Volume One: Research Component

DEVELOPING A PSYCHOLOGICAL UNDERSTANDING OF COMPLEX LOSS

By

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A thesis submitted to

THE UNIVERSITY OF BIRMINGHAM

for the degree of

DOCTOR OF CLINICAL PSYCHOLOGY

Department of Clinical Psychology
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The University of Birmingham
June 2016

Thesis Overview

This thesis was submitted in partial fulfilment of the requirements of the degree of Doctor in Clinical Psychology at the University of Birmingham. The thesis comprises of two volumes. Volume I consists of three chapters related to the research component of the degree. Volume two consists of five reports, each representing clinical work undertaken on clinical placements as part of the clinical component of the degree. To protect confidentiality, all identifying information relating to participants or service users has been changed within the thesis.

Volume I

Volume I focuses on developing a psychological understanding of complex loss. It contains three chapters: a meta-ethnography, an empirical paper and a public dissemination document. The meta-ethnography critically reviews qualitative literature of couple's experiences of a subsequent pregnancy and parenting following a pregnancy loss through miscarriage, stillbirth and/or neonatal death, and offers a high level interpretation of these findings. The empirical paper uses Interpretative Phenomenological Analysis (IPA) to offer an exploration of the lived experience of family members bereaved by heroin overdose, with particular attention to impact and meaning of the loss overtime. The findings were explored in relation to their applicability to existing models and theories of bereavement. The public dissemination document provides a brief summary using simple language of the first and second chapters, to be accessible to a wider audience.

Volume II

Volume II consists of four Clinical Practice Reports (CPR) and an abstract of an oral presentation, completed over clinical placements to provide evidence of practice development over the three years of the course. CPR I presents a Cognitive Behavioural and Psychodynamic case formulation of an 88-year-old lady called Rose*, who experienced high anxiety following a diagnosis of vascular dementia. CPR II details a clinical audit evaluating pre-assessment counseling practices of professionals against trust standards, in a community mental health service for older people for patients referred for dementia assessment. CPR III describes a single case experimental design evaluating the effectiveness of a Cognitive

Behavioural based intervention for depression in a 58-year-old Asian male. CPR IV is a case study of a 15-year-old girl Melanie* referred to Child and Adolescent Mental Health Services for anxiety. Case formulation and treatment were based on a behavioural framework. Finally, CPR V involved an oral presentation detailing a case study of a young midwife who showed signs of posttraumatic symptoms following the death of a baby in delivery. An abstract of the presentation is included.

Dedication

I dedicate my thesis to my beloved great grandmother, Maanji (1903-2004). Your unconditional love, free spirit and shared wisdom shaped my very being, and undoubtedly led me to fulfil this journey. *I love you and miss you deeply*.

The literature review is dedicated to the loving memory of my nephew Junior – *you live forever in my heart, love always, Gagan Pua ji x*

Little Snowdrop

(Author unknown)

Please click link to view this poem in the public domain.

Acknowledgments

I am sincerely grateful to a number of people, who have in their own various ways been instrumental in helping me to fulfil this journey.

I am eternally grateful to my parents, who have been my greatest source of inspiration. This would not have been possible without your love, support, and encouragement to follow my own path. I can only aspire to give what you have given us.

To my husband Gurpreet, your love, support, unwavering confidence and belief in me has carried me through the highs and lows of training. You are, and always will be my rock – I could not have done this without you.

To my friends and family - far too may to mention individually! Who have kept me motivated, filled my days with laughter and love, and occasionally wiped my tears through the many challenges faced through training. In particular, my gorgeous nephews and niece Reuben, Gian and Ambur who have kept me grounded and filled my life with endless joy!

I am forever indebted to Prof. Alex Copello, who took me under his wing as a novice, selflessly invested his time and energy in preparing me for, and guiding me throughout training. Thank you for always believing in me, for being there to support me personally and professionally, and filling me with much needed laughs and coffee (slash ‘therapy’) breaks along the way. For that I would like to say - Estare eternamente agradecida por tu presencia en mi vida!

I would also like to thank Dr Michael Larkin who co-supervised my empirical paper. For your guidance, creativity and ideas in helping me give voice, and do justice to the power and emotion behind participants’ words.

Dr Ruth Butterworth, I am grateful for your understanding, passion and enthusiasm when supervising my literature review. Thank you for your warm, encouraging words and ability to contain my anxieties throughout!

Special thanks to my appraisal tutor Dr Chris Jones, who has been an amazing source of support through these three years. Thank you for your sound advice and help in keeping the work life scales balanced. Chris comes as a duo, therefore I also need to extend my thanks to Dr John Rose, both of which provided me with many many laughs that echoed across the fifth floor!

I would also like to thank the organisations that helped to recruit participants for my empirical study; your time, enthusiasm and support was invaluable. Dot deserves a special mention, for going above and beyond her call of duty to support me in my recruitment. I am forever grateful for your support and passion for the project.

To the family members who were interviewed for the empirical project, thank you for kindly taking the time to share such difficult and emotional experiences. This would not have been possible without you.

Throughout training I have been fortunate enough to work with many fantastic teams and supervisors who have undoubtedly added to my skill set and helped me to become a better clinician. Thank you!

Finally, I would like to thank each and every client I have worked with over the last three years. You have been a great source of inspiration and learning.

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Chapter One – Literature review: The experience of subsequent pregnancy and parenting following miscarriage, stillbirth and neonatal death: A meta-ethnography.

Supervised by:

Ruth Butterworth

Abstract

Background: Miscarriage, stillbirth and/or neonatal losses are associated with negative psychological and emotional impacts on wellbeing. The psychological sequelae carry forward into subsequent pregnancy and parenting.

Objective: This meta-ethnography aimed to improve our understanding of the psychological experience of subsequent pregnancy and parenting following such losses, by synthesising and evaluating related qualitative studies.

Method: A systematic literature search of published qualitative research studies in five databases was conducted, and finalised in April 2016. A total of 18 relevant papers were identified and reviewed.

Findings: Three overarching categories, further divided into themes and subthemes emerged as third order concepts important in understanding experiences of subsequent pregnancy and parenting. The three overarching categories identified were: (i) 'The dark cloud' describing the psychological impact of loss on couples and creating lasting changes to their representations of pregnancy from a time of 'joy' to one of uncertainty with regards to outcome, leading to anxiety when entering a subsequent pregnancy; (ii) 'Weathering the storm of uncertainty' describing specific worries and anxieties experienced in subsequent pregnancy and the strategies used by couples to cope and emotionally protect themselves until birth; (iii) 'Parenting' highlighting how anxieties continue after birth and the importance for couples to continue separate and co-existing bonds with the deceased and live children.

Conclusion: The findings highlight the need for greater emotional and psychological help/support for families in subsequent pregnancy and parenting following loss. Clinical implications and directions for future research are discussed.

Keywords: Miscarriage, stillbirth, neonatal death, subsequent pregnancy, parenting, meta-ethnography, qualitative

Introduction

In 2013 UK perinatal mortality statistics recorded 3,286 stillbirths and 1,436 neonatal deaths, the equivalent to six of every thousand births (MBRRACE-UK, 2015).

The Experience of Loss

Societal expectations of pregnancy and childbearing have significantly changed over centuries; partly influenced by advancements in medical knowledge and more recently, technology. Once viewed as a highly risky time there is now a greater expectation, particularly in developing countries, that pregnancy will conclude well for mother and baby (WHO, 2006). This has significant implications for couples that experience perinatal loss (miscarriage, stillbirth and neonatal death[1]). Psychological models/theories of grief recognise that the emotional impact and process of adaptation following such losses can be more challenging compared to other significant losses (Parkes, 1998; Stroebe & Schut, 1999). Key aspects recognised in making pregnancy loss distinct and more difficult to grieve are that they are often sudden, associated with high levels of self-blame for mothers and fathers and not socially recognised as significant, leaving couples 'disenfranchised' with their grief (Doka, 2002). Such losses are often considered a taboo subject and not widely acknowledged in society by friends, family and/or professionals leaving most couples grieving in isolation (SANDS, 2009).

Women are often left consumed with the notion their bodies have failed them, and both (the couple) are left with a changed reality in their perception of pregnancy, that it does not always result in a live baby. As well as grieving the loss of a child, couples also have to adapt to a changed personal identity in the loss of the hopes and dreams attached to their anticipated role as a parent (Lamb, 2002). This is irrespective of weeks' gestation, as the meaning attributed to a loss is highly personal whether it occurs earlier or later in pregnancy (Fenstermacher & Hupcey, 2013). The associated negative impact on emotional and psychological wellbeing of couples has been heavily documented (Lamb, 2002; Mills et al.,

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[1] Terminology: Miscarriage, stillbirth and neonatal deaths are terms used throughout the review, a glossary of definitions is provided in Appendix One.

2014). Despite this 50-60% of women conceive again within a year (Armstrong & Hutti, 1998), although the psychological sequelae of the loss carry forward.

The impact on subsequent pregnancy and parenting: current knowledge

Subsequent pregnancies are characterised by intense anxiety levels, which are significantly higher than in women with no loss history (Côté-Arsenault, 2003; Côté-Arsenault & Donato, 2007). Research has historically focused more on the impact on women although over the past 15 years there has been increased recognition of distress experienced by men (Mills et al., 2014). The focus on women is unsurprising given the awareness that high levels of anxiety/stress in pregnancy are associated with an adverse impact on foetal neurodevelopment, maternal and child outcomes (Schetter & Tanner, 2012; Stein et al., 2014). Fuelled by fear of another loss men and women commonly describe a need to protect themselves, often exhibited by delaying attachment to the unborn child (Mills et al., 2014). There is growing concern about this, as the quantitative literature has highlighted associations between perinatal loss and parenting difficulties in subsequent children, including bonding difficulties and disorganised attachment styles. Such studies have reported the live child may trigger unresolved grief in parents; potentially leaving children more susceptible to developing psychological difficulties in infancy (Hughes, Turton, Hopper, McGaukley & Fonagy, 2001).

Previous reviews in the area have been published, most focusing on the impact of loss on the experience of subsequent pregnancy (DeBackere, Hill, & Kavanaugh, 2008; Geller, Kerns & Klier, 2004; Mills et al., 2014) or parenting alone (Oglethorpe, 1989). To date only one review has explored the impact of loss on both; Lamb (2002) reviewed and synthesised findings from qualitative and quantitative studies. Since then, qualitative research methods within the field have gained significant momentum, providing more detailed idiosyncratic understandings of the complexities and psychological impacts of loss on individuals or couples. This was recognised in the most recent review by Mills et al. (2014) which synthesised qualitative findings to highlight couples' experiences and expectations of professional care in pregnancy, subsequent to stillbirth or neonatal death. Implications for professionals to improve care were suggested. Whilst making a valuable contribution to the field, gaps in knowledge remain. Studies addressing the impact of miscarriage were not included which may have limited important insights. Furthermore, the review did not address impacts on future parenting, despite a recent surge of interest and publications in the area (Campbell-Jackson, Bezance & Horsch, 2014; Warland, O'Leary, McCutcheon & Williamson, 2011).

Current Review

UK clinical guidance acknowledges the need to support families following loss, in subsequent pregnancy and the postnatal period, especially if there are difficulties in the parent-baby relationship (NICE, 2014). Such support where available is delivered by Perinatal Mental Health Services until the infant is aged one, or by frontline staff. A recent report showed 40% of UK localities do not have access to such services and less than 15% provide what is needed; low delivery is attributed to insufficient funding (NHS Improving Quality, 2015). NICE guidance offers little direction on practical ways professionals can best support families, which may lead to variations in care (Mills et al., 2014).

In 2015 the UK government announced a £1.25 billion investment in perinatal services, recognising the importance of early intervention in preventing adverse psychological outcomes for families (H.M Treasury, 2015). Consequently, there may be greater funding to develop/train professionals to meet needs. Despite current services supporting parents in pregnancy and early parenting no attempts have been made in the last 14 years to review the impact of perinatal losses on both. Given the surge in qualitative research literature particularly pertaining to parenting, and a need to understand experiences at an idiosyncratic level to better inform interventions (Mills et al., 2014) a synthesis of such research appears timely.

Aim

The present review aimed to improve our psychological understanding of the experience of subsequent pregnancy and parenting following a previous pregnancy loss by miscarriage, stillbirth and/or neonatal death. A critical exploration, evaluation and synthesis of published qualitative studies in the area was undertaken.

Method

Meta-ethnography is the most widely applied method of synthesising qualitative literature (Hannes & Macaitis 2012). The analytical process moves beyond a simple aggregation of shared or dissonant findings, by producing a higher-level interpretation that retains original meaning/content from studies while offering new insights (Jensen & Allen, 1996; Walsh & Downe, 2005).

The meta-ethnography reported was guided by the original seven-stage approach by Noblit and Hare (1988), further developed by Atkins et al. (2008) and Toye et al. (2014). These stages involve an iterative process from developing a question to synthesising and expressing findings. Each stage is described in Figure 1.1 and discussed in detail in the sections to follow.

Stage One: Determining an area of interest and research question that could be informed by qualitative research. This involved a scoping exercise of research and reviews in subsequent experiences following a perinatal loss and consideration of the rationale/motivation for a synthesis in this area. This exercise identified the research question as an appropriate meta-ethnography.

Stage Two: Develop a focus for the synthesis and decide what to include. Involved an iterative process of conducting a systematic search and screening studies, defining the focus of the synthesis (inclusion/exclusion criteria) and deciding on quality assessment tools to be applied to included studies. Application of quality appraisal framework to each study in turn.

Stage Three: Reading the studies. This involved reading and re-reading papers and becoming familiar with the content of the studies; paying particular attention to the emerging themes, ideas, concepts and metaphors in the raw data. Part of this process also involved using a template to extract relevant background information from the studies (aims, sampling methods, methodology, results and contribution to the area).

Stage Four: Determining how the studies are related to each other. For each study a table was created extracting first order constructs (participants words/direct quotes) alongside corresponding second order constructs (interpretation of first-order constructs by the author/researcher of the paper); representing key themes and concepts. Meta-ethnography data is based on the analysis of second order constructs that are then developed into third order interpretations (The review author's interpretations of second order constructs) through stages five and six (Toye et al., 2014).

Stage Five: Studies were translated into one another. In stage five, second order constructs were used to examine relationships within and between studies, by arranging the tables created in stage four in chronological order and comparing second order constructs (themes/concepts) from paper one with paper two, a synthesis of these papers with paper three and so on. Themes (second order constructs) where meanings were linked within and across papers were grouped together in tables, alongside associated first order constructs to stay close to the data. The tables combined with the overall appraisal rating of the associated papers were used to develop preliminary piles (Toye et al., 2014).

Stage Six: Synthesising Translations. In stage six piles generated in stage five were synthesised by reciprocal translation (where second order constructs were directly comparable) and refutational syntheses (where findings contradicted one another) through constant comparative analysis to develop third order constructs (themes and subthemes as interpreted by GC; the author of the review), representing an overarching description of the findings.

Stage Seven: Expressing the synthesis. This meta-ethnography was written so it could be published to disseminate the findings and maximise their impact; with the hope it may facilitate effective appropriate knowledge transfer to clinical settings.

Figure 1.1. Description of the stages of meta-ethnography (Atkins et al., 2008)

Scoping Exercise and Systematic Search (Stages One and Two)

An initial scoping exercise was conducted to develop an understanding of the area, potential openings for review and identification of appropriate search terms. These search terms were applied to five electronic databases (Embase, MEDLINE, PsychINFO, CINAHL and ASSIA), searched individually in October 2015. A combination of keyword and subject heading searches were used as recommended by Shaw et al. (2004). Details of individual search strategies applied to each database can be seen in Appendix Two. The search was re-run on 25th April 2016; no new studies were identified.

Procedure

The search yielded 928 papers which were downloaded into one folder in RefWorks, and duplicates were removed. Inclusion and exclusion criteria identified in Figure 1.2 were applied, resulting in 12 papers. Reference lists of those papers were hand searched, identifying six further articles. Eighteen papers were included in the review. A flowchart of the search strategy can be seen in Figure 1.3.

