complex, and parents’ needs are paramount. The results highlight therapeutic benefits of being able to care for their baby in a way that they never had, space and time to adjust to the loss, precious time as a family, knowing where their baby is being cared for, nurturing care for the whole family, creating positive memories, and building relationships with hospice staff. The benefits shown complement existing literature on parental bereavement (Cacciatore et al., 2012; Broderick et al., 2013; Davies, 2004; Gaudet, 2010; Klass, 1993; Klaus et al., 1976). The results reported of external perceptions of the use of ‘cold’ facilities show insight into societal views and response to death and how this corresponds with theoretical understanding of death (Becker, 1973; Kubler-Ross, 1997) which is driven by fear and avoidance. Henceforth, the paper hopes to facilitate debate, discussion and understanding of death and grieving needs.

In addition, gaining a deeper understanding of grief and how this is expressed by mothers or fathers within a relationship could help shape the bereavement care. Traditional gender roles in society of men and women, how they act, respond, and behave have developed over centuries and while modern life challenges some of these views, they have left an incredible impact on society and our thoughts of men and women (Lindsey, 2015; Rice & Barth, 2017; Schmitt, Long, McPhearson, O’Brien, Remmert, & Shah, 2017). How grief is expressed by a man or a woman is

embedded within these societal views (Martin & Doka, 2000). The results from the systematic review mirror findings that suggest that male grievers may find themselves in a paradox: being strong vs. showing emotion, it corroborates the idea that patterns of grief should be seen on a continuum (Martin & Doka, 2000). Unsurprisingly, these differences of experience can have an impact of a marital relationship (Martin & Doka, 2000). However, the results gave light to a level of resilience and respect within a relationship to allow the other person to grieve in their own way.

The combined results are reflective of movement in grief and understanding over the past two decades; a shift to understanding stages (Kubler-Ross, 1969) or phases (Rando, 1993) of grief that are necessary to, ultimately, move to acceptance. The empirical paper mirrors a shift in our understanding of the importance of continuing bonds with the deceased (Klass, 1996; Valentine, 2008). The systematic review identifies the capabilities of parents' relationship to survive and negotiate their grief, in line with views that humans can show psychological growth out of devastating conditions (Hindmarch, 2009) and although the death of a child has a brutal effect on a family and/or parental relationship (Buckle & Fleming, 2011) that strength can also be drawn.

Accordingly, the male fathers within the empirical paper articulated expressing grief both in an affective and non-affective way. This is inline with results from the systematic review. It may be that this is indicative of fathers who chose not only to use cold facilities to spend time with their baby after death but of those that volunteered to participate in research about it. The results of the empirical paper show no difference between men and women for their experience of the cold

facilities. In fact, they reported the same needs and fulfilment as each other. For example, both men and women reported wanting to hold and cuddle their baby.

### **Strengths and limitations**

The nature of qualitative research means that results from both papers are limited due to sample size, albeit more refined. A degree of caution should be considered when interpreting results and applying to wider population. However, in general, it mirrors extensive research in grief and bereavement (Cacciatore et al., 2012; Broderick et al., 2013; Davies, 2004; Davies, 2005; Gaudet, 2010; Klass, 1993; Klaus et al., 1976; Forrester, 2008).

The ability to gain in-depth knowledge from the experiences of parents is invaluable to an area that has very limited research. The overwhelmingly positive response about using ‘cold’ facilities from parents in the empirical paper demonstrates the importance of the research undertaken. Informally, parents spoke of the importance of participating in research and adding to the legacy of their son or daughter; this was felt to be a positive side effect of the study.

A limitation of the thesis portfolio is that the social constructionist position was not consistently maintained. For example, within the results section ‘parental instincts’ are referred to, which does not suggest behaviours and needs were because of interaction but an innate component. This is due to various reasons, firstly, participants often referred to this within the interviews. This, along with personal parental views and history, shaped the primary researchers view of words to describe initial parental experiences. On reflection, the primary researcher would describe these ‘instincts’ are a result of social interaction, learnt roles, observed caring, and personal characteristics not as an innate quality a parent is born with. However, this

word was used by several of the parents and therefore felt to be part of an important narrative of the research.

### **Theoretical and clinical implications**

The main hope for this thesis portfolio is to compliment current movement in understanding of grief and bereavement services. Although considerable effort within the Western society to talk about death and the needs of those experiencing the effects of it (e.g. Kubler-Ross, 2009), parents still reported resistance and stigma regarding 'cold' facilities, which is also demonstrated within the literature (Talbot, 2002). Educating, communicating, and igniting discussions with wider society are essential in elevating improvements for this population.

Bearing in mind the systematic review results of grieving patterns and the fact that both mothers and fathers were interviewed in the empirical paper, results were significantly positive about benefits gained from spending time with their baby after death. Thus, indicating that, for the parents interviewed, this service was of benefit to both men and women. Parents gained a new narrative to their limited but precious time spent with their baby. In summary, although results were gained from a small sample, the overwhelmingly positive response regarding the time spent with their baby after death is undeniable and advocates the importance of giving parents choice in offering such services.

Results from the systematic review can help to guide practitioners working within this field. It is hoped that they would not presume a style of grieving, but as explained, these can be intrinsic within our belief systems. Using supervision to reflect upon how they may interpret behaviour and draw conclusions from this, for example, a father not expressing affect after the death of a child. Being aware and

able to reflect on our own and/or perceptions of grieving patterns could be used to inform practice.

Future research will be a vital component towards enhancing understanding of bereavement services and psychological benefits. Appropriate service evaluation could add to the evidence base. However, it is felt that a larger, multi-site study would be beneficial. In addition, it would be ideal to reach as many parents that have used the service and attempting to access those that are not as likely to volunteer; considering recruitment method and accessibility would be essential.