Inclusion Criteria

(i) Explored the experience of subsequent pregnancy and/or parenting after miscarriage, stillbirth or neonatal death.
(ii) Used qualitative methodology
(iii) Published in English

Exclusion Criteria

(i) Studies that included participants that had experienced losses other than miscarriage, stillbirth or neonatal death. (For example loss through termination, or beyond 28 days of life; infant death, sudden infant death syndrome or death of an older child.)
(ii) Studies that only explored the experience of loss (not subsequent pregnancy and/or parenting)
(iii) Non-research studies such as reviews, conceptual or position papers
(iv) Unpublished literature such as dissertations
(v) Studies specifically evaluating an intervention for families affected by loss, or in subsequent pregnancy
(vi) Studies using mixed method or quantitative methodology

Figure 1.2. Inclusion and exclusion criteria applied to articles

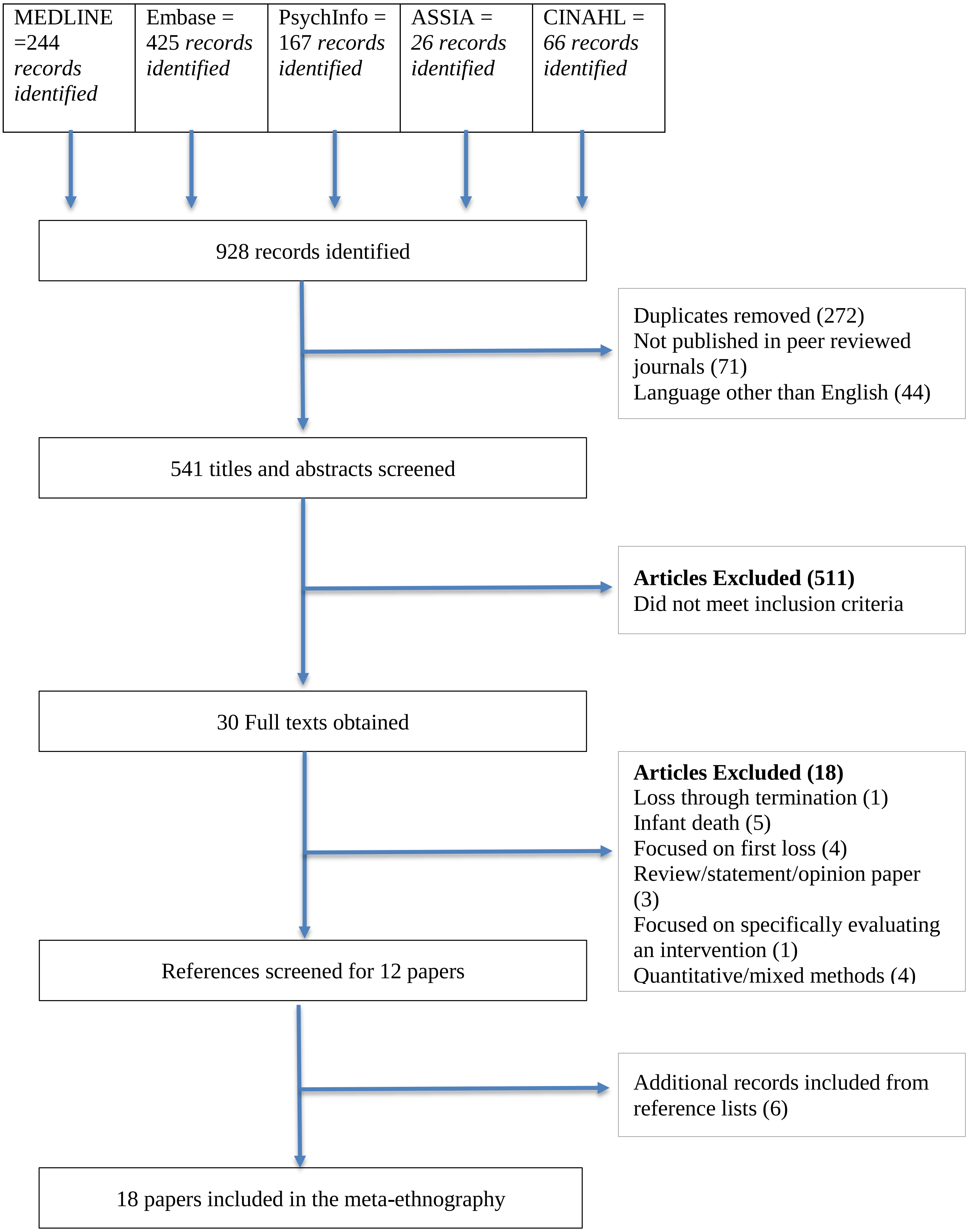

Figure 1.3. Flow chart of search strategy

Quality Appraisal – (Stage Two)

The application of quality appraisal in qualitative syntheses has significantly increased in the last decade (Hannes & Macaitis, 2012). Despite a range of tools available agreement is limited on their merit, the specifics of what exactly constitutes good quality research and how they should be applied (Toye et al., 2014). Atkins et al. (2004) suggest they can be used to summarise the quality of evidence, highlight gaps in reporting and in organising the contribution of papers to the synthesis. The author (GC) applied a tool for these purposes.

The Critical Appraisal Skills Programme (CASP; 2014) qualitative study checklist was selected for two reasons: (i) it is the most commonly applied appraisal tool in published meta-ethnographies (Campbell et al., 2012) and (ii) the tool consists of ten questions covering features widely considered pertinent indicators of good quality qualitative research (Willig, 2008).

GC and an independent reviewer (NS) separately appraised one of the final 18 papers selected at random, using the CASP framework. A numerical rating system used by Duggleby et al. (2010) was applied to each criteria to indicate whether it had been addressed (0='no', 1 = 'partially addressed' and 2 = 'fully addressed'). Inter-rater-reliability between reviewers was 70% and to reduce further subjectivity in interpretation GC and NS developed a mutually agreed rating system for each question; detailed in Appendix Three.

The CASP and numerical framework was systematically applied to all papers. Comments were made identifying strengths and weakness for each criteria, for each paper alongside ratings (see Appendix Four for an example). Sections rated zero were considered weak, those rated one as moderate and those rated two as strong. For each paper scores for each criteria were summed generating an overall quality rating. This score was used to categorise papers using a coding system developed by GC and supervisor RB: papers with a score 0-9 categorised as poor, 10-14 as moderate and 15-20 as good. Overall quality ratings were considered when developing third order constructs (themes/subthemes of the syntheses). See section headed 'data extraction and synthesis' for details on how weightings were equated in theme development. Numerical ratings for each CASP criteria as well as an overall rating for each paper are summarised in Table 1.1.

Ratings based on criteria fulfilment differed across papers. Method sections detailing recruitment, ethical considerations, design and reflexivity were often most poorly documented although appeared to improve over recent years. Table 1.1 shows that paper quality improved overtime; the two most recent publications were rated strong for most quality dimensions (Campbell-Jackson et al., 2014; Üstündağ-Budak, Larkin, Harris & Blisset, 2015).

Only one paper included was considered weak on 70% of evaluation criteria (Hense, 1994). In discussion with RB (supervisor) it was decided not to discount the paper for several reasons: (i) the methodology was largely unreported and this may have reflected poor reporting as opposed to methodological weaknesses (Atkins et al., 2008); (ii) many of the findings described in the study were reported in the majority of other studies, providing additional validity; (iii) meta-ethnography researchers argue insightful findings may be missed through exclusion (Dixon-Woods et al., 2007).

Table 1.1

Individual and overall ratings for each paper following application of the CASP

Criteria	Phipps (1985)	Hense (1994)	Côté-Arsenault & Mahlangu (1999)	Côté-Arsenault & Marshall (2000)	Armstrong (2001)	Côté-Arsenault, Bidlack & Humm (2001)	Côté-Arsenault & Morrison-Beedy (2001)	O'Leary (2005)	Côté-Arsenault, Donato & Earl (2006)	O'Leary & Thorwick (2006)	Côté-Arsenault & Donato (2007)	O'Leary & Thorwick (2008)	Sun, Sinclair & Kernohan (2011)	Anderson, Nilsson & Adolfsson (2012)	Lee, McKenzie-McHarg & Horsch (2013)	Ockhuijsen, Hoogen, Boivin, Macklon & de Boer (2014)	Campbell-Jackson, Bezance & Horsch (2014)	Üstündağ-Budak, Larkin, Harris and Blissett (2015)
1. Was there a clear statement of the aims of the research?	2	1	2	2	2	2	2	2	2	2	2	1	2	2	2	2	2	2
2. Is a qualitative methodology appropriate?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
3. Was the research design appropriate to address the aims of the research?	1	0	1	2	1	1	2	1	2	1	2	2	1	2	2	0	2	2
4. Was the recruitment strategy appropriate to the aims of the research?	1	0	1	2	1	2	0	1	1	1	1	1	1	1	2	2	2	1
5. Was the data collected in a way that addressed the research issue?	1	0	1	1	1	1	1	0	2	1	2	1	2	2	1	1	2	2
6. Has the relationship between researcher and participants been adequately considered?	0	0	0	0	0	0	0	1	1	0	0	0	0	0	0	0	2	2
7. Have ethical issues been taken into consideration?	0	0	0	1	2	1	1	1	2	1	0	1	2	2	2	1	2	2
8. Was the data analysis sufficiently rigorous?	1	0	1	1	1	2	2	1	1	1	2	0	1	1	2	2	2	2
9. Is there a clear statement of findings?	1	1	2	2	1	2	2	1	2	2	1	2	1	2	1	2	2	2
10. How valuable is the research?	2	0	2	2	1	1	2	2	1	2	1	1	2	2	2	2	2	2
Total Score	**11**	**4**	**12**	**15**	**11**	**14**	**14**	**12**	**16**	**13**	**13**	**11**	**14**	**16**	**16**	**14**	**20**	**19**

Data Extraction and Synthesis

Stages three to six involved extracting and synthesising data from studies to develop a higher-order interpretation; these steps are detailed in Figure 1.1. Throughout this process a number of methods were followed to maintain synthesis credibility and rigour (Jensen & Allen, 1996). A reflective diary was kept acknowledging the author's (GC) own experiences, values and assumptions. Regular supervision took place throughout stages five and six to validate interpretations and acknowledge sources of bias. GC had experienced a stillbirth in her family, and when synthesising the data was working in a perinatal service offering therapy to individuals who shared similar experiences to those reported in studies. RB is an experienced clinician and academic within Perinatal Psychology.

Finally, to maintain rigour in stage six quality ratings were considered when developing third order constructs from the piles generated in stage five. In supervision it was jointly decided that themes or subthemes would be discarded where 50% of the data was comprised from studies rated poor (Hense, 1994) and not found in any papers categorised as moderate or good. Similarly if refutations were found in poor papers but not in moderate or good papers, these were discounted. The aim was to prevent poor quality papers having too strong an influence/weighting on theme development.

Results

Description of studies

A total of 18 studies published over a 29-year period (1986-2015) were included and are summarised in Table 1.2. The majority reported findings from the United States (N=11)

Three papers reported data from one study, concentrating on different aspects of the data (O'Leary, 2005; O'Leary & Thorwick, 2006; O'Leary & Thorwick, 2008). Two papers represent early and late findings of a single study (Côté-Arsenault et al., 2006; Côté-Arsenault & Donato, 2007); therefore in total 15 studies were represented.

Two studies focused solely on men's experiences (Armstrong, 2001; O'Leary & Thorwick, 2006) there was some coverage of couples (Campbell-Jackson et al., 2014; O'Leary, 2005; O'Leary & Thorwick, 2008; Phipps, 1986) although the majority focused solely on women's experiences. Sample sizes varied between 4-73 participants depending on and suiting the method of data collection. These included semi-structured interviews conducted in person (N=11) over email (N=1), focus groups (N=2), questionnaires (N=2) and pregnancy calendars (N=2). The majority of samples included individuals of White ethnic background, who were employed, partnered with education ranging from eighth grade to university level.

Obstetric histories varied and included between 1-10 losses per woman covering the first, second and third trimesters and also included neonatal deaths. One infant death was represented however the couple also experienced a stillbirth (O'Leary, 2005; O'Leary & Thorwick, 2006; O'Leary & Thorwick, 2008). Time since previous loss when detailed varied between 6 months up to 34 years. In ten studies women were pregnant when taking part. Reporting of children prior or subsequent to loss varied across studies.

Just under half of studies referenced the parenting experience following loss, the majority of which explored only the early experiences of parenting; first few weeks/months (Côté-Arsenault et al., 2001; Hense, 1994; O'Leary & Thorwick, 2008; Phipps, 1986; Sun et al., 2011). Three studies offered a longitudinal perspective where couples had parented children between two to 34 years following a loss (Campbell-Jackson et al., 2014; Côté-Arsenault & Morrison-Beedy, 2001; Üstündağ–Budak et al., 2015). For further information see Table 1.2.

Table 1.2

Description of studies included in the synthesis

Author, Date and Country	**Research Question(s)/Purpose**	**Design:** ***Sampling Method/ Method of data collection /Analysis Method***	**Sample**	**Type of loss and time since loss (Obstetric history, if provided)**	**Results**	**Contribution**
Phipps (1986) ***United States (US)***	Preliminary exploration into the nature of the stresses produced in a subsequent pregnancy after stillbirth and how parents deal with those stresses.	Recruited through counselling centre and bereavement support group. One interview with 15 couples; 14 couples were interviewed together with the exception of one couple who were interviewed separately. Data analysed using grounded theory based methods	15 middle class couples. One black, one Hispanic and 13 Caucasian couples. Mean age mothers 30.2 and fathers (33.7) Two thirds of couples at least one parent was educated to college level.	Eight stillbirths and 7 neonatal deaths 9 experienced loss in first pregnancy, 6 had older living children.	Seven themes: (a) Pregnancy planning, (b) Initial Responses to pregnancy, (c) Social Issues, (d) psychological aspects, (e) response to medical interventions, (f) Delivery, (g) early response to child.	Highlights that psychological processes in subsequent pregnancy and parenting following loss are unique and different to pregnancy without loss. Largely due to a need for self-protection and control. Offers a first exploration of this.
Hense (1994) ***Canada***	To document a beginning understanding of the experiences of women in subsequent pregnancy following stillbirth.	No details about recruitment or analysis method. Three in-depth interviews with four women and one in-depth interview with 7 women.	Eleven women aged between 23 to 29 years, all married or in a stable relationship. Education varied from eighth grade to University degrees. Ethnicity was not reported	All women experienced a stillbirth between 20 weeks and up to and including full-term labour. Four women were pregnant when interviewed	Major themes identified: Reliving the previous loss, fearing recurrence, attempting to replace, mothering a live child	Most comprehensive study up to this point on understanding pregnancy after stillbirth – developed a model of the maternal processes of livebirth following stillbirth.

Côté-Arsenault & Mahlangu (1999) ***United States (US)***	To describe the experience of pregnancy after perinatal loss, more specifically: (i) What are the experiences of women in pregnancies after perinatal loss? (ii)What are the effects of past pregnancy experiences on the current pregnancy?	Convenience sample, recruited from quantitative component of the study. Tapped through quantitative measures on a questionnaire with follow up open questions to elicit the reason behind the previously given quantitative response. A blend of thematic analysis and question analysis	72 women aged from 19 to 44 years (M=32), primarily middle class, white, well educated and married.	Perinatal loss was predominantly in the first trimester (82%), 14% second trimester and 3% third trimester. One woman had a neonatal death. 35% had one to three live births since the loss. Time since most recent loss averaged 3 years (range 1-12 years), 51% reported a year since their loss.	Three dimensions of *past pregnancy*, *current pregnancy* and *self*, these constituted the overall framework for themes of pregnancy anxiety, significant points in time, ways of coping, safe passage, social acceptance, binding-in and grief and loss	Explores impact of loss extending to the first trimester. Also highlights changes to self following loss and that these could be lifelong.
Côté-Arsenault & Marshall (2000) ***United States (US)***	To gain insights into women's pregnancy after perinatal loss experiences, including major features and helpful provider responses. Specifically exploring: (a) experience of pregnancy after loss (b) Significance of specific or particular milestones during	Purposive Sampling Three focus groups and individual interviews with two participants (one in person and one on the telephone) – all using a semi-structured interview schedule. Guided by principles of comprehending, synthesizing, theorizing and recontextualizing.	Group 1 (n=4): Age range 24-38), education between 13-18 years, 3 Caucasian and one Asian/pacific Islander. All married, one employed. Group 2 (n=2): Age range 28-42), education between 13-18 years, both Caucasian, married and one was	Group 1: women experienced one loss either late miscarriage or stillbirth. Three had one living child. Three were pregnant (30-36 wks). Group 2: 2 losses per woman either early or late miscarriages. One had 2 the other had 5 living children. One was pregnant	Women found themselves living within contexts of: *(a) reliving the past, (b) trying to find a balance in the present, (c) recognizing their changed reality and (d) living with wavering expectations*. Seven themes chracterised navigation through the pregnancy: *(1) setting the stage, (2) weathering the storm, (3) gauging where I am,*	Irrespective of gestational age or loss history, women sought self-protection in their subsequent pregnancy by not totally investing themselves emotionally in a positive outcome.