## References

- Bennett, H. (2012). A guide to end of life care of children and young people before death, at the time of death and after death. *Together For Short Lives*. Retrieved from [http://www.togetherforshortlives.org.uk/assets/0000/1855/TfSL\\_A\\_Guide\\_to\\_End\\_of\\_Life\\_Care\\_5\\_FINAL\\_VERSION.pdf](http://www.togetherforshortlives.org.uk/assets/0000/1855/TfSL_A_Guide_to_End_of_Life_Care_5_FINAL_VERSION.pdf)
- Bovey, A. (2015, April 30). Death and the afterlife: how dying affected the living. *British Library*. Retrieved from <https://www.bl.uk/the-middle-ages/articles/death-and-the-afterlife-how-dying-affected-the-living>
- Buckle, J. L., & Fleming, S. J. (2011), *Parenting after the death of a child: a practitioner's guide*. East Sussex: Routledge.
- Chamberlain, K. (2015). Epistemology and qualitative research. In P. Rohleder & A. C. Lyons (Eds). *Qualitative research in clinical and health psychology*. Hampshire: Palgrave MacMillan.
- Cozzolino, P. J., Blackie, L. R., & Meyers, L. S. (2014). Self-related consequences of death fear and death denial. *Death Studies*, 38, 6-10.
- Coyle, A. (2016). Introduction to qualitative psychological research. In E, Lyons & A. Coyle. *Analysing qualitative data in psychology* (2<sup>nd</sup> ed). London: Sage.
- Coyle, N., Manna, R., Shen, M. J., Banerjee, S. C., Penn, S., Pehrson, C., & ... Bylund, C. L. (2015). Discussing death, dying, and end of life goals of care: a communication skills training module for oncology nurses. *Clinical Journal Of Oncology Nursing*, 19(6), 697-702.

- Davies, R. (2004). New Understandings of parental grief: literature review. *Journal of Advanced Nursing*, 46(5), 506-513.
- Davies, R. (2005). Mothers' stories of loss: their need to be with their dying child and their child's body after death. *Journal of Child Health Care*, 9(4), 288-300.
- Davis, D. (1991). *Empty cradle. broken heart: surviving the death of your baby*. Golden: Fulcrum Publishing.
- Forrester, L. (2008). Bereaved parents' experiences of the use of 'cold bedrooms' following the death of their child. *International Journal Palliative Nursing*, 14(12), 578-585.
- Goodey, J. (1997). Boys don't cry masculinities, fear of crime and fearlessness. *British Journal of Criminology* 37(3), 401-418.
- Gouin, M. (2015). The Buddhist way of death. In C. Parkes, P. Laungani, & B. Young, B (Eds). *Death and Bereavement across cultures* (2<sup>nd</sup> ed). East Sussex: Routledge.
- Haraldsdottir, E. (2017). Enhancing openness around death and dying through documentary film-making in a hospice. *European Journal Of Palliative Care*, 24(6), 268-271.
- Hindmarch, C. (2009). *On the death of a child*. Oxon: Radcliffe Publishing Ltd.
- Hooyman, N. R., & Kramer, B. J. (2006). *Living through loss: interventions across the life span*. New York: Columbia University Press.

- Hynan, M. T., Steinberg, Z., Baker, L., Cicco, R., Geller, P. A., Lassen, S., & ...  
 Stuebe, A. (2015). Recommendations for mental health professionals in the  
 NICU. *Journal Of Perinatology: Official Journal Of The California  
 Perinatal Association*, 35 Suppl 1S14-S18. doi:10.1038/jp.2015.144
- Isler, A. (2017). Palliative and hospice care versus standard care on quality of life  
 and suffering. *Kentucky Nurse*, 65(3), 6-7.
- Jasper, M. A. (2005). Using reflective writing within research. *Journal Of Research  
 in Nursing*, 10(3), 247-260.
- Keverne, E. (2017). *Beyond sex differences: genes, brains and matrilineal evolution*.  
 Cambridge: Cambridge University Press.
- King, J., Prout, B., Stuhl, A., & Nelson, R. (2016). Scrapbooking as an intervention  
 to enhance coping in individuals experiencing grief and loss. *Therapeutic  
 Recreation Journal*, 50(2), 181-185.
- Lindsey, L. L. (2015). *Gender roles: a sociological perspective*. Boston: Pearson.
- Martin, T. L., & Doka, K. J. (2000). *Men don't cry...women do: transcending gender  
 stereotypes of grief*. Philadelphia: Bruner Mazel Publishers.
- Matthews, B. L. (2018). Hospice informal caregivers' perception of a good death  
 experience: a servqual analysis. *Services Marketing Quarterly*, 39(1), 64-77.
- McClain, L., & Grossman, J. (Eds). (2009). *Gender Equality: dimensions of  
 women's equal citizenship*. Cambridge: Cambridge University Press.
- McNess, A. (2008). Happy to talk...to a point: bereaved young men and emotional  
 disclosure. *Youth Studies Australia*, 27(4), 25-34.

- Montgomery, J. E., Chaviano, C. L., Rayburn, A. D., & McWey, L. M. (2017). Parents at-risk and their children: intersections of gender role attitudes and parenting practices. *Child & Family Social Work, 22*(3), 1151-1160.
- Oliffe, J. L., Kelly, M. T., Bottorff, J. L., Johnson, J. L., & Wong, S. T. (2011). “He’s more typically female because he’s not afraid to cry”. Connecting heterosexual gender relations and men’s depression. *Social Science & Medicine, 73*775-782. doi:10.1016/j.socscimed.2011.06.034
- Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *The Qualitative Report, 13*(4), 695-705.
- Parkes, C., Laungani, P., & Young, B. (2015). *Death and Bereavement across cultures* (2<sup>nd</sup> ed). East Sussex: Routledge.
- Pittu & Laungani, A. (2015). Death in a Hindu family. In C. Parkes, P. Laungani, & B. Young, B (Eds). *Death and Bereavement across cultures* (2<sup>nd</sup> ed). East Sussex: Routledge.
- Quested, B. & Rudge, T. (2003). Nursing care of dead bodies: A discursive analysis of last offices. *Journal of Advanced Nursing, 41*(6), 553-560.
- Rice, L., & Barth, J. (2017). A tale of two gender roles: the effects of implicit and explicit gender role traditionalism and occupational stereotype on hiring decisions. *Gender Issues, 34*(1), 86-102. doi:10.1007/s12147-016-9175-4
- Rohleder, P., & Lyons, A. C. (2015). *Qualitative research in clinical and health psychology*. Basingstoke, Hampshire: Palgrave Macmillan.