	pregnancy (c) Major features of the women's concerns or worries (d) What healthcare providers did that was helpful or not helpful?		employed. Group 3 (n=5): Age range 24-33), education between 13-17 years, 1 Caucasian and one Hispanic. All married and four were employed.	(39wks). Group 3: 1-3 losses per woman either early, late miscarriages or stillbirth. One woman had 2 children, two had one child and to had no children. All women were pregnant (7-22wks)	*(4) honouring each baby, (5) expecting the worse, (6) supporting me where I am, and (7) realizing how I have changed.*	
Armstrong (2001) ***United States (US)***	To explore fathers' experiences of pregnancy after a prior perinatal loss.	Recruited participants through healthcare providers/medical practices. Two in-depth interviews; first interview was unstructured and the second was semi-structured and conducted between 3-4 weeks later. Phenomenology	Four fathers (3 married and one in a long term relationship). Three fathers were Caucasian and one was Black of Jamaican descent. Ages ranged from 29-44 years (M=35.3, SD=6.3). Educational levels ranged from 11-23 years (M=16.5, SD=5.1).	Experienced a pregnancy loss (12 to 20 weeks gestation) in the second trimester of a pregnancy in the last two years and were currently in the second half of another pregnancy	Effects of loss at time of fetal death; dealing with grief; spirituality; support; Influence of the pregnancy on the current pregnancy; replacement for the loss; milestones; influence of loss on life outlook	Offers a better understanding of fathers experiences or subsequent pregnancy following loss and highlights direction for associated nursing interventions to better support these families.
Côté-Arsenault, Bidlack & Humm (2001)	To determine the specific emotions and concerns of women who are pregnant following a	Convenience sampling – questionnaire sent to participants of pregnancy-after-loss support groups in a	73 women aged between 25 to 47 years (M=35, SD 4.89). The women were mainly	At the time of survey completion 23.3% of respondents were pregnant. They had a range of 1-10	Women described feeling (a) anxious, (b) worried, (c) fragile, (d) tentative, (e) angry, (f) isolated and (g) hopeful	First qualitative study to specifically explore primary emotions and concerns women have in pregnancies after

United States (US)	perinatal loss.	hospital Data collected through mailed questionnaire using an open responses. Analysed using content analysis.	Caucasian (89%), well educated (50.7% college).	perinatal losses per person including 80 miscarriages, 3 ectopic pregnancies, 27 births and 24 neonatal deaths. Time since loss not documented. Number of live births not clear	in pregnancy following loss. Concerns in pregnancy after loss focused on (a) losing another baby, (b) the overall health of the baby, (c) their own negative impact on baby, (d) fear of bad news, (e) emotional stability for self, (f) lack of support from others, (g) impact of another loss on my future and (h) worries never end.	perinatal loss. First to report that women thought their babies might be adversely affected by their fear and anxiety in pregnancy.
Côté-Arsenault & Morrison-Beedy (2001) ***United States (US)***	To describe women's experiences of pregnancy after loss and the long-term effects of perinatal loss. To gain insights into women's pregnancy after perinatal loss experiences, including major features and helpful provider responses. Specifically exploring: (a) experience of pregnancy after loss (b) Significance of	Snowball sampling Three focus groups conducted for 6-9 women in 1996. The focus groups lasted for 90 to 120 minutes and discussion was aided by the use of an interview guide. Phenomenology – Analysis guided by Colaizzi's procedural steps.	Group 1(n=6): Age range 39-60), education between 17-19 years and all were Caucasian. Five were married and five were employed. Group 2 (n=6) Age range 31-45), education between 12-19 years, and all were Caucasian. All women were married and five were employed out of the 6. Group 3 (n=9) Age	Group 1: number of pregnancies per person 3-10, miscarriages 0-6), stillbirth 0-2, ectopic 0-1. Time since loss ranged from 5 to 34 years. Group 2: number of pregnancies per person 2-5, miscarriages 0-3), stillbirth 0-2, ectopic 0-1. Time since loss ranged from 4 to 13 years.	Six Themes: (a) Dealing with uncertainty; (b) daily worries - wondering if the baby is healthy; (c) waiting to lose the baby; (d) holding back their emotions; (e) acknowledging that loss happened and it can happen again, and (f) changing self.	Demonstrate that the impact of perinatal loss is long term: effect on women's lives and their memories of the event are vivid even decades after the loss. Despite differences in obstetric histories pregnancies following loss share a number of similarities.

	specific or particular milestones during pregnancy (c) Major features of the women's concerns or worries (d) What healthcare providers did that was helpful or not helpful?		range 27-44), education between 13-19 years. Eight were Caucasian, one Syrian/Italian. Seven were married. Eight were employed.	Group 3: number of pregnancies per person 2-10, miscarriages 0-3), stillbirth 0-3, ectopic 0. Time since loss ranged from 1 to 14 years.		
O'Leary (2005) ***United States (US)***	To understand the experience of ultrasound during a pregnancy following a perinatal loss.	Recruited participants using a bereavement newsletter, through staff at a perinatal center and through other parents aware of the study. Individual interviews with mothers and fathers (lasting 60-90 minutes) Data analysed using descriptive phenomenological methods	Twelve mothers and nine fathers, which were all partners of the mothers interviewed.	Participants were between 22 and 35 weeks gestation in a current pregnancy. All experienced a loss in the previous year. Number of losses ranged from 1-3 and occurred between 9 weeks to 41 weeks gestation. Eight women and five men had 1 or 2 children prior to the loss whose ages ranged from 3-6 years.	Two themes emerged: (1) *Trauma memories become conscious* and (2) *flashbacks triggered PTSD symptoms.*	The ultrasound examination can be a source or reassurance and anxiety – it can reactivate memories of a previous loss and in some instances cause re-living PTSD like symptoms
Côté-Arsenault, Donato and Earl (2006)	To describe women's early pregnancy after loss experiences (up to 25 weeks gestation), to	Qualitative component of a quantitative triangulated study, women were recruited through snowball	Eighty two women of which 86.7% were Caucasian, 7.2% African American and 6% other.	Women were between 10-17 weeks gestation when entering the study. History of one	Four major themes: Growing confident, fluctuating worry, interpreting signs, managing pregnancy	First to explore documented timing and frequency of common discomforts and ways of coping in

United States (US)	document the timing and frequency of their common discomforts and events, and to explore changes in these over time.	sampling Women recorded events of their pregnancy through text and stickers on a Events in Pregnancy (EiP calendar). Field notes were by researchers when participants completed surveys as part of the quantitative study. Thematic analysis and content analysis	Education ranged from 10 to 21 year, 72.3% were married.	to seven losses per woman (M=2.1; SD=1.3) ranging from 3.5 weeks to 40.5 weeks gestation. 171 losses in total in the sample (82.4% miscarriages, 4.7% ectopics, 8.2% stillbirth, 4.7% neonatal death) Time since loss not documented	and having dreams. Theme managing pregnancy includes sub themes of being hypervigilant, seeking reassurance, and relying on internal beliefs.	women in early pregnancy (up to 25 weeks) after loss experiences, and explore these over time.
O'Leary & Thorwick (2006) ***United States (US)***	To explore the fathers perspective during the experience of a pregnancy following perinatal loss.	Recruited participants using a bereavement newsletter, through staff at a perinatal center and through other parents aware of the study. One semi-structured interview (between 60-90 minutes). Data was analysed using descriptive phenomenological methods.	Ten fathers whose ages ranged between 28 and 59 years, All were employed.	All experienced the loss of a baby in the previous year, one father experienced two losses. Their partners were currently pregnant at the time of interview and were between 23 and 34 weeks gestation. Five fathers had one living child, one father had two.	Four themes: recognition, preoccupation, stoicism and support.	Gives voice to fathers (only) perspectives of pregnancy following perinatal loss. Highlights emotional needs for fathers during first loss and subsequent pregnancy and barriers to possible interventions to meet these.
Côté-Arsenault & Donato	Long term follow up to study above. To describe women's	Same as above	69 women aged 21 to 42 (M=30.4, SD=5.11); well	Obstetric history included 2 to 13 pregnancies per	Two main themes and subthemes (*presented in italics*): (a) precarious	To describe and understand women's loss experiences

(2007) ***United States (US)***	late pregnancy after loss experiences (up to 25 weeks gestation), to document the timing and frequency of their common discomforts and events, and to explore changes in these over time.		educated (M=14.88 years, SD=2.58); majority married (72.5%) or partnered (14.5%). Majority were white (88.4%), 5.8% African American, 6% other.	woman (M=4.18; SD=1.99), 0-5 live children per woman (M=1, SD=1) and 1 to 7 losses per person (M=1.97; SD=1.29) totaling 133 losses ranging from 3.5 weeks to 40.5 weeks gestation and 5 neonatal deaths. Years since loss ranged from 0-13 years (M=2.17; SD=2.49)	pregnancy security: *(informed awareness and varying emotions);* (b) Prudent baby preparations *(physical, social and emotional preparation).*	In latter half of gestation (25 week plus)
O'Leary & Thorwick (2008) ***United States (US)***	An exploration of parents' subjective experience during a pregnancy following the loss of a baby.	Recruited participants using a bereavement newsletter, through staff at a perinatal center and through other parents aware of the study In depth interviews with mothers and fathers (structure not clear, together separate) Descriptive phenomenology	18 mothers and 12 fathers aged between 26-59. No further demographic details provided	Participants were between 22 and 35 weeks gestation in a current pregnancy. Number of losses varied from 1-3 and occurred between 9 weeks to 41 weeks gestation). All experienced a loss in the previous year. All women were pregnant.	Three major themes: (1) Attaching and differentiating babies, (2) Foetal Movement And (3) Mental images of pregnancy and the unborn baby	Using a prenatal attachment framework the study enhances our understanding of how loss can change representations of the unborn baby and pregnancy for parents
Sun, Sinclair, Kernohan,	To explore the holistic lived experience of Asian	Women recruited through postnatal wards.	Six women aged between 23 to 38 years and were	All women experienced a loss during their first	Metaphor 'sailing against the tide' tide emerged to depict three	Provides insight into the journey's of Taiwanese women in

Chang & Paterson (2011) ***Taiwan***	women in Taiwan, who are adjusting to motherhood following previous pregnancy loss. To describe their experiences and understand the meaning of those experiences.	Two in depth interviews (60-90 minutes). The first very recently after the birth and the second interview 4-6 weeks post-partum Data analysed using Interpretative Phenomenological Analysis.	Asian. Five women had a university degree and one was a high school graduate.	pregnancy, 3 experienced a subsequent loss and two had living children at home. Gestational weeks at loss varied from 9 to 37 weeks. Years since loss varied from 1.3-3.5 years	stages of the women's journey which were listed as themes: (1) Remembering the journey of *"loss,"* (2) The rising sun brings new life within; and (3) changing tide brings new birth.	subsequent pregnancy and mothering roles after loss. Highlighting crucial differences from Western cultures.
Andersson, Nilsson & Adolfsson (2012) ***Sweden***	To investigate how women who have experienced one or more miscarriages manage their feelings when they become pregnant again.	Participants contacted following participation in a previous study. Participants also included women referred to the study by women already taking part. One semi-structured interview between 2002-2006 Data analysed using content analysis with an inductive approach.	13 women from a similar geographical location No information regarding specifics of sample	Women were between 9-12 weeks pregnant and experienced at least one miscarriage. Details of obstetric history not provided.	Five categories: (1) distancing herself from her pregnancy, (2) focusing on her pregnancy symptoms, (3) searching for confirming information, (4) asking for ultrasound examination and (5) asking for professional and social support.	Highlights how most women self-manage difficult emotions and feel isolated in their worries and concern when becoming pregnant after a miscarriage. The support they feel they need is not provided by professionals.
Lee, McKenzie-McHarg & Horsch (2013)	To improve understanding of women's thoughts and feelings in relation to a subsequent	Selected sample of participants from a previous research study. Sent a letter of information and opt in letter.	11 women aged between 26 and 43 (M=32, S.D=4.4). The majority (8) were White British,	Stillbirth (at 24 weeks' gestation or later) within the previous 6-12 months. Stillbirth occurred between	Four themes and 11 categories. Four themes included: (1) factors contributing to the decision making process, (2) outcome of	First to improve our understanding of women's experiences of decision making in relation to a subsequent pregnancy

United Kingdom (UK)	pregnancy following a stillbirth and what factors, if any, influenced this over time.	One semi-structured interview Modified grounded theory was used to guide research methodology and analyse data.	one was Slovakian, one Italian and one White Asian. Eighty two percent were working	25-40 weeks gestation. Eight women were pregnant at the time of the interview (mean 14 weeks, range 9-25 weeks). All had made a decision about subsequent pregnancy. Eight women had no children prior to the stillbirth, 3 had at least one child living at home.	decision making, (3) The emotional experience of subsequent pregnancy, and (4) Coping with the emotional experience of subsequent pregnancy and maintaining hope.	and of the pregnancy itself, following a previous stillbirth. The authors illustrate these processes by developing an illustrative model.
Ockhuijsen, Hoogen, Boivin, Macklon & de Boer (2014) ***Netherlands***	How do women experience miscarriage, conception, and the early pregnancy waiting period, and what types of coping strategies do they use during these periods?	Opportunity sampling of women attending an early pregnancy unit and/or recurrent miscarriage clinic; invited by telephone to take part. Semi-structured interviews conducted with women 8+ weeks in a subsequent pregnancy after having a miscarriage. Thematic analysis	All 24 women were heterosexual and married or partnered. Age ranged from 27 to 38 years (M=33.2, SD=3.0). Educational level ranged from secondary school to university.	The number of miscarriages experienced by women ranged from 1 to 5 (median=2). Weeks at which they occurred not detailed. Only one woman had a living child	Overarching theme described as *balancing between loss of control and searching for control* which encapsulates the uncertainty faced during the miscarriage, conception and early pregnancy period.	Qualitative study provides insights into three different waiting periods (the miscarriage, conception period and early pregnancy) in women with a history of miscarriage embarking on another pregnancy

Campbell-Jackson, Bezance & Horsch (2014) ***United Kingdom (UK)***	To explore mothers and fathers experiences of becoming a parent to a child born after a recent stillbirth, covering the period of the second pregnancy and up to two years after the birth of the next baby.	Invitation letter – had taken part in a previous study by the author. One in-depth interviews; each partner interviewed separately. Interpretive Phenomenological Analysis (IPA)	Seven couples that were all married and employed (14 participants; 7 male and 7 female). Ethnic background of females included 5 British, one polish and one Brazilian. For males, 6 British and one polish)	Experience of a stillbirth (after 24 weeks of gestation). Mean age of stillbirth was 36.1 weeks (SD=4.6). Mean age of subsequent child was 16.6 months (SD=7.4)	Five superordinate themes: *Living with uncertainty; coping with uncertainty; relationship with the next child; the continuing grief process; identity as a parent.*	First to illuminate lived experiences of mothers and father of becoming a parent to a child born after a recent stillbirth, covering the period of the second pregnancy and up to two years after the birth of the next baby.
Üstündağ-Budak, Larkin, Harris and Blissett (2015) ***United Kingdom (UK)***	To explore the meaning of the stillbirth experience to women and its influence on the subsequent pregnancy and subsequent parenting from the mothers' own perspectives.	Purposive sampling through internet-based. Semi-structured interviews conducted through email. Written accounts were analysed using IPA.	6 women aged between 30 to 48 years.	Women who previously experienced a stillbirth (gestation from 25- 41 weeks) and since had a living infant (between 4 months and 4 years). The time gap between the stillbirths to the subsequent live births varied from 15 to 20 months.	Three overarching themes describing an ongoing process (1) *Broken canopy* -where women accepted a new unsafe world, (2) *how this happened* - re-evaluated their view of self and others and (3) *Continuing bonds* - established relationships with both the deceased and the living infant.	First to have an existential focus on what the stillbirth experience means to women and it's influence on subsequent pregnancy and parenting.

Structure of synthesis

Three overarching categories, further divided into themes and subthemes emerged as third order constructs (GC's interpretations of findings as reported/interpreted by authors), important in understanding experiences of subsequent pregnancy and parenting following loss. The order of the categories represents a chronological journey as reported in most studies, starting from conception through to subsequent pregnancy and parenting. A diagrammatic overview of third order constructs is presented in Figure 1.4. Furthermore Table 1.3 details which papers contributed to the development of each category, theme and subtheme.

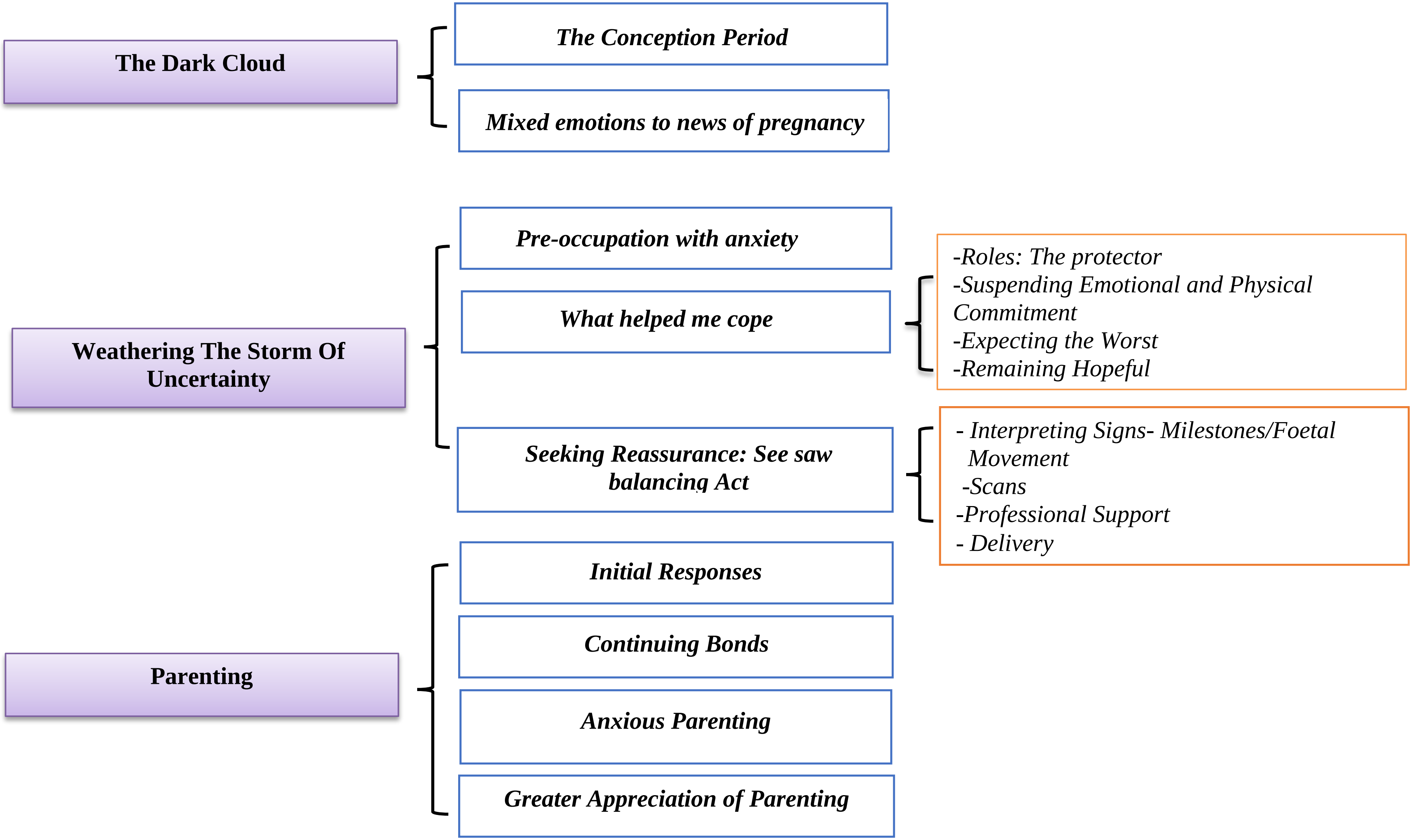

Figure 1.4: Conceptual overview of third order constructs

Table 1.3

Details of papers that contributed to the development of each third order construct

	Phipps (1985)	Hense (1994)	Côté-Arsenault & Mahlangu (1999)	Côté-Arsenault & Marshall (2000)	Armstrong (2001)	Côté-Arsenault, Bidlack & Humm (2001)	Côté-Arsenault & Morrison-Beedy (2001)	O’Leary (2005)	Côté-Arsenault, Donato & Earl (2006)	O’Leary & Thorwick (2006)	Côté-Arsenault & Donato (2007)	O’Leary & Thorwick (2008)	Sun, Sinclair & Kernohan (2011)	Anderson, Nilsson & Adolfsson (2012)	Lee, McKenzie-McHarg & Horsch (2013)	Ockhuijsen, Hoogen, Boivin, Macklon & de	Campbell-Jackson, Bezance & Horsch (2014)	Üstündağ-Budak, Larkin, Harris and Blissett (2015)
The Dark Cloud	✓	✓	✓	✓	✓		✓	✓			✓	✓	✓	✓	✓	✓	✓	✓
The Conception Period	✓	✓					✓						✓		✓	✓		
Mixed emotions to news of pregnancy	✓	✓	✓	✓	✓			✓			✓	✓	✓	✓	✓	✓	✓	✓
Weathering The Storm of Uncertainty	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Pre-occupation with anxiety	✓	✓	✓	✓	✓	✓	✓				✓		✓		✓	✓	✓	✓
What helped me cope	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Roles: The Protector	✓	✓	✓		✓				✓	✓			✓	✓		✓	✓	
Suspending Emotional and Physical Commitment	✓	✓	✓	✓			✓				✓	✓		✓	✓		✓	✓
Expecting the Worst	✓		✓				✓				✓		✓		✓	✓	✓	✓
Remaining Hopeful				✓		✓	✓		✓		✓		✓		✓		✓	✓
Seeking Re-assurance: See-saw Balancing Act	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

	Phipps (1985)	Hense (1994)	Côté-Arsenault & Mahlangu (1999)	Côté-Arsenault & Marshall (2000)	Armstrong (2001)	Côté-Arsenault, Bidlack & Humm (2001)	Côté-Arsenault & Morrison-Beedy (2001)	O'Leary (2005)	Côté-Arsenault, Donato & Earl (2006)	O'Leary & Thorwick (2006)	Côté-Arsenault & Donato (2007)	O'Leary & Thorwick (2008)	Sun, Sinclair & Kernohan (2011)	Anderson, Nilsson & Adolfsson (2012)	Lee, McKenzie-McHarg & Horsch (2013)	Ockhuijsen, Hoogen, Boivin, Macklon & de Boer (2014)	Campbell-Jackson, Bezance & Horsch (2014)	Üstündağ-Budak, Larkin, Harris and Blissett (2015)
Interpreting Signs-Milestones/Foetal Movement	✓	✓	✓		✓		✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	
Scans	✓		✓	✓	✓		✓	✓			✓		✓	✓	✓		✓	✓
Professional Support	✓	✓	✓				✓		✓		✓		✓	✓	✓			✓
Delivery	✓	✓											✓					
Parenting	✓	✓				✓	✓			✓		✓	✓				✓	✓
Initial Response	✓	✓										✓	✓				✓	
Continuing Bonds	✓	✓										✓					✓	✓
Anxious Parenting	✓	✓				✓	✓					✓	✓				✓	✓
Greater Appreciation of Parenting	✓	✓					✓			✓			✓				✓	✓

The Dark Cloud

The shock, devastation and pain of losing a child appeared to leave a lasting imprint on couples' lives and changed the position in which they entered the subsequent pregnancy and parenting. Many expressed how the loss had signified newfound knowledge of the 'fragility of life;' nothing was certain, even pregnancy. The sense of 'innocent joy' previously attached to pregnancy was lost forever; subsequent pregnancies be it their own or others were no longer viewed with the expectation they would result in a live baby (Cŏté-Arsenault & Mahlangu, 1999; Hense, 1994; O'Leary & Thorwick, 2008; Ockhuijsen et al., 2014). This 'dark cloud' was irreversible and manifested as anxiety in subsequent pregnancy. From mothers descriptions this appeared to begin as early as the conception period. Although this period is not a main focus of the meta-ethnography, this was described in over a third of papers and therefore included as a subtheme. The dark cloud also influenced couples responses to confirmation of pregnancy, which was often met with ambivalence.

The conception period

This period was discussed only by women and commonly expressed as inducing feelings of fear and anxiety (Andersson et al., 2013; Lee et al., 2013; Phipps, 1986). This was more evident in women who chose to become pregnant immediately, citing reasons of wanting to heal or replace the 'empty' feeling of the lost child, or a desperate desire to be a mother (Hense, 1994; Lee et al., 2013). Women who waited until they felt emotionally and physically prepared to be pregnant appeared to find strength over this time and adapted better in the conception period and subsequent pregnancy (Lee et al., 2013). Professional advice, although offered, did not appear important in influencing women's decisions of when it felt right to conceive again (Lee et al., 2013; Ockhuijsen et al., 2014).

Women described adopting a number of strategies to increase their chances of becoming pregnant, including using ovulation tests, planning sexual activity, taking vitamins and eating healthier foods (Lee et al., 2013; Ockhuijsen et al., 2014). These approaches were more evident in women who attempted pregnancy immediately after loss and/or those that struggled over a long period to conceive the baby that died (Andersson et al., 2012; Lee et al., 2013; Ockhuijsen et al., 2014). Negative pregnancy tests led women to feel their bodies had failed them (Lee et al., 2013; Sun et al., 2011). It appears professional support was unavailable at the time but could have lessened distress (Sun et al., 2011).

Mixed emotions to news of pregnancy

Confirmation of a subsequent pregnancy was met with mixed emotions. For couples the news was characterised by feelings of joy and heightened fear this pregnancy could also end in loss (Hense, 1994; Lee et al., 2013; O'Leary & Thorwick, 2008; Sun et al., 2011). Some women described withholding excitement because of this (Armstrong, 2001; Cǒté-Arsenault & Marshall, 2000). These emotions appeared to be intensified by those who felt they were still grieving for their lost child (Phipps, 1986; O'Leary & Thorwick, 2008). Two studies suggested some mothers experienced guilt; worrying the lost child may feel dismissed and judge them for conceiving sooner than if they had had a live-born. To these mothers it appeared important to convey to others the subsequent pregnancy was not a replacement child (Lee et al., 2013; Üstündağ–Budak et al., 2015).

Many couples postponed sharing news of pregnancy with family and friends, or were more selective about who to tell compared to previous pregnancies. Couples assumed their networks would be largely unsupportive should they have another loss based on limited support received during their previous loss, or mistakenly interpret the pregnancy as a replacement child (Andersson et al., 2012; Côté-Arsenault, Donato & Earl, 2006; Cǒté-Arsenault & Mahlangu, 1999; Côté-Arsenault & Morrison-Beedy, 2001; Cǒté-Arsenault & Marshall, 2000; O'Leary & Thorwick, 2008; Phipps, 1986).

Weathering the storm of uncertainty

The dark cloud or psychological imprint of the loss carries forward and significantly impacts upon the way in which the subsequent pregnancy is experienced. Across studies pregnancy is described as a task to endure, the uncertainty of the outcome manifests as a desperate need to find control and self-protect from further pain. Mothers and fathers describe finding their own ways to navigate through this with strategies adopted often offering short-term relief.

Pre-occupation with anxiety: 'always on my guard'

Irrespective of time since loss all studies described a changed reality for men and women in their experience of subsequent pregnancy; characterised by an overwhelming sense of anxiety. Worries were marked by a constant fear of another loss that did not dissipate even after birth (Côté-Arsenault et al., 2001; Côté-Arsenault & Donato, 2007; Cǒté-Arsenault &

Mahlangu, 1999; Cŏté-Arsenault & Marshall, 2000; Côté-Arsenault & Morrison-Beedy, 2001; Hense, 1994; Phipps, 1986). A perceived lack of control appeared to fuel anxiety, given new found knowledge of the risk of loss and feeling the need to prepare for this (Cŏté-Arsenault & Mahlangu, 1999; Côté-Arsenault & Morrison-Beedy, 2001).

Women more frequently described this period to be ‘stressful’ and the concern was expressed to be akin to physical pain; ‘ache’ (Cŏté-Arsenault & Mahlangu, 1999; Côté-Arsenault & Morrison-Beedy, 2001; Üstündağ–Budak et al., 2015). Concerns often extended to fears the baby would be born unhealthy or with abnormalities. Women doubted their bodies could physically and/or mentally cope and worried about their own health, and their body’s ability to successfully produce a live baby (Côté-Arsenault et al., 2001; Phipps, 1986; Sun et al., 2011). Anxiety appeared more intense in women who had experienced multiple losses or did not have any prior warning (symptoms or pains) before pregnancy loss (Cŏté-Arsenault & Marshall, 2000; Ockhuijsen et al., 2014). Some women expressed meta-worry of the impact their anxiety would have on the health of their baby (Côté-Arsenault et al., 2001; Hense, 1994). This is particularly significant given the newfound literature emphasising the negative impact of anxiety on biological, psychological and behavioural development of offspring (Shahhosseini, Pourasghar, Khalilian, & Salehi, 2015). Women did not reach out to friends and family to discuss concerns for fear others would not understand and perceive them as irrational (Phipps, 1986).

For many couples worries overshadowed any ability to enjoy the pregnancy, it was seen as something to ‘survive’ with the goal to produce a healthy baby (Côté-Arsenault & Morrison-Beedy, 2001; Hense, 1994; Lee et al., 2013; Phipps, 1986).

‘What Helped Me Cope’

Roles: ‘The Protector’

The synthesis lends some evidence to stereotypical scripts of gender differences in grief responses and coping in subsequent pregnancy through cultural conditioning. Most men described taking a stoic stance in subsequent pregnancy, rarely communicating their own anxieties or concerns with partners, perceiving their role as supporting their partner and providing reassurance. Men expressed a need to stay strong for their families and saw themselves as important in maintaining hope; this was shared across Eastern and Western cultures (Campbell-Jackson et al., 2014; O'Leary & Thorwick, 2006; Phipps 1986; Sun et al., 2011). Some men felt the experience was more intense for their partners as they were carrying the baby (Campbell-Jackson et al., 2014; O'Leary & Thorwick, 2006). Women were appreciative of support from partners and acknowledged it was significant in helping them cope.

Work appeared to provide a welcome distraction in helping men cope with the 'heavy burden' of staying strong and carrying their own worries (Campbell-Jackson et al., 2014; O'Leary & Thorwick, 2006). However this was temporary; fathers often found themselves worrying about the baby and in few cases described reaching out to family and friends to share the burden (O'Leary & Thorwick, 2006). Most fathers expressed the need to obtain their own reassurances of the baby's wellbeing, by asking partners about foetal movement or attending medical appointments (Armstrong, 2001; O'Leary & Thorwick, 2006; Phipps, 1986).

Women appeared to see themselves as a vessel whose primary role was to ensure the baby's wellbeing through a balanced diet, exercise and avoiding activities felt to have caused the previous loss; including working too much or consuming too much caffeine. The main motivating factor appeared knowing they did enough, to reduce feelings of responsibility should they face another loss (Andersson et al., 2012; Côté-Arsenault et al., 2006; Cǒté-Arsenault & Mahlangu, 1999; Hense, 1994; Ockhuijsen et al., 2014)

Suspending Emotional and Physical Commitment

Advancements in technology have somewhat changed prenatal attachment, with some arguing seeing the baby in greater detail has strengthened development of psychological and emotional bonds between parents and their unborn child (Brandon, Pitts, Denton, Stringer & Evans, 2009). Counterintuitive to common societal conceptions of appropriate pre-natal bonding behaviours, most couples actively engaged in strategies to emotionally and physically distance themselves from the pregnancy. Also referred to as 'emotional cushioning' or 'shielding' this appeared to be motivated by self-protection and the need for control in a position of uncertainty (Andersson et al., 2012; Campbell-Jackson et al., 2014; Cǒté-Arsenault & Marshall, 2000; Côté-Arsenault & Morrison-Beedy, 2001; Hense, 1994;

Lee et al., 2013; Phipps, 1986; Üstündağ–Budak et al., 2015). Couples, mothers in particular, recognised they behaved differently from pregnancies prior to loss; they were no longer dreaming or fantasising about the baby or parenthood (Cǒté-Arsenault & Marshall, 2000; Hense, 1994; Lee et al., 2013; Phipps, 1986). By investing in the subsequent baby in the same way women felt they were exposing themselves to the same psychological pain and were unsure of their ability to cope should this be a reality. Delays in physical preparation were also common; couples delayed preparing nurseries or buying clothes. In some studies this appeared to lessen closer to term, where fathers in particular encouraged attachment behaviours by their partners; reading to the baby or listening to music together (Côté-Arsenault & Donato, 2007; Cǒté- Cǒté-Arsenault & Marshall, 2000; Arsenault & Mahlangu, 1999; O'Leary & Thorwick, 2008).

Distancing strategies during subsequent pregnancy appeared to induce feelings of guilt in couples during pregnancy and after birth, more commonly in women as they felt they had not 'invested' or 'prepared' enough for the baby (Campbell-Jackson et al., 2014; Côté-Arsenault & Morrison-Beedy, 2001; Hense, 1994; Lee et al., 2013; Phipps, 1986).

'Expecting the worst'

There was a sense of increased vulnerability in subsequent pregnancy as couples were now aware loss was a real possibility; the 'innocent bliss' of pregnancy was gone. In the majority of studies couples described mentally 'bracing' themselves for another loss to cope with the uncertainty of the outcome (Campbell-Jackson et al., 2014; Lee et al., 2013; Ockhuijsen et al., 2014; O'Leary & Thorwick, 2008; Phipps, 1986; Üstündağ–Budak et al., 2015). Women often described waiting to lose the baby whilst also maintaining hope the baby would be alive and healthy (Cǒté-Arsenault & Marshall, 2000; Côté-Arsenault & Morrison-Beedy, 2001). Cǒté-Arsenault & Marshall (2000) described this as mothers having 'one foot in and one foot out of the pregnancy' where women engaged in behaviours that maximised their chances of a positive outcome, but the other foot stood in the reality that things could go wrong.