- Rosner, R., Pfoh, G., & Kotoucova, M. (2010). Treatment of complicated grief. *European Journal Of Psychotraumatology*, 1, 1-10.
- Schmitt, D. P., Long, A. E., McPhearson, A., O'Brien, K., Remmert, B., & Shah, S. H. (2017). Personality and gender differences in global perspective. *International Journal Of Psychology*, 5245-5256.
- Shalev, A., Phongtankuel, V., Kozlov, E., Shen, M. J., Adelman, R. D., & Reid, M. C. (2018). Awareness and misperceptions of hospice and palliative care: a population-based survey study. *American Journal Of Hospice & Palliative Medicine*, 35(3), 431-439.
- Singer, L. T., Salvator, A., Guo, S., Collin, M., Lilien, L., Baley, J. (1999). Maternal psychological distress and parenting stress after the birth of a very low-birth-weight infant. *Journal Of American Medical Association*, 281(9), 799–805.
- Spinelli, M., Frigerio, A., Montali, L., Fasolo, M., Simonetta Spada, M., & Mangili, G. (2016). 'I still have difficulties feeling like a mother': The transition to motherhood of preterm infants mothers. *Psychology & Health*, 31 (2), 184–204,
- Talbot, K. (2002). *What forever means after the death of a child: transcending the trauma, living with the loss*. London: Brunner-Routledge.
- Taylor, J., & Aldridge, J. (2017). Exploring the rewards and challenges of paediatric care work – a qualitative study of a multi-disciplinary children's hospice care team. *BMC Palliative Care*, 16, 1-11.

- Valentine, C. (2008). *Bereavement Narratives: continuing bonds in the twenty-first century*. Oxon: Routledge.
- Wigert, H., Johansson, R., Berg, M., & Hellstrom, A. L., (2006). Mothers' experiences of having their newborn child in a neonatal intensive care unit. *Scandinavian Journal of Caring Sciences, 20*, 35-41.
- Wortman, C. B., & Silver, R. C. (1989). The myths of coping with loss. *Journal Of Consulting and Clinical Psychology, 57*(3), 349-357.
- Yilmaz, K. (2013). Comparisons of quantitative and qualitative research traditions: epistemology, theoretical, and methodological differences. *European Journal Of Education, 48*(2), 311-325.
- Zimmerman, C. (2012). Acceptance of dying: A discourse analysis of palliative care literature. *Social Science & Medicine, 75*, 217-224.
- Zimmermann, C., & Rodin, G. (2004). The denial of death thesis: sociological critique and implications for palliative care. *Palliative Medicine, 18*(2), 121-128.

## Appendices

Appendix A: Author guidance for journal.....	109
Appendix B: CASP.....	114
Appendix C: Letter to participants.....	117
Appendix D: Information sheet.....	119
Appendix E: Consent to contact form.....	123
Appendix F: Demographic sheet.....	124
Appendix G: Interview topic guide.....	125
Appendix H: UEA ethical approval.....	127
Appendix I: Hospice ethical approval.....	128
Appendix J: Consent form.....	129
Appendix K: Ethical amendment request.....	130
Appendix L: Ethical amendment approval.....	131
Appendix M: Table of themes discussed by research team.....	132
Appendix N: Reflective journal example.....	133
Appendix O: Example of transcript and initial coding.....	134
Appendix P: Example of excel extract.....	136

## Appendix A

Journal

### **Death Studies**

**This journal**

- [Aims and scope](#)
- [Instructions for authors](#)
- [Society information](#)
- [Journal information](#)
- [Editorial board](#)
- [Related websites](#)
- [News & offers](#)
- [Subscribe](#)

## Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our [Author Services website](#).

**AUTHORSERVICES**  
Supporting Taylor & Francis authors

### SCHOLARONE MANUSCRIPTS™

This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the [guide for ScholarOne authors](#) before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

### [Click to Submit Online](#)

#### About the journal

*Death Studies* is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

#### Peer review

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for

suitability by the editor, it will then be double blind peer-reviewed by expert referees. Find out more about [what to expect during peer review](#) and read our guidance on [publishing ethics](#).

## Preparing your paper

### **Submission types**

*Death Studies* accepts the following types of submissions: full-length research articles or reviews of the literature and brief reports. Though exceptions can be made for methodologically complex studies, it is suggested that full-length articles not exceed 25 pages, including abstract, references, tables, and figures. Brief reports are encouraged and should be no longer than 15 pages

### **Formatting and templates**

Papers may be submitted in any standard file format, including Word and LaTeX. Figures should be saved separately from the text. The main document should be double-spaced, with one-inch margins on all sides, and all pages should be numbered consecutively. Text should appear in 12-point Times New Roman or other common 12-point font.

### **Style guidelines**

Submissions to *Death Studies* should follow the style guidelines described in the *Publication Manual of the American Psychological Association* (6th ed.). *Merriam-Webster's Collegiate Dictionary* (11th ed.) should be consulted for spelling.

## References

Please use this [reference guide](#) when preparing your paper.

### **Checklist: what to include**

- 1. Author details.** Please include all authors' full names, affiliations, postal addresses, and email addresses on the cover page. Where appropriate, please also include [ORCiDs](#) and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the published article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that authorship may not be changed after acceptance. Also, no changes to affiliation can be made after your paper is accepted. Read more on authorship [here](#).
- 2. Abstract.** This summary of your article is normally no longer than 100 words. Read tips on [writing your abstract](#).

3. **Keywords.** Keywords are the terms that are most important to the article and should be terms readers may use to search. Authors should provide 3 to 5 keywords. Please read our page about [making your article more discoverable](#) for recommendations on title choice and search engine optimization.

4. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:

*For single agency grants*

This work was supported by the <Funding Agency> under Grant <number xxxx>.

*For multiple agency grants*

This work was supported by the <Funding Agency #1> under Grant <number xxxx>; <Funding Agency #2> under Grant <number xxxx>; and <Funding Agency #3> under Grant <number xxxx>.

5. **Disclosure statement.** With a disclosure statement you acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance, please see our page on [what is a conflict of interest and how to disclose it](#).

6. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file, or anything else which supports (and is pertinent to) your paper. Supplemental material must be submitted for review upon paper submission. Additional text sections are normally not considered supplemental material. We publish supplemental material online via Figshare.

7. **Figures.** Figures should be high quality (600 dpi for black & white art and 300 dpi for color). Figures should be saved as TIFF, PostScript or EPS files. Figures embedded in your text may not be able to be used in final production.

8. **Tables.** Please supply editable table files. We recommend including simple tables at the end of your manuscript, or submitting a separate file with tables.

9. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. Please see our page on [mathematical symbols and equations](#) for more information.

### **Author agreement / Use of third-party material**

Authors are responsible for obtaining permission to reproduce copyrighted material from other sources and are required to sign an agreement for the transfer of copyright to the publisher. As an author you are required to secure

permission if you want to reproduce any figure, table or extract text from any other source. This applies to direct reproduction as well as "derivative reproduction" (for which you have created a new figure or table which derives substantially from a copyrighted source). Please see our page on [requesting permission to reproduce work\(s\) under copyright](#) for more guidance. Authors are required to sign an agreement for the transfer of copyright to the publisher. All accepted manuscripts, artwork, and photographs become property of the publisher.

### **Submitting your paper**

*Death Studies* uses ScholarOne Manuscripts to manage the peer-review process. If you have not submitted a paper to this journal before, you will need to create an account in ScholarOne Manuscripts. Please read the guidelines above and then submit your paper in the relevant Author Center, where you will find user guides and a helpdesk.

If you are submitting in LaTeX, please convert the files to PDF beforehand (you will also need to upload your LaTeX source files with the PDF). Your manuscript must be accompanied by a statement that it has not been published elsewhere and that it has not been submitted simultaneously for publication elsewhere.

We recommend that if your manuscript is accepted for publication, you keep a copy of your accepted manuscript. For possible uses of your accepted manuscript, please see our page on [sharing your work](#).

### **Data sharing policy**

This journal applies the Taylor & Francis [Basic Data Sharing Policy](#). Authors are encouraged to share or make open the data supporting the results or analyses presented in their paper where this does not violate the protection of human subjects or other valid privacy or security concerns.

Authors are encouraged to deposit the dataset(s) in a recognized data repository that can mint a persistent digital identifier, preferably a digital object identifier (DOI) and recognizes a long-term preservation plan. If you are uncertain about where to deposit your data, please see [this information](#) regarding repositories.

Authors are further encouraged to cite any data sets referenced in the article and provide a [Data Availability Statement](#).

At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

Where one or multiple data sets are associated with a manuscript, these are not formally peer reviewed as a part of the journal submission process. It is the author's responsibility to ensure the soundness of data. Any errors in the data rest solely with the producers of the data set(s).

LAST UPDATED

25-01-2018

### **CrossRef Similarity Check**

Please note that *Death Studies* uses CrossRef Similarity Check™ (Powered by iThenticate) to screen papers for unoriginal material. By submitting your paper to the journal you are agreeing to originality checks during the peer-review and production processes.

### **Color Reproduction**

Color art will be reproduced in color in the online publication at no additional cost to the author. Color illustrations will also be considered for print publication; however, the author will be required to bear the full cost involved in color art reproduction. Please note that color reprints can only be ordered if print reproduction costs are paid. Print Rates: \$400 per figure for the first four figures; \$75 per figure for five or more figures. Art not supplied at a minimum of 300 dpi will not be considered for print. Please ensure that color figures and images submitted for publication will render clearly in a black and white conversion for print.

### **Complying with funding agencies**

We will deposit all National Institutes of Health or Wellcome Trust-funded papers into PubMedCentral on behalf of authors, meeting the requirements of their respective open access (OA) policies. If this applies to you, please ensure that you have included the appropriate funding bodies in your submission's funding details section. You can check various funders' OA policy mandates [here](#) and find out more about [sharing your work here](#).

### **Open access**

This journal gives authors the option to publish open access via our [Open Select publishing program](#), making it free to access online immediately on publication. Many funders mandate publishing your research open access; you can check [open access funder policies and mandates here](#).

Taylor & Francis Open Select gives you, your institution or funder the option of paying an article publishing charge (APC) to make an article open access. The APC fees for *Death Studies* are \$2,950, £1,788, €2,150.

### **Accepted Manuscripts Online (AMO)**

Manuscripts submitted to the journal are eligible for rapid online posting if a valid copyright form is received and nothing is missing from the paper. The original manuscript will be available on Taylor & Francis Online in a section on the journal's page entitled "Latest Articles." Posted papers will be clearly labeled as the "Accepted, uncorrected manuscript" versions and will include DOI numbers so that the papers can be cited and referenced. Authors will also receive notification from Taylor & Francis when the manuscript is posted, when typeset proofs are available, and once again when the final version is posted. The papers in this section will be removed once the edited and final typeset version is posted online. To ensure rapid publication of the accepted manuscript, we ask you to complete and sign your publishing agreement as quickly as possible.

### **Proofs**

Page proofs are sent to the corresponding author using Taylor & Francis' Central Article Tracking System (CATS). They should be carefully checked and returned within 48 hours.

### **Reprints**

Authors for whom we receive a valid e-mail address will be provided an opportunity to purchase reprints of individual articles, or copies of the complete print issue. These authors will also be given complimentary access to their final article on Taylor & Francis Online.

For enquiries about reprints, please contact the Taylor & Francis Author Services team at [reprints@tandf.co.uk](mailto:reprints@tandf.co.uk). To order a copy of the issue containing your article, please contact our Customer Services team at [Customer.Service@taylorandfrancis.com](mailto:Customer.Service@taylorandfrancis.com).

### **My Authored Works**

On publication, you will be able to view, download and check your article's metrics (downloads, citations and Altmetric data) via [My Authored Works](#) on Taylor & Francis Online. We are committed to promoting and increasing the visibility of your article. Here are some tips and ideas on how you can work with us to [promote your research](#).

## Appendix B

### CASP checklist

©Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist 13.03.17

## Screening Questions

**1. Was there a clear statement of the aims of the research?**  Yes  Can't tell  No

HINT: Consider

What was the goal of the research?

Why it was thought important?

Its relevance

**2. Is a qualitative methodology appropriate?**  Yes  Can't tell  No

HINT: Consider

If the research seeks to interpret or illuminate the

actions and/or subjective experiences of research participants

Is qualitative research the right methodology for

addressing the research goal?

## Is it worth continuing?

Detailed questions

**3. Was the research design appropriate to address the aims of the research?**  Yes  Can't tell  No

HINT: Consider

If the researcher has justified the research design

(E.g. have they discussed how they decided which method to use)?

**4. Was the recruitment strategy appropriate to the aims of the research?**  Yes  Can't tell  No

HINT: Consider

If the researcher has explained how the participants

were selected

If they explained why the participants they selected were

the most appropriate to provide access to the type of knowledge sought by the study

If there are any discussions around recruitment (e.g. why

some people chose not to take part)

**5. Was the data collected in a way that addressed  Yes  Can't tell  No the research issue?**

HINT: Consider

If the setting for data collection was justified

If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)

If the researcher has justified the methods chosen

If the researcher has made the methods explicit (e.g.

for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?