Remaining hopeful

The importance of remaining hopeful of a positive outcome in the midst of the storm was an important coping strategy mentioned in over half of studies. Hope appeared stronger towards the end of pregnancy when signs suggested a greater sense of security of a healthy outcome such as foetal movements, or in women who had previous successful live births (Campbell-Jackson et al., 2014; Côté-Arsenault et al., 2001; Côté-Arsenault et al., 2006; Côté-Arsenault & Donato, 2007; Cǒté-Arsenault & Marshall, 2000; Côté-Arsenault & Morrison-Beedy, 2001; Lee et al., 2013; Sun et al., 2011; Üstündağ–Budak et al., 2015). Men most commonly reported cognitive strategies such as positive self-talk (Campbell-Jackson et al., 2014). Cross-culturally faith appeared integral for some couples in trying to remain positive during pregnancy (Côté-Arsenault et al., 2006; Sun et al., 2011; Üstündağ–Budak et al., 2015). Hope or signs of reassurance as discussed below were fragile and easily shaken.

Seeking Reassurance: 'Seesaw' balancing act

Reassurance provided by certain signs/behaviors/strategies was often fragile and short-lived, as they were also a source of anxiety. Similar to a 'seesaw' couples anxiety and sense of reassurance fluctuated throughout pregnancy.

Interpreting Signs – Milestones and Foetal Movement

Couples appeared to take more of a 'clinical view' of subsequent pregnancy akin to professionals managing their care; watching out for objective signs indicating foetal wellbeing. Passing milestones and wanting to know details of the baby's development at each stage was no longer met with the same enthusiasm and excitement as in previous pregnancies, as most felt this made the possible loss of the child harder. Although culturally seen to be counterintuitive, in this pregnancy it felt safer not to connect with the unborn child and view signs and symptoms of pregnancy with greater distance (Armstrong, 2001; Campbell-Jackson et al., 2014; Côté-Arsenault & Donato, 2007; Côté-Arsenault et al., 2006; Cǒté-Arsenault & Mahlangu, 1999; Côté-Arsenault & Morrison-Beedy, 2001; Hense, 1994; Lee et al., 2013; Ockhuijsen et al., 2014; Phipps, 1986; Sun et al., 2011).

Focusing on passing small pregnancy milestones helped couples feel more in control and led to stronger beliefs they were able to cope. Passing the gestation at which previous loss occurred was central to this and appeared to instill greater hope and reassurance this outcome would be positive (Armstrong, 2001; Côté-Arsenault et al., 2006 ; Cŏté-Arsenault & Mahlangu, 1999; Côté-Arsenault & Morrison-Beedy, 2001; O'Leary & Thorwick, 2006). This was most evident in women who experienced early pregnancy losses (Côté-Arsenault et al., 2006 ; Cŏté-Arsenault & Mahlangu, 1999; Côté-Arsenault & Morrison-Beedy, 2001). This state however was transient; anxiety appeared to come and go in 'peaks and troughs.' It was reported highest in the days prior to previous loss where there was increased hyper-vigilance of symptoms confirming pregnancy viability; sore breasts, nausea and/or foetal movement (Andersson et al., 2012; Côté-Arsenault et al., 2006 ; Ockhuijsen et al., 2014) .

Women and men acknowledged hyper-vigilance once the second trimester was reached, looking out for foetal movements that were taken as an indication of baby wellbeing. Most authors' interpreted hyper-vigilance as a safety behaviour helping couples feel a temporary sense of security and control. In most studies mothers described 'panicking' if the baby had not moved for a period of time, which for some resulted in a flooding of emotions associated with the previous loss (Lee et al., 2013). Others expressed how they tried to induce movement through singing or eating certain foods and when unsuccessful contacted professionals (Campbell-Jackson et al., 2014; Sun et al., 2011). This provided relief for a few days until anxiety was triggered again. Couples acknowledged these behaviours were characteristically different from pregnancies before loss, where foetal movement encouraged pre-natal attachment behaviour. These were documented across cultures (Sun et al., 2011) and women most frequently commented their concerns made it difficult to enjoy the pregnancy, although some were still determined to do so (O'Leary & Thorwick, 2008).

Scans

Pregnancies subsequent to loss were considered 'high risk' hence ultrasound scans were offered more frequently and highly valued. Most couples described wanting more, as reassurance was short-lived (Campbell-Jackson et al., 2014); some achieved this by paying for private scans (Sun et al., 2011) and/or through research participation (Andersson et al., 2012).

Waiting for a scan induced high levels of anxiety. This was likely because ultrasound scans were in most cases directly associated with confirmation of previous loss; many anticipated this would happen again (Côté-Arsenault et al., 2001; Lee et al., 2013; O'Leary, 2005; Phipps, 1986). The scan room triggered fear as for some situational and sensory cues often led to reconnecting with memories of the previous loss (Côté-Arsenault et al., 2001; Lee et al., 2013; O'Leary, 2005) that many felt unprepared for. In extreme cases although rare this resulted in trauma in the form of flashbacks; '*that* [the ultrasound] *really set it off for the two of us…it just bought everything back*' (O'Leary, 2005). Despite initial anxiety, scans also offered 'relief' and reassurance once couples had objective evidence of foetal wellbeing; able to visually see the baby on the monitor and hear the heartbeat (Andersson et al., 2012; Armstrong, 2001; Côté-Arsenault & Donato, 2007; Cŏté-Arsenault & Mahlangu, 1999; Côté-Arsenault & Marshall, 2000; Côté-Arsenault & Morrison-Beedy, 2001; Sun et al., 2011; Üstündağ–Budak et al., 2015). Relief was temporary as within 2-3 days most women expressed the need for further reassurance as their anxiety heightened again; the most cited trigger being lack of foetal movement (Campbell-Jackson et al., 2014; Cŏté-Arsenault & Marshall; Sun et al., 2011). Cŏté-Arsenault and Marshall (2000) described this as the 'reassurance/non-reassurance cycle' as this continued throughout pregnancy.

Professional Support

Women acknowledged an increased dependency on professionals in subsequent pregnancies however they were better able to assert their needs. They expressed greater confidence in what they wanted from their care leading many to stay with the same obstetrician that dealt with the loss, or change providers if they felt their needs could be better met elsewhere (Cŏté-Arsenault & Mahlangu, 1999; Phipps, 1986; Sun et al., 2011). Changes were motivated by greater expertise and/or a desire to limit direct connections with the previous loss experience e.g. visiting the same hospital.

Interactions with professionals and their communication styles were considered significant in shaping couples' experience of subsequent pregnancy. Many couples valued increased opportunities provided by healthcare professionals in discussing their concerns through personal and/or telephone contacts at 'anytime,' and the opportunity for increased foetal monitoring (Côté-Arsenault & Morrison-Beedy, 2001). Having such reassurances was often cited as helping couples manage their anxiety. Some women's descriptions suggest such support was not always utilised, due to fears they could be perceived as 'needy' by professionals (Côté-Arsenault et al., 2001).

Positive experiences included professionals being flexible in their availability, having an awareness of past obstetric histories and offering personalised approaches to care. In particular, being aware of the previous loss including the baby's name, actively listening and providing reassurance in response to concerns (Andersson et al., 2012; Côté-Arsenault & Morrison-Beedy, 2001; Côté-Arsenault et al., 2006; Côté-Arsenault & Donato, 2007; Cŏté-Arsenault & Marshall, 2000; Hense, 1994). In contrast, contacts were described as unhelpful where professionals were poorly informed of obstetric histories and unaware of the loss, or were aware and dismissive showing what was perceived as a lack of concern (Andersson et al., 2012; Côté-Arsenault & Morrison-Beedy, 2001; Üstündağ–Budak et al., 2015).

The extent to which professional support was provided in subsequent pregnancy varied across and within countries. One UK study described access to available support as being a 'lottery,' with support limited to certain areas. An undertone of unfairness and sadness was evident in women's descriptions, particularly if services were not available to them (Andersson et al., 2012; Lee et al., 2013). Whilst in Western cultures there is now growing awareness politically and professionally of the need to support women in pregnancy after loss, it is not clear whether this is the case in Eastern cultures where loss may be interpreted differently due to cultural taboos (Sun et al., 2011). In the only study with women from an Eastern culture it was unclear whether extra interactions with healthcare providers were provided following loss, although the need for such support was stressed by women and authors (Sun et al., 2011).

Delivery

In four studies women expressed conflicting desires when mentally preparing for birth; not wanting to deliver or visualise delivering their baby as they felt they would be safer inside the womb, but at the same time requesting early elective cesarean sections. This was only reported in studies of women following stillbirth as these women associated giving birth with death, the emotional and psychological impact created heightened anxiety for the impending birth. Authors described these behaviours as motivated by self-protection and control, for mothers to ensure the best possibility of a positive outcome (Phipps, 1986; Hense, 1994; Lee et al., 2013; Sun et al., 2011).

Parenting

The birth of a healthy child appeared to be a time of joy that was also met with rekindled grief for the lost child. It was important to see the living child and deceased as separate individuals and for these bonds to coexist. Fear of loss continued even after a healthy child was born, however over time parents found a way to live with the uncertainty. Couples reported greater appreciation and priority in their role as a parent, attributed to the changed meaning this role had for them having lived through the loss experience; suggesting post traumatic growth (Lee et al., 2013)

Initial Response

Meeting new-borns for the first time in the few studies this was reported, was for fathers characterised by a sense of relief (Phipps, 1986) and for many mothers disbelief *'that I had actually given birth to a healthy child'* (Üstündağ–Budak et al., 2015). This could be attributed to mothers delaying attachment or fantasising about a live child in the current pregnancy, as a way to protect themselves from pain of further loss (Cǒté-Arsenault & Marshall, 2000; Hense, 1994; Lee et al., 2013; Phipps, 1986). This way their hopes and dreams could not be destroyed. Couples were excited to meet their living child although some mothers expressed reactivation of past feelings from when they conceived. They felt concerned they were betraying the deceased infant particularly if they loved this baby; *'will she look down from heaven and feel jealous'* (Campbell-Jackson et al., 2014; Üstündağ–Budak et al., 2015).

Continuing Bonds

Many couples expressed the birth of a living infant reawakened grief for their 'injustice' (Campbell-Jackson et al., 2014) or lost child (Hense, 1994; Phipps, 1986). The experience of parenting the newborn child was seen in light of the changed view of the world the loss had left them with. When making sense of this it was important for parents to recognise their children as distinct beings, each with their own sense of identity, place in the family, continually co-existing side by side. Authors highlighted that this appeared to be an important part of the healing process (Armstrong, 2001; Cŏté-Arsenault & Marshall, 2000; Hense, 1994; Üstündağ–Budak et al., 2015). In few instances couples described the process of drawing this distinction as difficult if both the deceased and live baby were the same gender (Hense, 1994; O'Leary & Thorwick, 2008). Conscious strategies aided this process allowing a coexistence of separate bonds, including: commemorating anniversaries of the lost child and plans to tell the living infant about them so they remained in the family narrative; sharing toys bought for the baby that died with the subsequent child; and talking about both as distinct beings with others (Campbell-Jackson et al., 2014; Hense, 1994; O'Leary & Thorwick, 2008; Üstündağ–Budak et al., 2015). Family and friends often asked about the new-born and little about the deceased; couples felt it was important to talk about their lost child to keep their memory alive and for others to recognise they were a distinct being and the subsequent child was in no way a replacement (Campbell-Jackson et al., 2014; Hense, 1994; O'Leary & Thorwick, 2008; Phipps, 1986; Üstündağ–Budak et al., 2015).

Some mothers described difficulty bonding with their newborn immediately after birth particularly in cases where they felt the threat of death was still evident, however this improved within the first few weeks (Campbell-Jackson et al., 2014; Phipps, 1986).

Anxious Parenting

The 'off-script' experience of losing a child left a lasting mark for couples of an uncertain world no longer safe. This manifested as high anxiety in subsequent pregnancy that also appeared to translate into the experience of parenthood once the child was born (Üstündağ–Budak et al., 2015). Couples remained preoccupied with the fear of loss, which now transcended to worrying about cot death or sudden infant death (Campbell et al., 2013; Côté-Arsenault et al., 2001; Hense, 1994). There was a compelling instinct amongst parents, especially mothers to engage in strategies/behaviours they felt protected their child, including; being overprotective by not separating from the child and/or letting others hold them and engaging in high frequency checking behaviours to ensure they were still breathing (Côté-Arsenault & Morrison-Beedy, 2001; Phipps, 1986; Üstündağ-Budak et al., 2015). Anxiety was raised when facing certain parenting milestones such as the child's first illness; reassurance was often sought from professionals over this time (Phipps, 1986). Many authors recognised for most parents given their past experiences such behaviours made sense to them, however were not always recognised by professionals (Üstündağ–Budak et al., 2015).

Campbell-Jackson et al. (2014) noted parents may benefit from home visits or extra support/reassurance during this time.

Some mothers expressed high expectations in their parenting role; this was more prevalent in women who experienced stillbirth where the cause was unknown. This appeared motivated by a desire to prove to themselves they would have been a good parent to the child that died. This included the desire to breastfeed and 'succeed' and trying to ensure their child met developmental milestones early (Campbell-Jackson et al., 2014; Üstündağ–Budak et al., 2015). Campbell-Jackson et al. (2014) highlight how such pressure could lead to high stress levels, which could have an adverse effect and reduce the quality of subsequent parenting. These anxieties appeared to reduce overtime (Campbell-Jackson et al., 2014).

Greater appreciation of parenting

'I would never be the same person that I was; it changed me; it taught me a lot. I live my life differently because of all those children who are not here' (Côté-Arsenault & Morrison-Beedy, 2001). The previous loss shattered couples' assumptions about the world however through this difficult experience many reflected how this positively changed the value they attributed to their parenting role; it had a greater sense of priority in their lives (Campbell-Jackson et al., 2014; Côté-Arsenault & Morrison-Beedy, 2001; Phipps, 1986; Sun et al., 2011; Üstündağ–Budak et al., 2015). Authors noted this appeared to have a positive impact on parenting styles (Campbell-Jackson et al., 2014; Phipps, 1986). Fathers described changing their working hours to spend more time with their children (Campbell-Jackson et al., 2014). Most parents differentiated themselves from 'normal' parents who had not experienced a loss, in that despite parenthood being more difficult than anticipated, they did not complain about sleepless nights and embraced this as part of the experience. They felt 'normal' parents did not understand them and therefore could not relate to them or their experiences (Campbell-Jackson et al., 2014; Phipps, 1986).

Many couples expressed excitement, as this was their first living child and an opportunity for them to fulfil hopes and dreams of parenthood (Campbell-Jackson et al., 2014). At times this activated grief for the lost child (e.g. first bath), as parents were aware of what they missed first time around. Others felt parenting allowed them to heal some of the wounds from their previous loss. Many parents reported becoming more relaxed in their parenting style as the child became more interactive (Côté-Arsenault & Morrison-Beedy, 2001; Sun et al., 2011; Üstündağ–Budak et al., 2015). Some described being more relaxed in their discipline, as they were ’thankful’ to have the child (Côté-Arsenault & Morrison-Beedy, 2001).

Discussion

This meta-ethnography was the first to synthesise qualitative research literature to enhance our understanding of the experience of subsequent pregnancy and parenting following miscarriage, stillbirth and/or neonatal death. Key findings highlight a number of complex internal and external psychological processes and experiences, contextually shaped by the lasting impact of a previous loss. Couples had lost their sense of ‘innocence’ attached to pregnancy and were left facing a lasting and changed reality that loss before life was always possible. Preoccupation with this appeared to intensify and manifest as anxiety in subsequent pregnancies, from conception through to the parenting experience. Professional support was considered important and beneficial for most in providing reassurance, although support received was more practical with couples describing limited emotional and psychological support.

The synthesis provides support to contemporary grief models/ theories that specify certain features of pregnancy loss (the unexpected nature, isolation, self-blame and loss of dreams of parenthood) heighten psychological distress and adaptation for couples over time (Stroebe & Schut, 1999; Worden, 2008). Whilst such models identify the need for a continued and distinct bond with the deceased child as part of healthy adaptation to loss in *general* (Klass, 2006), they do not specifically detail the psychological impact this has in adapting/coping to a *subsequent pregnancy*. The synthesis adds to this knowledge by highlighting emotional and behavioural responses of couples in a subsequent pregnancy to manage rekindled grief for the lost child, but also to self-protect from the possibility of further emotional pain through another loss. The implications of these findings are discussed below.

Interpretation and Clinical Recommendations

Starting with the conception period, the synthesis highlights a need for greater psychological and emotional support for women. The entirety of related literature was not represented, as the term ‘conception’ was not included in the main search. Despite this in the many papers reviewed where it was mentioned, many described negative body and gender image following loss and limited professional support. Emotional support may be most beneficial when actively trying to conceive as women perceived negative pregnancy tests as a sign their bodies were incapable of fulfilling a ‘female reproductive’ role. Those psychologically and physically more prepared to conceive following loss coped better in subsequent pregnancy, however the key helpful factors remain unclear in the literature, limiting development of appropriate interventions (DeBackere et al., 2008; Geller et al., 2004). Older reviews have emphasised the need to understand support needs during this period (Lamb, 2002).