If methods were modified during the study. If so, has

the researcher explained how and why?

If the form of data is clear (e.g. tape recordings, video

material, notes etc)

If the researcher has discussed saturation of data

**6. Has the relationship between researcher and  Yes  Can't tell  No participants been adequately considered?**

HINT: Consider

If the researcher critically examined their own role,

potential bias and influence during

(a) Formulation of the research questions

(b) Data collection, including sample recruitment and choice of location

How the researcher responded to events during the study

and whether they considered the implications of any changes in the research design

**7. Have ethical issues been taken into consideration?  Yes  Can't tell  No**

HINT: Consider

If there are sufficient details of how the research was explained

to participants for the reader to assess whether ethical standards were maintained

If the researcher has discussed issues raised by the study (e.g.

issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)

If approval has been sought from the ethics committee

**8. Was the data analysis sufficiently rigorous?  Yes  Can't tell  No**

HINT: Consider

If there is an in-depth description of the analysis process

If thematic analysis is used. If so, is it clear how the

categories/themes were derived from the data?

Whether the researcher explains how the data presented

were selected from the original sample to demonstrate the analysis process

If sufficient data are presented to support the findings

To what extent contradictory data are taken into account

Whether the researcher critically examined their own role,

potential bias and influence during analysis and selection of data for presentation

**9. Is there a clear statement of findings?**  Yes  Can't tell  No

HINT: Consider

If the findings are explicit

If there is adequate discussion of the evidence both for

and against the researchers arguments

If the researcher has discussed the credibility of their

findings (e.g. triangulation, respondent validation, more than one analyst)

If the findings are discussed in relation to the original

research question

**10. How valuable is the research?**

HINT: Consider

If the researcher discusses the contribution the study

makes to existing knowledge or understanding e.g.

do they consider the findings in relation to current practice or policy?, or relevant research-based literature?

If they identify new areas where research is necessary

If the researchers have discussed whether or how the

findings can be transferred to other populations or considered other ways the research may be used

## Appendix C



Dear

Understanding parents experiences' of using cold cot/cold room facilities following the death of a baby: A qualitative study

Thank you for taking the time to read this letter which [REDACTED] [REDACTED] has sent on my behalf.

I am a trainee Clinical Psychologist at the Faculty of Medicine and Health Sciences, University of East Anglia. As a part of my training, I am carrying out a study looking at parent's experience of using cold cot/room facilities at [REDACTED]. I hope the information gathered will help shape services offered nationwide for parents who are bereaved of a baby many of whom have not had the option to use such a resource.

As you used the cold room facilities at [REDACTED] after the death of your baby, I am sending you information about the study for you to consider. It would involve you participating in a face-to-face interview with myself. Please find enclosed an information sheet detailing the study further. This research has been approved by UEA Faculty of Medicine and Health Sciences Research Ethics Committee.

I am writing to ask if you would be willing for me to contact you to discuss this study further. Please find enclosed a consent to contact form. If you would be interested in discussing further then please complete this form and return in the stamped address envelope enclosed.

My contact details are listed below should you wish to contact me directly. I will not contact you again should I not hear back from you.

I look forward to hearing from you,

Yours sincerely,

A handwritten signature in blue ink that reads 'E. Norton'.

Elisabeth Norton

Trainee Clinical Psychologist

Faculty of Medicine and Health Sciences

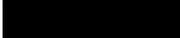
Doctoral Programme in Clinical Psychology

University of East Anglia

Norwich Research Park

Norwich

NR4 7TJ

[Elisabeth.norton@uea.ac.uk](mailto:Elisabeth.norton@uea.ac.uk), Mobile number: 

## Participant Information Sheet

### **We invite you to take part in a research study**

- Before you decide to take part, it is important for you to understand why the research is being done and what it will involve.
- Please take time to read the following information carefully. Discuss it with family and friends if you wish.
- You are free to decide whether or not you take part in this study. If you chose not to, this will not affect you in any way.
- Ask us if there is anything that is not clear or if you would like more information.

### **Introduction**

You have been invited to take part in a study exploring parents' experiences of using cold cot facilities at a hospice. Before you decide whether you would like to take part, please take the time to read the following information, which has been written in order to help you understand why the research is being carried out and what it will involve.

### **The researchers**

My name is Elisabeth Norton. I am a Trainee Clinical Psychologist and I am carrying out this study as part of a Doctoral qualification in Clinical Psychology at UEA (University of East Anglia). The research is being supervised by Kiki Mastroyannopoulou (Clinical Lecturer in Clinical Psychology), and Dr Imogen Rushworth (Clinical Tutor in Clinical Psychology). The research is supported by [REDACTED].

### **What is the purpose of the research?**

This study aims to aid the understanding of services provided in hospice settings and establish if and how they help the grieving process for families. It is hoped that this study will promote new ideas and ways of thinking about bereavement care in hospice and hospital settings.

### **Why have I been invited to take part in the study?**

You have been identified through [REDACTED] because you have used the hospice facilities, following the death of your baby.

### **Do I have to take part?**

No. You are under no obligation to take part and even after agreeing to do so you may change your mind up to 2 weeks after your interview without having to give a reason (unless you wish to give us a reason). The reason for this time limit is that once you have completed the interview, the researcher transcribes the interview and it will form part of the write-up.

In making your decision you may wish to seek advice from somebody independent, for example, a friend, family member, colleague, or trusted professional.

If you decide that you would like to take part then please contact me using the contact details below. If you have any more questions or queries, please email me on the email address below. You can also email my research supervisor Kiki Mastroyannopoulou on the email given below.

### **What will my participation involve?**

Once you have expressed an interest in participating, I will contact you via phone or email to answer any questions you may have. If you are still interested in participating I will book in a suitable time/date to meet with you in a convenient location this could be at [REDACTED], University of East Anglia or at your home, if this is convenient to you, to give you a consent form to read. If you are happy to sign this and consent to take part then we will carry out the interview at this meeting as well. This will be between the hours of 8am-6pm, Monday to Friday, and will last up to an hour and a half.

During the interview, we will discuss your experiences after the loss of your baby, the choices you were given, the bereavement care you received, and your experience of using the cold cot/ room facilities at the hospice. I will also be interested to hear about any barriers or difficulties during this process. The interviews will be audio-recorded. After the interview you will have an opportunity to ask any questions and raise any concerns you may have.