A key theme to emerge concerned changes in the understanding and psychological experience of pregnancy, following loss. Pregnancy was perceived as an objective ‘task to endure’ resulting in delayed physical and emotional attachment behaviours considered by many authors to be adaptive self-protective approaches to cope with fear of further loss. Similar findings have been reported previously (DeBackere et al., 2008; Geller et al., 2004; Lamb, 2002; Mills et al., 2014). Such behaviours fall contrary to societal expectations of behaviours in pregnancy and cannot be accounted for by normal developmental models of pregnancy, which focus on the development of maternal/paternal emotional bonds before birth (Condon & Corkindale, 1997; Rubin, 1975). It is important for professionals to be aware of these to aid accurate interpretation of delayed attachment as a potential risk.

Couples reported experiencing similar anxieties in subsequent pregnancy. However, the findings highlight gender differences in coping styles and ways of expressing concerns, evident across cultures. Such differences in coping have only recently been highlighted (Mills et al., 2014). Men reported minimising distress to support their partners and favouring cognitive strategies such as self-talk whilst being less willing to talk to others about their emotions (Campbell-Jackson et al., 2014; O’Leary & Thorwick, 2006; Phipps 1986; Sun et al., 2011). Men still need emotional support as some accessed this through family. Professionals can be encouraged to routinely ask men about their wellbeing or provide information about support services.

Distancing and coping behaviours in pregnancy did not appear to impact on parenting. There was however limited exploration of initial bonding experiences and most studies focused on parenting explored experiences of the first few days/weeks after birth, rather than longer-term outcomes. Mother-infant bonding following loss has received less attention compared to the emotional impact of loss. The studies published report positive relationships, with no difference in mother-infant bonding in women who have experienced loss compared to controls (Kinsey, Baptiste-Roberts, Zhu, & Kjerulff, 2014). Findings reported do not extend beyond one year; longer-term follow-ups of bonding and parenting experiences are needed to understand if and what type of support may be helpful.

Following stillbirth many women expressed fears of giving birth and requested caesarean sections: Often in such cases women do not understand the associated risks (Gardner, 2003). In some UK services counselling and guidance is offered to support couples to feel more in control and positive about the next birth, through clinics exploring the costs and benefits of different delivery options (National Maternity Review, 2016). Couples may benefit from accessibility or awareness of such resources.

Guilt in leaving the lost child behind was a prominent theme for mothers across pregnancy and parenting, and where present placed greater pressure on parenting. The longer-term impact of this on mothers and children is unclear, however some parents reported being more lenient in their discipline with subsequent children. It was unclear whether this was linked to guilt although this association requires further exploration (Côté-Arsenault & Morrison-Beedy, 2001). It may be beneficial to develop interventions in early pregnancy to reduce guilt; compassion focused interventions have been found effective in reducing shame and guilt (Cree, 2015)

Another important emerging theme for most couples was the need for professionals and/or their social networks to validate the personhood of the lost child. It was important others recognised and differentiated the live and deceased child as unique individuals; couples found their own ways to maintain bonds with both. When friends and family saw subsequent children as a replacement during pregnancy or after birth, this created discord between couples and their networks. These findings suggest the notion of 'replacement child syndrome' where parents conceive to replace the lost child is outdated and may reflect findings of older studies (Mills et al., 2014). Furthermore, the need to maintain a connection with the deceased has been recognised by more recent bereavement models as an adaptive psychological response to loss (Klass, 2006), and not a sign of unresolved grief (Bowlby, 1980). Professionals may benefit from understanding this.

Recent studies in the synthesis shed light on self-growth following loss; couples' attitude/philosophy to life changed leading to a greater appreciation of their parenting roles

(Lee et al., 2013; Üstündağ–Budak et al., 2015). Also referred to as 'posttraumatic growth' this concept is relatively new to the area (Lee et al., 2013), which may reflect why it has not been discussed in previous reviews. Contemporary grief models such as the Dual Processing Model (DPM; Stroebe & Schut, 1999) acknowledge that loss leads to a changed reality for individuals, through which many acquire personal growth. In areas such as cancer, social support has been shown to be positively associated with posttraumatic growth and subjective wellbeing, which has implications for developing interventions (McDonough, Sabiston & Wrosch, 2014). More research to explore these associations within perinatal loss is needed.

The findings also emphasised important cross-cultural differences in practices and norms in response to loss, as well as individual differences within cultures which may act as a barrier to access professional or family support in subsequent pregnancy (Sun et al., 2011). Such findings echo the need to further develop our understanding of diversity in family structure/social class/ethnicity/cultures and the impact this has on internal and external factors influencing grief responses, access to, and type of support needed. This knowledge may help inform practice and promote more sensitive communication and therapeutic styles with parents.

Support currently provided commonly takes the form of extra scans, or emotional and psychological support through support groups and more recently nurse led home interventions. Interventions offering emotional support have been shown to be effective for women who report feeling understood and their fears normalised, leading to improved self-confidence and reduced anxiety (Côté-Arsenault & Freije, 2004; Côté-Arsenault, Schwartz, Krowchuk & McCoy, 2014). The review highlights these factors as facilitators of good care. Currently most interventions are provided by doctors, nurses and midwives. Psychologists also have an important contribution to make and are key members of UK perinatal teams. Many already provide training and support to medical teams to improve their understanding, communication style and care to families subsequent to loss, as well as providing individualised support to families (British Psychological Society, 2016). Examples of good practice need to be published, particularly within the psychological literature indicating how best to support families and teams, particularly given increased government investment in their services.

Clinical recommendations are summarised in Table 1.4.

Table 1.4

A summary of clinical recommendations from the meta-ethnography

Recommendations
1. To develop a raised awareness amongst all professionals not just doctors, nurses and midwives of the needs of families in subsequent pregnancy and parenting and that support may need to be provided as early as the conception period.
2. Better guidelines for professionals on how best to support families during these periods, acknowledging individual differences. Including details of cultural practices and norms that may be useful to consider in communication. Men may be less forthcoming in accessing support.
3. Professionals to be made aware of the importance of knowing obstetric history before appointments and to acknowledge the first loss.
4. Professionals need to be aware of anxieties expressed by couples and strategies used to seek control such as delayed attachment so they are not inappropriately raised as red flags. Where possible to provide reassurances and emotional support. If not possible families need to be signposted to appropriate services.
5. Professionals need to encourage families to access support from family where possible as this has been shown to be important in improving psychological wellbeing.
6. It may be helpful for professionals to put couples into contact with others who have been through a similar experiences; this may help in providing hope in pregnancy and parenting. If possible services need to facilitate or provide a space for support groups; this may help to keep alive a continuing yet separate bond from the living child through sharing experiences.
7. Couples may benefit from additional home visits after birth, to normalise anxieties/concerns and offer interventions to support bonding and/or other areas of parenting if appropriate.
8. Professionals need to have a clear understanding of pathways for support and have information readily available for patients. Many charitable organisations have information for professionals that can be distributed by team leaders.

Strengths Weaknesses and Directions for Future Research

It is important to consider conclusions/recommendations drawn from the meta-ethnography in light of the strengths and weaknesses. A strength of the synthesis was it contained rich qualitative data providing detailed understandings of the meaning couples ascribed to their experiences. Furthermore, it provided some insights beyond Western cultures as one study included a Taiwanese sample, despite highlighting the need for more cross-cultural research. Areas that remain unaddressed were also illuminated providing direction for future research. Most studies represented heterosexual couples either married or in relationships. There is limited understanding of the impact of loss on subsequent pregnancy and/or parenting in single parents or same sex couples. Furthermore, the generalisability of the findings may be limited by underrepresentation of black and minority ethnic groups and low socio-economic status across studies. This has important implications as a recent UK report highlighted individuals in either or both groups are at greater risk (up to 50%) of perinatal mortality (MBRACCE-UK, 2015).

The search strategy was limited to papers written in English, which may have excluded important insights, particularly cross-culturally. The search was broadened to capture experiences of not just couples but also extended family. Sibling and grandparent experiences of pregnancy loss and infant loss in the family have been reported; associated intergenerational interventions have been developed and found effective (Roose & Blanford, 2011). Such studies are limited to describing the experience of the actual loss. No studies were found addressing the topic under review; in exploring the *extended impact* of loss on wider family experiences *of subsequent pregnancy or parenting.*

Studies exploring parenting were also limited to reflecting on relationships with subsequent live-born children, despite some having living children prior to loss. There remains little understanding of the impact of loss on parenting styles towards prior children and whether support is needed. Future research could explore this from parent and sibling perspectives. This appears important as sibling grief has been described as significant as losing a parent (Kempson & Murdock, 2010), and greater social support during and after pregnancy following loss has been associated with greater psychological wellbeing in mothers (Rajan & Oakley, 1993). Such knowledge may help develop intergenerational interventions that may open up communication and support within families.

Professional experiences of providing support and evaluations of existing interventions in subsequent pregnancy and parenting were not included, although an initial scoping exercise showed little published research in both. More research is needed as this may raise important understandings of potential facilitators and barriers from a different perspective, when developing and delivering interventions.

The CASP framework showed reflexivity was poorly addressed by most studies; essential components and how interpretations were derived were not clearly detailed threatening the validity of the findings. However confidence in the interpretation, conclusions and recommendations drawn are strengthened by convergence with the literature and previous reviews (Atkins et al., 2008).

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Chapter Two – Empirical Research Paper: Family members' lived experience of bereavement following the loss of a close relative to heroin overdose

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Abstract

Introduction: According to bereavement theory unexpected, untimely and traumatic circumstances of some deaths (including drug deaths) impact significantly on the process of grief. However, there is limited understanding of how such models apply to those bereaved by heroin overdose. The present study aimed to address this gap by exploring grief processes overtime, from the participants' view.

Methods: Semi-structured interviews conducted with a purposively selected sample of seven family members (six parents, one aunt) bereaved following the loss of a close relative to heroin overdose. Interviews were transcribed and analysed using Interpretative Phenomenological Analysis (IPA).

Results: The richness and complexity of family members' experiences were captured using an earthquake metaphor, which arose through shared language and imagery evoked through interview transcripts. Three superordinate themes, further divided into themes and subthemes were identified. Superordinate themes included: (i) 'the earthquake hits' detailing the immediate psychological and emotional impact of news of the loss leading to participants' worlds falling apart; (ii) 'standing in the rubble' representing early stages of grief characterised by sense-making of how the earthquake came to be; (iii) 'building a new foundation' detailing strategies used to cope and move forward in a new world without the deceased relative. Maintaining some connection to the deceased was important throughout the bereavement journey. This was achieved through storytelling, reflecting on memories, looking at photographs or possessions.

Conclusions: Findings provide support to the applicability of contemporary bereavement models, but also highlight challenges unique to those bereaved by drug overdose not previously described. Suggestions for clinicians providing support are made.

Keywords: Heroin overdose, drugs, families, death, bereavement, adjustment to loss, Interpretative Phenomenological Approach (IPA), qualitative

Introduction

The United Nations Office on Drugs and Crime (UNODC) estimated 187,100 individuals lost their lives worldwide through drug related deaths in 2013. Overdose was the most commonly cited cause, with mainly opioids implicated in such deaths (UNODC, 2015). The Office for National Statistics (ONS, 2015) recently highlighted increases of almost two thirds in opiate related fatalities in England and Wales from 2012 (579) to 2014 (925); the latter being the highest rate in 33 years. The number affected by such deaths remains unknown (Templeton et al., 2016a).

The adverse on-going impact and stress of having a living close relative with an addiction problem on the physical and psychological wellbeing of the family members, has been documented and globally estimated as large and significant (Copello, Templeton & Powell, 2010; Orford, Velleman, Natera, Templeton & Copello, 2013). Despite this, there is a dearth of knowledge of the psychological impact of bereavement on family members following drug overdose of a close relative, and the associated challenges and/or adaptation processes faced. This has only recently gained attention within addiction bereavement research (Valentine, Bauld & Walter, 2016).

Bereavement theory/models and research focusing on psychological responses and adaptation following loss, emphasise some deaths are more emotionally and mentally challenging to grieve due to circumstances associated with the death. Key features of such losses include falling outside of normal societal parameters in that they are unexpected, ‘untimely,’ and associated with high levels of trauma where circumstances of the death are viewed as self-inflicted and avoidable (e.g. suicide or substance related deaths). As a consequence high levels of social stigma are directed at the user or bereaved, leaving family members feeling unworthy of their loss and in receipt of little public acknowledgment of their grief (Guy, 2004; Valentine et al., 2016). Guy and Holloway (2007) have labelled such deaths as ‘special deaths,’ in that they threaten the ‘ontological security’ of those close to the user. Furthermore, Neimeyer, Burke, Mackay and van Dyke Stringer (2009) report those affected are at greater risk of psychological difficulties.

A lack of social support following a ‘special death’ has been found to heighten grief (Guy, 2004) leading researchers to draw parallels between families bereaved by suicide and drug related deaths. In a large cross sectional survey Feigelman, Jordon and Gormon (2011) reported parents bereaved by suicide and drug overdose experienced similar psychological difficulties including depression, complicated grief, stigma, less social support from immediate family and blaming comments (directed at family members or user), that were greater than those bereaved by natural or accidental deaths. Since then research has suggested the stigma experienced following drug related deaths may be greater, through negative cultural scripts often portrayed by media associating drug use with illegal activity and immoral lifestyles (Templeton et al, 2016a; Valentine et al., 2016).

Studies focusing specifically on the impact of death through drugs are limited. Only four studies (two based on the same participant sample) all using qualitative enquiry, have been published and focused on exploring the impact and experiences of bereavement in those close to the substance misuser. The two earlier studies focus solely on relatives (grandparent, parents and sibling) experiences: a British study of four family members bereaved by heroin and ecstasy (Guy, 2004) and a Brazilian study of six family members bereaved through drug overdose (mainly cocaine; DaSilva, Noto and Formigoni, 2007). Commonalities in core experiences of bereaved relatives were identified across both studies including reports of high levels of shock, depression, shame and stigmatisation from family and friends, spoiling the identity of the deceased and leaving many to feel it was ‘wrong’ to grieve. The emotional impact of the death appeared to be more extensive in parents, who described feeling guilty, helpless and losing confidence in their ability to parent other living children. Furthermore, DaSilva et al. (2007) reported family members’ psychological responses to grief can be compounded by whether they were aware of drug use prior to the death. Relatives unaware expressed greater anger and guilt they could have prevented the death, whereas those aware felt prepared for the death through previous overdoses and spoke of ‘relief from the suffering’ when the user was alive. The findings, in line with bereavement literature, highlight the unique and heightened psychological challenges faced by those affected by drug deaths, and their ability to complicate grief.

Similar findings have been reported in two more recent studies from a UK national project capturing broader experiences of a larger sample (n=106) of relatives, friends, siblings and partners bereaved through substance use. The first explored experiences and needs of those bereaved through alcohol and/or drugs suggesting key differences according to the substance implicated (Templeton et al., 2016a). Whilst all interviews were analysed together the authors discuss how the needs of those bereaved through drugs may be more challenging given the sudden nature of the death, leaving those close to the user unprepared in comparison to alcohol related deaths which are likely to be more prolonged. The authors report higher levels of stigma through greater media attention and/or involvement with officials in drug related deaths, may create greater social censure and therefore access and support needs may be different. This was the first study to explore *experiences of support* by others including professionals in the early periods following loss. Positive experiences included compassion, non-judgmental and personalised approaches by staff at funeral parlours, inquests and those breaking news of the death. Conversely negative experiences included isolation, and where access to counselling/support was available long waits and professionals with limited understanding of the bereavement type and associated challenges to the individual.

The second study reports on a subset of results from the original sample (n=32) exploring the unique challenges of those bereaved through drug overdose (Templeton et al., 2016b). The authors emphasise the experiences of those bereaved following drug overdose are qualitatively different to other drugs in that those affected are more likely to be exposed to the death, the events/circumstances of which are not always clear and involve a range of legal and official procedures which significantly intensify grief processes. Similar to previous findings those bereaved echoed feelings of guilt, experiences of stigma and shame in openly expressing their grief, but felt they needed greater support through official processes (Guy, 2004; DaSilva et al., 2007). Insights generated were used to consider overdose prevention initiatives to reduce such deaths. Collectively the findings from both studies have informed generic guidelines developed for practitioners in various settings (police, paramedics, funeral directors, bereavement counsellors), to support those bereaved by alcohol or drug related deaths. The guidelines focus on compassion, simplified language and unified working to help support the bereaved. Whilst helpful in opening and providing supportive communication to those affected and highlighting the challenges faced, there remains limited knowledge of how individuals themselves cope and adjust to such losses.

Given the complexity and diversity of experiences of loss across substances, it is surprising no studies to date have focused on developing a more in-depth understanding of grief processes following a ‘special death’ beyond the immediate psychological impact of loss. There is little to no understanding of grief processes over time; whether or how these change and the strategies/resources used to adapt and move forward. This limits our understanding of the applicability of bereavement models to substance bereaved families (Valentine et al., 2016). Such knowledge is important in developing effective interventions and improving clinicians’ practice in identifying and fulfilling specific care needs. Furthermore, given the rise in heroin related deaths, such research appears timely.

The current study aimed to address this gap in our knowledge to develop an in-depth understanding and exploration of the lived experience of family members bereaved following heroin overdose. An Interpretative Phenomenological Approach (IPA) was chosen as it is committed to capturing the lived experience and personal meaning ascribed to a particular phenomenon (Smith, Flowers & Larkin, 2009)**.**

The specific aims of the study were to develop an in depth understanding of:

- The immediate psychological impact and meaning attributed to the lived experience of loss and whether this was influenced by the circumstances of the death
- Whether the psychological impact and meaning changed over time and if so how
- Strategies/resources used and found to be helpful/unhelpful in adapting to the loss over time

Method

Design

A qualitative semi-structured interview study conducted with a purposively selected sample of seven participants bereaved following the loss of a close relative to heroin overdose. Given the sensitive nature of the topic, ethical guidelines for bereavement research (Parkes, 1995), findings and recommendations from researchers and participants in the literature (Dyregrov, 2004) were considered carefully and incorporated into the design (see Appendix Five for details).

Sample size

The study aimed to recruit 5-8 participants, which is considered appropriate for doctorate research (Smith et al., 2009).

Materials

Interview Schedule

A semi-structured interview schedule was developed by the researcher which flexibly guided interviews, and facilitated open dialogue (see Appendix Six). The schedule was developed by initially reviewing the relevant addiction and bereavement literature to identify important subtopics. Guidance was then sought through IPA literature (Smith et al., 2009) and meetings with supervisors (AC and ML). The final interview schedule consisted of nine open-ended questions covering four subtopics: (i) Reflections of relationship with deceased relative; (ii) Circumstances and reaction to the death; (iii) Aftermath of the death (responses of social network, changes in relationships, coping strategies, support); and (iv) The impact and meaning attributed to the death (then vs now). Prompts and probes to elicit examples or clarify meaning were included under each question.

Demographic Information sheet

Information regarding participants' age, gender, ethnicity, occupation, relationship with the deceased, number of years since loss and drug implicated in the death were directly obtained at the end of interviews (Appendix Seven). Furthermore, if the information did not emerge during interview, participants were asked to provide brief demographic information of the deceased relative at the time of their death; age, gender, ethnicity and occupation (Appendix Eight).

Participants

Seven participants were recruited. Five through two charities providing support to families affected by substance misuse, and two participants (a couple Daniel*[2] and Sandra*) through known contacts of the principal supervisor (AC). Principal criteria for inclusion were that participants were aged over eighteen and had experienced the death of a relative to illicit substance misuse. Family members who had lost a relative in the previous six months were ineligible on the assumption the death occurred too recently (Dyregrov; 2004), and it could be emotionally too difficult to explore at length the loss.

Demographic details of participants are summarised in Table 2.1. The sample consists of four mothers, two fathers and one aunt. The aunt described her relationship with her nephew as maternal, reflecting a mother-son relationship. The majority of deceased relatives were White male (6), aged between 16-29 (7) and employed (4) when they died. Time since loss ranged between 1-17 years.

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[2] Participant names have been replaced by pseudonyms to maintain anonymity

Table 2.1

Demographic Information of Participants and of the Deceased Relative

Participant Number and Pseudonym		**Age (years)**	**Gender**	**Ethnicity**	**Occupation**	**Relationship with the deceased**	**Time elapsed since loss (years)**	***Deceased Family Member***					
								Deceased relative Pseudonym	**Age (years)**	**Gender**	**Ethnicity**	**Occupation**	**Substance implicated in death**
1	Daniel*	71	Male	White British	Retired	Father	2	Ethan*	29	Male	White British	Unemployed	Heroin
2	Sandra*	69	Female	White British	Retired	Mother	2	Ethan*	29	Male	White British	Unemployed	Heroin
3	John*	62	Male	White British	Employed	Father	1	Dylan*	23	Male	White British	Employed	Heroin
4	Patricia*	59	Female	White British	Student	Mother	8	Andrew*	21	Male	White British	Employed (voluntary)	Heroin
5	Seren*	41	Female	White British	Employed	Aunt	4	Luke*	23	Male	White British	Employed	Heroin
6	Linda*	57	Female	White British	Employed	Mother	14	Matthew*	18	Male	White British	Employed	Heroin
7	Becky*	59	Female	White British	Employed	Mother	17	Beth*	16	Female	White British	Unemployed	Heroin

Procedure

Three clinical and/or research psychologists independently reviewed the study protocol. Ethical approval for the study was granted by The University of Birmingham Ethics Committee (ERN_14-1232; approval email in Appendix Nine).

The author (GC) approached charitable organisations supporting families affected by substance misuse through telephone and/or email to request help in identifying eligible participants. Interested organisations were visited or sent an email explaining the nature of the study, recruitment procedures and provided information sheets to be distributed to potential participants. Principal supervisor (AC) also emailed information sheets to known eligible participants, based on contacts developed from experience in the field. Eligible participants were forwarded information sheets (see appendix Ten) by AC and organisations, detailing in simple terms the purpose, methodology, risks/benefits of participation and were encouraged to take a minimum of 24 hours to decide on participation. Those expressing an interest were invited to contact the researcher directly, or consent to have their details passed onto the researcher to make initial contact.

Subject to participants' preference, telephone contact was made providing the opportunity to discuss participation in detail. For participants wishing to continue a suitable time, date and preferred choice of interview venue were arranged. The interview schedule was posted/emailed so participants were aware of the topics to be covered and had the opportunity to identify areas they may find difficult to explore. The researcher met with participants in the preferred interview setting, which facilitated the opportunity to talk openly and comfortably. Participants were provided the opportunity to ask questions and if they wished to continue written consent was obtained (Appendix Eleven). The consent form reminded participants that participation was voluntary, they had the right to withdraw at any time, interviews would be audio-recorded, and data would be annonymised. Participants were reminded they could stop the interview at any time and they had the opportunity to have shorter interviews (up to three) to minimise potential distress, which could be decided once the interview had started.

Five interviews were conducted in participant homes and two in a room offered by an organisation supporting recruitment.

One individual interview was conducted with each participant. Interviews were audio-recorded with consent and guided by the semi-structured interview schedule. Interviews took place between July 2015 and February 2016 lasting between 59 to 135 minutes. At the end of interviews participants were asked to complete demographic information sheets for themselves and the deceased relative if this information had not emerged during the interview. They were thanked for their participation, offered the opportunity to debrief and provided information of support agencies (see Appendix Twelve).

All interviews were transcribed verbatim and identifiable information was removed or modified to maintain anonymity.

Analysis

The analyses were flexibly guided using procedures outlined by Smith et al. (2009). This method was followed for each transcript in turn. To retain IPA's idiographic commitment, the researcher did their best to acknowledge and set aside emerging ideas for each transcript (see section headed 'reflexivity') before moving onto another. Stages are described in Table 2.2.

Table 2.2

Stages of IPA analysis

Stage	**Description**
1.	The first stage involved reading and re-reading the transcript whilst listening to an audio recording of the interview, to encourage deeper familiarity and active engagement with the data (e.g. by establishing the tone).
2.	The next stage involved working through a printed copy of the transcript line by line, making note on the right hand margin of significant observations in the text; allaying key concerns, worries or claims, with a clear focus on the meaning of these to the participant (Larkin, Watts & Clifton, 2006).
3.	Initial coding was then condensed into phrases (emerging themes) that captured the essence of significant sections of the transcript; these were noted on the left hand margin.
4.	Using Excel, emerging themes, corresponding quotes and line/page numbers text locations, were listed chronologically (see Appendix Thirteen for example).
5.	A hard copy was printed and emerging themes were cut out and connections/patterns (similarities and differences) between these were explored, and related themes were

clustered together and given names to represent superordinate themes (see Appendix Fourteen).

6. Next using Excel, a table representing the development of each superordinate theme was created that included a list of corresponding emerging themes, direct quotations from the transcript detailing line/pages they could be found (see Appendix Fifteen).
7. The final stage involved laying out hard copies of the tables generated for each participant in the previous stage and looking for patterns across these. This involved a process of selecting, restructuring and shedding themes to generate a master table in Excel of superordinate themes representing data from all participants, listing corresponding emerging themes, quotes, line and page numbers for each participant (see Appendix Sixteen). A narrative of family members' experiences was then developed.

Reflexivity

IPA is often described as involving a 'double hermeneutic;' the researcher offers an interpretation of how a participant experiences and constructs meaning, in relation to a particular phenomenon. This second order interpretation is inherently influenced by the researcher's own preconceptions, interests and experiences and it is important to acknowledge and be aware of these during the research (Smith et al., 2009; Willig, 2008). At the time of the study the researcher (GC) was a 28-year-old female with experience of working with drug users and families affected by substance use, through local and national projects exploring provision of support and treatment. She was also a third year trainee clinical psychologist with experience of delivering bereavement support, and being a recipient through personal therapy.

Several steps were taken by GC to limit the potential influence of prior conceptions on the research process. These included keeping a reflective diary noting important opinions, reflections and observations throughout (e.g. important themes, processes), that were used to aid interpretation, reduce bias and therefore enhance transparency in the analysis (Malterud, 2001; Ortlipp, 2008). The researcher attempted to stay close to the data as possible throughout the analysis; using transcript excerpts when developing themes. Furthermore, where possible 'in vivo' (direct quotes from participants) codes and/or theme labels were used to remain grounded in participants' descriptions. Regular and close supervision took place throughout the research process, which allowed careful examination of the researcher’s interpretations. Data interpretations were also discussed with a postgraduate peer support IPA group; collectively these helped to reduce bias, offer a more balanced (ensuring all aspects of data were equally represented) and credible interpretation of the findings.

Results

Three superordinate themes emerged from the analysis to embody participants' experiences; key features of these were underpinned by ten themes, one of which was further divided into three subthemes. Where possible, title labels reflected participants' words. The complexity and diversity of grief experiences appeared to converge on participants' descriptions of how the death had led to their world falling apart; the surface beneath them was no longer solid and the world would never be the same again. Shared representations and language across accounts created a sense that grief was experienced like a natural disaster: this led to the development of an earthquake analogy to capture the depth of experiences.

Once the earthquake hits, participants appeared to find themselves embedded in a new world that is unfamiliar, surreal, akin to a film or nightmare. The first superordinate theme reflects this, detailing the immediate psychological impact that the news and circumstances of the death has on participants and others. The second superordinate theme addresses the early stages of participants trying to make sense of their grief. There is a sense they are standing in the ruins of the earthquake feeling lost, trying to make sense of how the earthquake came to be. The final superordinate theme relates to how participants move forward in their new world; the strategies that helped them to redesign, adjust and build a new foundation in a life without the living presence of the deceased relative.

A common thread that appeared to pull through and to help participants throughout their bereavement journey, was remembering and maintaining a connection with their loved one as they lived/existed in the old world. Examples of this included sharing stories/memories about the deceased relative with others, looking at photographs and/or possessions. This was significant in helping relatives accept the loss but also keep the deceased relative alive in their new world. A diagrammatic representation of the structure is presented in Figure 2.1 and details of participants that contributed to theme development are summarised in Table 2.3.

Each superordinate theme, associated themes and/or subthemes using associated number labels in Table 2.3 for clarity, will be presented in turn with selected (for brevity) supportive illustrative verbatim quotes. All quotes will be presented in *italics* and square brackets with three dots […] situated in quotes indicate some text has been removed for brevity.

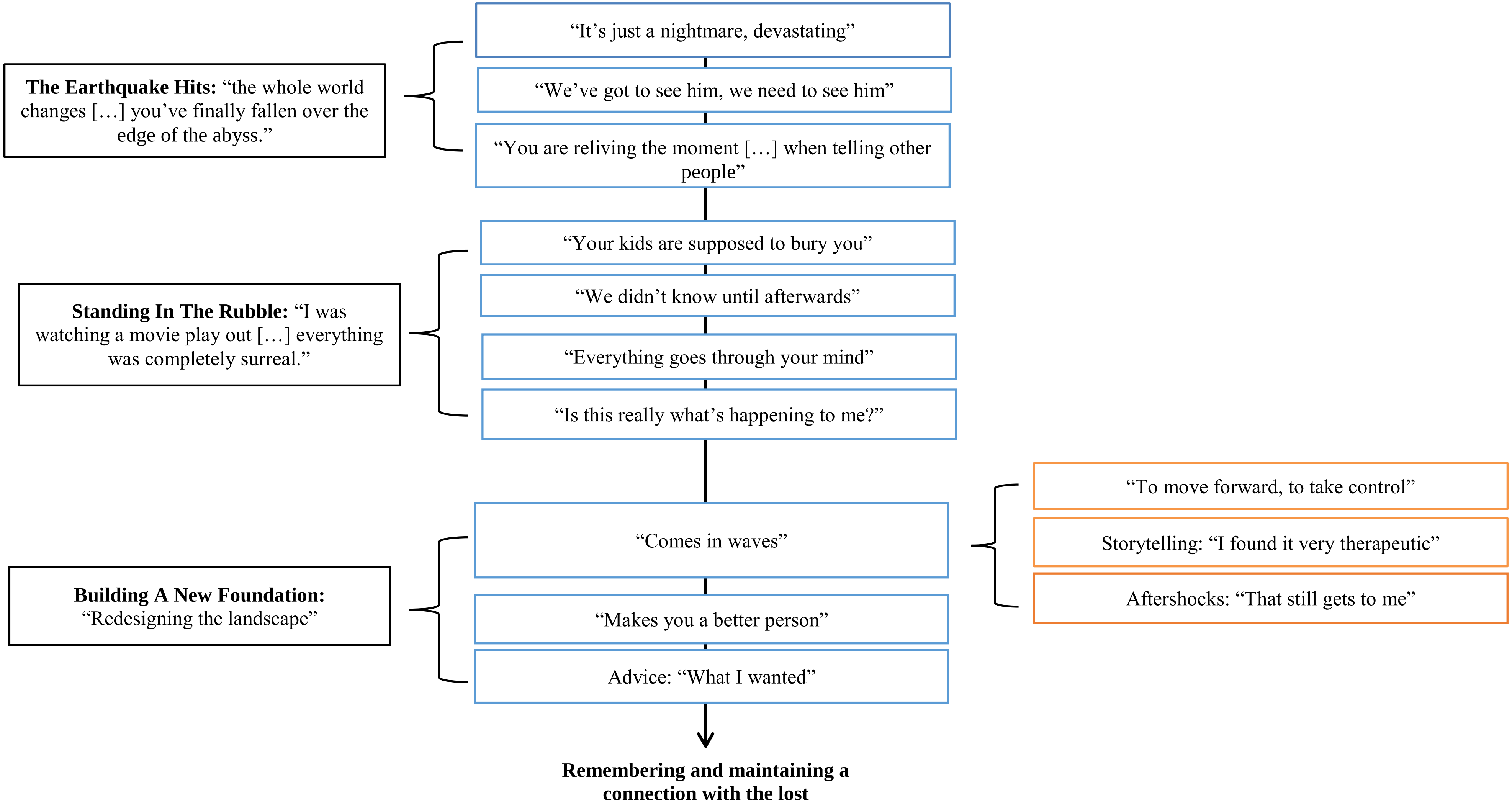

Figure 2.1. Diagrammatic summary of superordinate themes, associated themes and subthemes

Table 2.3

Details of participant's that contributed to each superordinate theme, associated theme and subthemes

	Daniel*	Sandra*	John*	Patricia*	Seren*	Linda*	Becky*
1. The Earthquake hits: *"the whole world changes […], you know. It's as if a shutter comes down, and then you've gone. It's as if you've finally fallen over the edge of the abyss."* (John*)	✓	✓	✓	✓	✓	✓	✓
1.1 *"It's just a nightmare, devastating"*	✓	✓	✓	✓	✓	✓	✓
1.2 *"We've got to see him, we need to see him"* (Sandra*)			✓	✓	✓	✓	
1.3*"You are reliving the moment […] when telling other people"* *(*John*)	✓	✓	✓	✓	✓	✓	✓
2. Standing in the rubble: sense of being lost) *"I was watching some movie play out […] everything was completely surreal"* (Becky*)	✓	✓	✓	✓	✓	✓	✓
2.1 Funeral: *"Your kids are supposed to bury you"* (John*)		✓	✓		✓	✓	✓
2.2 *"We didn't know until afterwards"* (Patricia*)	✓		✓	✓	✓	✓	✓
2.3 *"Everything goes through your mind"* (Daniel*)	✓	✓	✓	✓	✓	✓	✓
2.4 *"Is this really what's happening to me?"* (Becky*)	✓	✓	✓	✓	✓	✓	✓
3. Building a new foundation: *"Redesigning the landscape"* (John*)	✓	✓	✓	✓	✓	✓	✓
3.1 Waves of grief	✓	✓	✓	✓	✓	✓	✓
3.1.1 *"To move forward to take control"* (Patricia*)	✓	✓	✓	✓	✓	✓	✓
3.1.2 Storytelling*: "I found it very therapeutic"* (Linda*)	✓	✓	✓	✓	✓	✓	✓
3.1.3 Aftershocks: *"that still gets to me"* (Becky*)		✓	✓	✓	✓	✓	✓
3.2 Growth *"makes you a better person"* (John*)			✓	✓	✓	✓	
3.3 Helping others move forward "what I wanted" (Becky*)	✓	✓	✓	✓	✓	✓	✓

The Earthquake hits: *“the whole world changes* […]*, you know. It’s as if a shutter comes down, and then you’ve gone. It’s as if you’ve finally fallen over the edge of the abyss.”* (John*)

This superordinate theme captures the distress felt by participants when they became aware of their relative’s death. Participants provided detailed accounts evoking strong imagery of how everything around them collapsed; they had lost every tangible sense of being, and the world they once knew and felt secure in had gone and would never be the same again. In telling others, they felt they were reliving this moment over and over again.