### **What will happen to my information?**

The recording of the interview will be typed out so that the information can be looked at in detail. The aim of this is to uncover common themes that are important in understanding the experiences we have discussed. The typed out transcripts will be made anonymous and kept confidentially in a locked storage facility as well as in a secure electronic file at the University of East Anglia.

Anonymised sections of the information collected from the interview will be looked at by my supervisors, and may also be looked at by representatives from academic and professional assessment bodies in order to assess the quality of this doctoral research study. As part of the doctoral programme, I will write up a report of the research. Within this report I will include some anonymous extracts of the interviews to illustrate themes that have been discussed. All names will be changed however aside from this the quotes will be word for word. I may also write shorter articles for

publication, which may also include brief anonymous extracts from the interviews. Your name will never be associated with any published extracts.

I will also ask if you would like me to send you a summary of the research findings when the project is complete.

**What are the possible disadvantages and risks of taking part?**

You will be asked to discuss your experiences of hospice care following the death of your baby. This could be very distressing, if during the interview you are asked a question that you are not happy to answer you can skip it, and if you do become upset, you will be given the option to take a break or stop the interview altogether. Following the interview, you will have open access to [REDACTED] should you require any additional support, I will be able to help facilitate any referral or you can make contact with them yourselves. This will be talked about in more detail should you wish to take part.

**What are the potential benefits of taking part?**

We hope that the information we get from this study will help improve understandings of hospice care for future service users. Some people can find value and comfort in talking about their experience of the bereavement care they have received. The findings of this study will be fed back to [REDACTED] to help inform future care practices.

**What will happen if I don't want to carry on participating in the study?**

If you decide you want to withdraw from the study either before or after your interviews please let me know either face to face or by contacting me on the email address or phone number given at the end of this information sheet. You are not required to state why you have decided to withdraw. If you have completed the interview you will be asked what you would like to happen to your interview data and you can decide whether you would like it to be used or destroyed. You have the opportunity to do this up until 2 WEEKS after the interview, at which point your data cannot be destroyed, as it will have formed the write-up of a report.

**What if there is a problem?**

If you have a concern about any aspect of this study, you can contact me and I will do my best to answer your questions. Alternatively you can contact my research supervisor, Kiki Mastroyannopoulou (see contact details below). If you remain unhappy and wish to complain formally, you can contact Professor Ken Laidlaw (Director of the UEA Clinical Psychology Course: 01603 593076).

**Will my taking part in this study be kept confidential?**

**YES.** All information which is collected about you during the course of the research will be kept confidential. However, if you disclose any information which suggests

that either you, or someone else, are at risk of harm then I am obliged to breach confidentiality and inform someone. I will do my best to discuss this with you first.

**Who has reviewed the study?**

This study has been reviewed and approved by the UEA Faculty of Medicine and Health Sciences Research Ethics Committee and [REDACTED]  
[REDACTED]

**Contact Details:**

Elisabeth Norton:

Email: Elisabeth.norton@uea.ac.uk. Tel: [REDACTED]

Kiki Mastroyannopoulou:

Email: k. mastroyannopoulou@uea.ac.uk

## Appendix E

### Consent to Contact Form

Please complete this form and return it to me if you wish to find out more about taking part in this study. This form is not a consent form and you are under no obligation to take part in the study after being contacted. **I will only get in touch with you if you provide me with your contact details.**

<b>Your Details</b>			
<b>Surname (last name):</b>	<b>First Name:</b>		
<b>Title:</b> Mr / Mrs / Miss / Ms / Other _____			
<b>If you have a preferred method of contact please circle one:</b>			
<b>By Telephone</b>	<b>By Post</b>	<b>On your mobile</b>	<b>By email</b>
<b>Please give details required for this contact method:</b>			

**Elisabeth Norton**

Trainee Clinical Psychologist

Faculty of Medicine and Health Sciences

Doctoral Programme in Clinical Psychology

University of East Anglia

Norwich Research Park

Norwich

NR4 7TJ

[Elisabeth.norton@uea.ac.uk](mailto:Elisabeth.norton@uea.ac.uk), Mobile number: XXXXXXXXXX

**Appendix F**

Study Title: Understanding parents' experiences of using cold cot/cold room facilities at [REDACTED] following the death of a baby: A qualitative study

**Participant Number:** \_\_\_\_\_

<b>Demographic</b>	<b>Details</b>
Age of Participant	
Gender	
Ethnicity	
Length of time using facilities	
Education level	
Number of other children (if any)	

## Appendix G

### Preliminary Parental Interview Questions

Thank you for agreeing to participate in our interview. In the interview today, we will be asking you questions about your involvement with [REDACTED], particularly the time you spent at [REDACTED] after the death of (baby).

We understand that talking about events around the time of your baby's death can be difficult, and want to reiterate that staff from [REDACTED] will be happy to offer you any support they can. You can also contact your GP.

Your involvement in our study will help us determine the value of the service offered by [REDACTED].

#### Possible settle in questions:

- Tell me a little bit about your family.
- Could you tell me about the first time [REDACTED] was mentioned to you
- Can you think back to the time when it was made clear to you that (baby) would not survive and therefore that palliative care would be initiated.
- Tell me about the first time you were told about the possibility of transferring (baby) to [REDACTED]

#### Hospice

- I would now like to talk about the transfer of (baby) to [REDACTED].
- Can you remember those first conversations?
- I would like to ask you some more details regarding where (baby) died?
- (If baby died on the unit) – How long were you on the unit for after (baby) died? Did you feel this was the right amount time? If not, why?
- What do you feel made you decide to transfer (baby) to the hospice after his/her death?
- Who else visited or stayed with you and (baby) at the hospice at this time?
  - (If there were siblings...)
  - Were (baby's) brothers and sisters able to spend time with you and (baby)? What are your thoughts about the time they spent with (baby)?
  - (If Grandparents were around)
  - Were (baby's) grandparents able to spend time with you and (baby)?
- How much time were you able to spend with (baby)
- What did you find most comforting?
- What could have been done to make your stay more comfortable?
- Do you think using these facilities shaped the initial stages of grief for you?
- How were you supported by staff?
- Did the hospice staff offer to make keepsakes and memories of (baby)?

- Did you have any religious or spiritual requests at this time? Having spent time both at the hospice and the neonatal unit, what would you say about the difference in the environment between the two?

### **Going home**

- I would now like to talk about the time after you left the hospice.
- How long after you moved to the hospice with (baby) did you go home?
- Have you been back to the hospice since?
- What was that like?
- Are you in contact with any parent groups through the hospice? Do you find this has been helpful to you?
- How did you feel the support from the hospice was after you went home?
- Looking back, do you feel you made the right decision in transferring (baby) after his/her passing to the hospice?
- If another family were in the situation you were in at the time of (baby)'s passing, what would you say to them? Would you recommend that they use the hospice in the way that you did? Why?
- If I could pass along a message from you to the hospice staff on how to help families through this difficult time, what would it be?

## Appendix H

Faculty of Medicine and Health Sciences Research Ethics Committee

Dear Elisabeth,

Title: Understanding parents' experiences of using cold cot/cold room facilities at East Anglian Children's Hospice (EACH) following the death of a baby: A qualitative study.

Reference: 2016/2017 - 40

The amendments to your above proposal have been considered and I can confirm that your proposal has been approved.

Please could you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance and also that any adverse events which occur during your project are reported to the Committee. Please could you also arrange to send us a report once your project is completed.

Yours sincerely,

Mark Wilkinson

Chair FMH Research Ethics Committee

cc. Kiki Mastroyannopoulou

Elisabeth Norton

MED

Research & Enterprise Services West Office (Science Building) University of East Anglia

Norwich Research Park Norwich, NR4 7TJ

Telephone: +44 (0) 1603 591490

Email: [fmh.ethics@uea.ac.uk](mailto:fmh.ethics@uea.ac.uk)

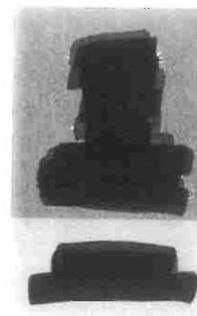
Web: [www.uea.ac.uk/researchandenterprise](http://www.uea.ac.uk/researchandenterprise)

24th March 2017

## Appendix I

### Hospice Ethics

Elisabeth Norton  
Trainee Clinical Psychologist  
Norwich Medical School  
Faculty of Medicine and Health Sciences  
University of East Anglia  
Norwich Research Park  
Norwich NR4 7TJ



23 May 2017

Dear Elisabeth,

**Re: Understanding parents' experiences of using cold cot/roid room facilities at [redacted] during the death of a baby: A qualitative study.**

The Clinical Governance Committee has reviewed the proposal, and approved [redacted] participation in this evaluation.

If there are any changes made to the proposal the CGC will need to be notified.

We wish you well with your research and look forward to seeing the outcome in due course.

Yours Sincerely,

Dr Virginia Warren MD



## Appendix J

### UNIVERSITY OF EAST ANGLIA

#### DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY

Patient Identification Number for this trial:

---

#### CONSENT FORM

---

**Title of Project:** Understanding parents experiences' of using cold cot/room facilitates following the death of a baby on the neonatal unit: A qualitative study

**Name of Researcher:** Elisabeth Norton

Please initial  
all boxes

- |   |                          |
|---|--------------------------|
| 1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw up to 2 weeks after my interview without giving any reason, without my medical care or legal rights being affected.     | <input type="checkbox"/> |
| 3. I agree to the interview being taped recorded, with possible use of verbatim quotation   | <input type="checkbox"/> |
| 4. I understand that all material will be stored securely and that identifying information will be removed  | <input type="checkbox"/> |
| 5. I agree to take part in the above study.   | <input type="checkbox"/> |

Name of Participant	Date	Signature

Name of Person	Date	Signature

taking consent.

## Appendix K

From: Elisabeth Norton (MED - Student)  
Sent: 15 December 2017 13:18  
To: FMH Ethics <[fmh.ethics@uea.ac.uk](mailto:fmh.ethics@uea.ac.uk)>  
Cc: [REDACTED]  
<[mark.wilkinson@nnuh.nhs.uk](mailto:mark.wilkinson@nnuh.nhs.uk)>; Kiki Mastroyannopoulou (MED - Staff)  
Subject: Minor amendment re. parents experience of cold cot facilities after the death of a baby.

Dear Chair,

Please accept my request for a minor amendment to my ethics protocol. Due to request from participants, who are parents of a deceased baby, they wish for the real names to be used in any written information. They have made it clear that using a pseudonym would cause them distress and that it was very important for their real name to represent their journey and story. Literature on parental grief shows that having a legacy from their tragedy can often bring comfort to parents and it is felt that being involved with this research project and sharing their experience could help with that.

Please see email copied below from a participant regarding this matter. I can provide comments from other parents should you require.

With kind regards,

Elisabeth

Email from participant:

Mon 06/11, 20:17  
Hi Elisabeth

With regards to using Archies real name, I would really like that it is used for anything you may use it for.

Archie is my son and just because he is no longer with me, I Dont feel he should be anonymised. I talk about him daily and he is no secret.

I understand if this is not possible but my preference would be for you to use his details.

I hope this helps

Regards, Name removed for confidentiality

Elisabeth Norton  
Trainee Clinical Psychologist  
Norwich Medical School  
Faculty of Medicine and Health Sciences  
University of East Anglia  
Norwich Research Park  
Norwich NR4 7TJ  
[elisabeth.norton@uea.ac.uk](mailto:elisabeth.norton@uea.ac.uk)<<mailto:elisabeth.norton@uea.ac.uk>>

## Appendix L

Faculty of Medicine and Health Sciences Research Ethics Committee

Dear Elisabeth

Title: Understanding parents' experiences of using cold cot/cold room facilities at [REDACTED] following the death of a baby: A qualitative study.

Reference: 2016/2017 - 40

Thank you for your e-mail notifying us of the amendments you would like to make to your above proposal. These have been considered and we can now confirm that your amendments have been approved.

Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and also that any adverse events which occur during your project are reported to the Committee.

Please can you also arrange to send us a report once your project is completed.

Yours sincerely,

Professor M J Wilkinson

Chair FMH Research Ethics Committee

cc. Kiki Mastroiannopoulou

Elisabeth Norton

MED

Research & Enterprise Services West Office (Science Building) University of East Anglia

Norwich Research Park Norwich, NR4 7TJ

Telephone: +44 (0) 1603 591490

Email: [fmh.ethics@uea.ac.uk](mailto:fmh.ethics@uea.ac.uk)

Web: [www.uea.ac.uk/researchandenterprise](http://www.uea.ac.uk/researchandenterprise)

5/1/18

## Appendix M

Table used to discuss codes and themes within the research team

<b>Table: Initial codes and emerging themes</b>				
<b>Code</b>	<b>Code</b>	<b>Code</b>	<b>Code</b>	<b>Possible Theme?</b>
People think its ....weird	Others wouldn't understand	Other people not wanting to see baby		<b>Other peoples perceptions</b>
'being a mummy' dressing, bathing, caring for deceased	Attachment/bonding	Touch	Difference from hospice vs. hospital	<b>Being able to care for my baby in a way I never had</b>
Time as a family, only opportunity to be altogether	Siblings involved			<b>Family Time with the deceased</b>
Flexibility, tailored to family, and their need, "no pressure"	Above and beyond 'care around them': lifts, food, washing	Quality of facilities: homely, other family members able to stay,	Sibling support	<b>Supportive/caring /personal/nurturing for the whole family nurturing</b>
Speaking with someone outside of the family, who is "neutral"	Speaking with someone who deals with this level of distress everyday	Able to say things can't to others	Support Keeping baby alive in memory, speaking to someone that knew baby as well	<b>Building a relationship</b>
Importance of reframing "nice" and "amazing"	Process of making sense; body changing	In the moment, Adjustment to role of loss and grief over joy and motherhood practices	Night of death: where baby died, impact of story on how influenced their experience	<b>Time to adjust: the process of their grief through using the hospice</b>
Making nice memories e.g. going for a walk, all sleeping in the same room	Keepsakes from time with deceased e.g. moulds, photos, books, scrapbooks			<b>Memory making/mementoes</b>

## **Appendix N**

### **Reflective Journal Extract**

All extracts were written free hand in a paper journal to allow for a natural flow in my writing of thoughts and feelings. It also made it very accessible, enabling me to record things 'in the moment'.

#### **Post interview 5, father**

The interview left me with a sense of sadness for his feelings of inadequacy for his daughter: that he couldn't help her. It made me think about my systematic review and how men are primed to be 'protectors', he said he felt he was not fulfilling his role, his grief was embodied by his sense of what, as a father, he should have been able to do. I listened back to the rest of the interview and I am aware that my questioning reflects the internal process that I was experiencing (like my internal supervisor), 'how he would react to me asking this?', 'will this question reassure him?'. I notice that I have a yearning for him to feel ok about what happened but on reflection, I feel that is my own agenda and he may not need to feel ok about that part. Living with a sense that he 'should' have been able to do something may be important to his identity and how he views his role within his family. My literature review had shaped my feelings about grieving patterns and, maybe, I have a bias towards equality in genders and for him not to feel the pressure that, because he is a man, he should have been able to do something. On reflection, even as I am writing I am thinking that this may have been more about a parental role and that his baby was so young and helpless, not that he was trying to be the 'man' of the family. At the time, during the interview it felt and from his words, that he felt inadequate as a man. I will be mindful of this when I go into the next interview.

## Appendix O

### Example of Transcript

#### Guide

I = participant

I = Interviewer

Overlapping text in brackets

... = pause

- Items colour coordinated before transferred to excel
- Brackets after highlighted text were initial codes

I: and you had choice in all of those?

P: we had every single choice that we, they were really, really good you know they never pushed us (I: um hum) they told us to have as much time and the family needed time but they were gonna get the motions going with (hospice) it was our decision they said would you like (hospice) to come in and we said yeah it's time now

I: and did you have any idea that (hospice) coming in at that point meant being able to take Callum with you? (P: no) ok

P: didn't have any idea at all... what was actually going to happen kind of thing, so it was all quite scary as well (I: yeah) so the parents were all brought in and we had like photos (I: umm) (hospice) was there then when (hospice) got there very very quickly (I: um hum) and they said right take as many photos cause these photos are the most important (keeping memories) and you know say whatever you want to say

and they were going to get the motions going but at that time (hospice) was actually shut because erm there was no funding for it, so they had actually closed the hospice down (I: oh gosh) so they was gonna have to open it for us to take Callum back (I: umm) so erm it took all day to get the hospital to get all the drugs sorted and nurses...because we had to have a nurse with us (I: umm) and so she came to (hospice) with us just for the journey (I: umm) erm so and then (hospice) was like what are the hospital doing because it was just like this was like 8 o'clock in the morning (I: umm) at 5 o'clock we were still (I: still waiting?) In hospital waiting (I: yeah) but (hospice) really did hurry it up (I: yeah) and they were getting like, we didn't have a car seat and (hospice) said well it doesn't matter, just carry him, just hold him do you know what I mean, so they were brilliant you know, they broke all the rules and I've never drove so quick over there (additional help from hospice) so we erm, we got to (hospice) and I remember getting there and I was thinking now what happens and our family was invited, like our mums and dads which was really nice (I: umm) they had a room and we had a room, I remember going in to the room and it was just like being at home (I: umm) and with that I felt really like ah this is, this is nice you know, we could lay him on a bed, we could cuddle him, we could take his clothes off, we could just have that contact with him, you know and I don't know, his little eyes opened(caring for baby, experience of 'cold' facilities) and I remember (husband) saying well you know he's doing alright being off all these drugs and everything like that and um it was getting like late it was about 11 and I don't know we just then, we were still cuddling him and everything because you know the hospice was just brilliant they just left us to it to be a family (reflecting on moment able to have as a family).

## Appendix P

### Excel Spreadsheet Example of Codes and Themes

P: Yeah, no he was, I think he was really clingy because he was still yeah very ill (: I can imagine) yeah I think we just sat and read books and it was still really cold as well because it was February and it was still really really cold (: umm) and erm, yes so there was toys, so we would make use of the toys and books and Emma did really well the first two or three days, taken her off more and more monitors I think we had times when she wasn't attached to any monitors (: umm) so again we were hoping that she would be improving and (: um) make it (: um) and the day before she, she died, she had a really bad, so she stopped breathing and the nurse looking after her, really struggled to resuscitate her (: right) so we thought ok, it's probably not, she is going downhill (: umm) but still we had a lovely afternoon so we went for a walk with (son) afterwards and it was a lovely day and again we spent erm time together all the family so we had that move to the family bit, it was, that family living room and bedroom for the family (: yeah) so we stayed there and played together and yeah Emma had a really good afternoon so we really enjoyed time together

I: and having more tubes and things off her, I can imagine just being able to have even closer cuddles and things like that

P: yeah that was nice and trying to be a normal family

173

"we really enjoyed time together" lost dreams, loss of time together as a family, making good memories