1.1 “It’s just a nightmare, devastating”

This theme reflects the ‘shock,’ ‘devastation’ and despair experienced by all participants when made aware of their deceased relative’s ‘sudden, untimely death’ (Patricia*). A contextual summary of the circumstances surrounding each death including how participants came to learn about the loss is summarised in Table 2.4.

Table 2.4

Contextual summary of the circumstances surrounding the deceased relative’s death

Participant Pseudonym	**Contextual summary of circumstances surrounding the death**
Daniel*	Received a phone call from the police that their son had been found by a cleaner in a B&B. He had recently been released from a rehabilitation clinic and had lost his tolerance and overdosed on heroin. Daniel and his wife Sandra* were away on a break in the UK at the time.
Sandra*	Same as above: Sandra’s husband Daniel* broke the news of her son’s death to her in person.
John*	Received a call from his son’s best friend that his son had had a heart attack after injecting heroin, he was in hospital for two days and died of complications.
Patricia*	Received a call/email to let her know her son was missing, a few hours

	later was told he had been using heroin (she was unaware of this) and then received a phone call that he had been found in an apartment. An autopsy revealed it was a heroin overdose.
Seren*	Received a call from the drug team that her nephew had uncharacteristically not turned up to an appointment, went searching for him and found him in his bedsit. He had overdosed on heroin 3 days before being found.
Linda*	Received a call from her son’s boss to say he had not turned up for work, went to his bedsit and found his body and drug paraphernalia. He had overdosed a few days before and his body had started to decompose and he was black. She was unaware of his drug use.
Becky*	Had not heard from her daughter, woke up with a sense something was wrong. Went to where she was living and Becky’s* friend went inside, she came down to tell her she had called an ambulance. A police car, drug squad and funeral directors arrived at the same time which confirmed what Becky suspected, her daughter had died of a heroin overdose.

All participants described experiencing extreme psychological distress in the moment and days following news of the death. There was a strong sense this was particularly difficult for participants who had discovered the bodies themselves (Seren*and Linda*); in both cases the deceased relative had died a few days before being found and bodies were badly decomposed. Seren’s* excerpt illustrates the sheer horror of this experience; the emotional impact of which manifested as regular and vivid *“huge flashbacks”* in the proceeding days and months.

> *“We opened the door, and it wasn’t locked; anyone could’ve walked in. And, erm, we opened the door and he sat there… cross-legged like this. So, we opened the door and just got his back to you. And, erm… I went, ‘Luke*! Luke** [calling]!*’ and I grabbed him by his should, shoulder and I could tell straightway he was like stone. Looked down, his foot was black.” (Seren*)*

Independent of whether they found the body themselves, Patricia* and Linda* described how their immediate reaction was to consider the mental impact this had on other professionals: *"She* [police officer], *thought he was black because of the decomposure* […] *that must have been awful."* (Linda*).

Participants (Daniel*, John* & Patricia*) informed of the loss by professionals' generally cited positive experiences: most were recognised as being *"sympathetic."* In contrast, some experienced insensitivity through stigma and labelling; Becky* expressed her disappointment and anger towards a police officer who attended the scene and referred to her daughter's death as *"Oh it's just another junkie."*

Most participants described experiencing one or more foreshocks before the earthquake struck, which triggered fear and threatened their sense of security in a world with the deceased relative living in it. Such foreshocks took the form of previous overdoses (Daniel* and Sandra*) or missing episodes (Patricia*, Seren*, Linda* & Becky*), over years to days before news of the death. The level of anxiety evoked by such foreshocks differed across the sample and appeared highest in those participants where such episodes were infrequent and/or they had a sense that *"something's happened"* (Patricia*, Linda*). Daniel* and Sandra* shared previous overdose experiences had *"semi-prepared"* them for the loss:

> *"We were semi-prepared for it, because of what happened, whereas other people know kids that go out and overdose on ecstasy and alcohol or whatever. It could be a bolt from the blue, so we err we did have a few trial runs if you like* […] *through the drug overdoses and the opportunity to perhaps realise what the situation might be."* (Daniel*)

The devastation and intensified grief experiences in response to the loss did not appear to be lessened by these foreshocks, even in those who felt 'prepared'; a finding consistently found for all participants. However painful, certainty around such periods appeared important and emotionally easier than not knowing; Patricia* reflected she felt 'fortunate' her son was missing only 12 hours before being informed of his death.

1.2 "We've got to see him, we need to see him" (Sandra*)

This theme captures four participants' instinctive feeling in needing to be with the deceased immediately after news of the loss, irrespective of how far away their bodies were.

Patricia* identified this need as being part of her role as a parent, in continuing to care for her son who was living in Hong Kong at the time:

> *"We just felt, we've just got to go and be with him, you know. He can't be on his own. It was all very sudden, you know, if it was part of your continuing looking after your son, you can't just leave him out there on his own* […] *had to book a plane and [exhales] get out there as quick as we could,."* (Patricia*)

Four participants described seeing the deceased relative's body in the mortuary as surreal and *"bizarre."* Seeing the body appeared to be important in helping to process the fact their world had changed forever and the only remaining connection with the deceased relative as a being was their body, or as Seren* described *"just a shell."* This appeared to be a challenging process as many had had contact with the deceased days before:

> "*Only a couple of days previous I'd been speaking to her, and she was just lay on this table* [unbelievably]" (Becky*).

1.3 "You are reliving the moment **[…]** *when telling other people"* (Daniel*)

Central to all discussions were participants describing experiences of having to break the news to friends and family whilst they themselves were in a state of shock:

> *"Just bizarre thing to say, to say, 'Well, well, yeah, we did find him, but…' I guess my brain wasn't thinking straight. And she said, it was like, 'And* [slowly and loudly]?*' And, er, and I said, 'And he's gone, mam. He's dead. Luke's dead* [sadly].*' She, she started screaming, and my father was in the background screaming, and…"* (Seren*)

The personal impact of hearing others *"breaking"* or *"screaming"* appeared for most participants to create a strong sense of *"reliving"* the raw emotional pain of the moment they were informed of the death. Most were open to revealing the circumstances of the death to others emphasising that they *"refused to be ashamed"* (Seren*). This appeared easier for relatives who were open about the deceased family member's drug use with others when they were alive, although in contrast more challenging for relatives unaware of drug use until after the death. In the latter instances, ambivalence was expressed about not wanting to tell others until the autopsy results confirmed the cause of death: *"Let's wait until we know*" (Patricia*).

Participants emphasised the importance of the deceased relative being acknowledged independent of their drug use, when sharing the news of the death with others. Some expressed tones of anger and disappointment when recollecting perceived unsympathetic responses from others, where this was not the case. Sandra* described disappointment at her mother's response when sharing the news as it was potentially perceived to dismiss the value of her son's life:

> *"Well she sort of said well it was no life anyway, well er words to that sort of effect…..She just then went and made herself a sandwich" (Sandra*)*

In summary, the death of the deceased relative was a shock for all family members, including those that had experienced the prospect of death through previous overdoses. Participants appeared to be in a dreamlike state, living a nightmare that replayed every time they told others about their loss. Participants struggled to see the deceased's body, although this appeared to be central in processing their new reality.

2. Standing in the rubble: *"I was watching some movie play out* […] *everything was completely surreal"* (Becky*)

This superordinate theme describes participants' sense making in the immediate aftermath to the first few weeks after the death. Films were referenced by many as being the only tangible source of comparison to make sense of their experiences. Participants' voiced that only in motion pictures had they seen such devastation, pain and scenes related to what they had been, or were going through. The imagery evoked from participants' accounts suggests they felt lost. There was a sense they were now standing in a new world with the foundations of the old world crumbled at their feet. They were left trying to make sense of what led to the earthquake (death), seeking answers and reflecting on their old world to establish the trajectory of what had led them to that place.

2.1 *“Your kids are supposed to bury you”* (John*)

This theme reflects most participants’ descriptions of the funeral as an *“unnatural process.”* There appeared to be a strong belief in the notional idea that one dies before their children, making the reality of cremating/burying the deceased relative a difficult experience. Becky* and Sandra* described still being in a state of shock which protected them like a *“cocoon”* from experiencing the raw pain that was to follow. Funerals were largely experienced as a celebration of the life lived and connected in some meaningful way to the world the deceased relative lived in. Becky* described how her daughter’s wake was mistaken for a *“wedding.”* John* makes a striking reflection of his initial shock and then comfort at his son’s friends dancing on his grave:

> *“They all jumped up and down and danced on his grave* [unbelievably], *you know. And, initially, I remember seeing that, being shocked. And then I thought, ‘No, he’d love that.” (John*)*

John*s language in the above excerpt *“he’d love that”* suggests it was important to connect to his deceased son and that his views were important despite him physically not being present in this world. An extension of this connection were descriptions of the desire to bury/scatter ashes in places ‘loved’ or connected to the deceased relative in the world they lived in:

> *“Matthew’s ashes were scattered on a hillside just outside of* [Location], *er, which is one of the places that he loved to be” (Linda*)*

2.2 *“We didn’t know until afterwards”* (Patricia*)

This theme captured participants’ reflections on the personal impact of finding out information about events leading up to, or circumstances surrounding the death from either legal investigations (autopsy, inquest) or personally from others. Sometimes participants actively sought this information in their attempts to make sense of the death, and this appeared more complicated for those unaware of heroin use: *“We didn’t know anything about the heroin, and we had to start from square one really”* (Patricia*). Collectively these processes did not always provide definitive answers. For many participants this complicated their grief and prevented them from moving forward. Some participants attempted to put themselves in the shoes of the deceased, imagining how they were feeling at the time, hypothesising what led to the drug use or death: "*I think he was…* [pause]… *trying to block out what had happened to him at school" (Linda*).*

A striking account by one mother illustrates the dilemma of whether she was able to trust information provided *"out of the blue"* from the individual whose flat her son was found in, as he was a drug user:

> *"Turned out that he'd disappeared to the flat of a friend who had been in the drug place, but had relapsed.* [Tuts*] And… and then we don't really know, because we only know that person's word, and everybody said, 'We don't know how much we would trust his word."*
> (Patricia*)

A salient issue for another mother was how the press were free to attend the inquest and when they refused to speak to them *"they made up their own story anyway"* (Linda*). Other participants echoed similar discord with the press in their need to defend their relative as a person as opposed to them being labelled as an 'addict.'

2.3 ***"Everything goes through your mind"*** (John*)

A key theme emerging from all respondents' accounts was the death triggering recollections of situations and decisions by the deceased relative, participants themselves and/or professionals in the old world, who they felt were responsible or contributed to the trajectory of the death. Participants' narratives suggested this was almost experienced as emotional *"torment,"* evoking high levels of blame and guilt that in some cases led to families 'falling apart.' John* described this as the *"the worst place to be"* following the death, where one *"questions everything"* and Sandra* emphasised this was more frequent for her because she was blind *"so thing go around in your mind more."*

Participants appeared to experience an internal interrogation. Most expressed questioning their decisions and *"parenting style"* over the deceased's lifespan and reflecting on their changing relationships as a result of this, and whether they *"had let him down"*

(Patricia*) in some way. All described the last communication they had with the deceased and some expressed regret for being *"busy"* in their own lives and consequently not being in contact with the deceased relative days before they died. Tones of anger and confusion were initially expressed by many and centred on whether the deceased relative wanted to die. Months to years after the death this moved to an acceptance that these were questions they would *"never know"* answers to. This was evidently stronger for participants who were unaware of drug use:

> *"Did he mean to do it? Was somebody there to help him? These are some of the questions I, probably I'll never know the answer to."* (Linda*)

Few participants also expressed *"anger"* towards the deceased for putting them through the earthquake *"after everything I have done for you?"* (Becky*).

Resonating through all participants' narratives was a reflection on reasons for the deceased relative's drug use. Four respondents detailed how the deceased struggled with mental health difficulties and made sense of their drug use as a coping mechanism. A salient issue for participants was they questioned and expressed feeling let down by the system, which they felt counter-intuitively prioritised treating the addiction over the mental health problem:

> *"If you could cure the underlying mental health problem, the acute anxiety then you would have had a good chance at curing the drugs. Then what you would have to do is stabilize the drugs whether it was on methadone or morphine or whatever and work on the other one, and try and get some sort of resolution with that and then work on the drugs. Which actually seems to be the opposite to the way in which the whole system works. If you've got drugs you have to get rid of the addiction before you try and deal with the underlying mental health problem, which is absolutely crap [laughs] you know?" (Daniel*)*

One parent described feeling relieved as the day to day pressures of living with his son and his behavioural difficulties alongside caring for his wife with Multiple Sclerosis, were getting too much for him to cope with:

> *"And you know it had been difficult, particularly you know, living with him, his behaviour. He was driving and he should not have been driving,* […] *the fact Sandra is blind and got MS erm…I felt an awful lot of pressure, and I felt I was at a point where I could not go on much longer* [pause] *without something having to give* [Sigh]." (Daniel*)

Daniel's* references to *"pressure"* and *"something having to give"* suggests a sense of feeling stuck in his situation. Other relatives (Becky*, Linda*) described similar relief responses from siblings who felt the deceased relative contributed to unnecessary pressure on family dynamics.

2.4 "Is this really what's happening to me?" (Becky*)

This theme developed from participants' reflections on their initial *"battle"* with grief and how they *"survived"* through the difficulties of a new and less secure world. Many acknowledged this was the stage where their shock at the loss had dissipated and they were now beginning to live in the reality of their *"nightmare."* All provided rich descriptions of how they coped through the early days (first few months) of their grief and the challenges this placed on their own physical and psychological health. It appeared that the impact this had on participants and the strategies they used to overcome these were individual. Many discussed working through their grief in separate/different ways from spouses and/or other family members, which included heavy drinking, smoking and being in denial about the death. Table 2.5 summarises examples across family members. A common thread echoed through participants' descriptions of coping was the comfort found in activities/things which connected them to the deceased relative when they were alive. For example Patricia* looked forward to sleeping as she would *"dream about Andrew*"* and for Seren* smoking led to a sense of Luke* being *"around her."*

Table 2.5

Extracts of strategies which family members used to initially cope with the loss

Participant	Quote
John*	*I probably…well, obviously, mentally I was more delicate. I was, I was quieter, more, spent more time on my own*
Patricia*	*Oh, blow this, I'm going to get what I want rather than what I think I can afford.' And… you know, actually, I think, probably, I know it's doesn't really match what you might talk about bereavement, but probably… eating and enjoyment of eating, and food and a glass of wine, and so on, I felt, 'I'm hating life, but I'm enjoying my food.'*
Patricia*	*and I liked going to bed, because I used to hope and, you know, often would pray, I just wanted to dream about Andrew* and, you know, most of my dreams were nice dreams about Andrew**
Seren*	*I started smoking again, and I used to, erm… go out, have, have a cigarette, because when I, when I went out for a cigarette, I used to feel him close to me, and sometimes I could feel his arms, like his arms around me, or something; so it's, did that for about four months, smoked for about four months. …*
Linda*	*I had about six weeks of heavy drinking, and, and I'm a smoker as well. Erm… poor diet, erm…*
Becky*	*I did say to some people, 'Yeah, my daughter lives in Australia. She goes to university there. I don't see her very often.' But that was just to keep, yeah, again, and then I'd suddenly get a grip, and be like, 'Becky*, what are you doing [unbelievably]?* […] *I couldn't accept that she'd gone, so I needed to tell people that she was still alive, if that makes sense.*

One mother described feeling confused and almost suicidal as the foundations (beliefs) that she had held solidly in her old world and shaped her very sense of being, then collapsed and were being questioned; paralleling an existential crisis:

> *"I mean one of the big things for me was… well,…* [long pause]*… I had to make sense of the world again, in, in a context of my own faith, erm… and that was a very big thing for me.* […], *well, who am I now? What's my faith now? Do I believe in God anymore? If I don't believe in God, that's fairly major implications since Peter's a vicar* […]*I wanted, I did, I wanted to die. I did. I wanted to die, and yet I didn't really want to, you know, it's that con, that confusion."* (Patricia*)

Patricia's* deep questioning of her purpose and faith highlights her vulnerability and difficulty she experienced in renegotiating the meanings in her life, further complicated by the fact her husband was connected and remained grounded in the very foundations that for her had collapsed. The use of the phrase *"major implications"* suggests coping and re-evaluation occurred with others in mind. John* echoed similar difficult experiences:

> *"Death completely redesigns that landscape. You've now got, the path that you walk isn't the same anymore. There's a hill where it shouldn't be* […], *so, you've got to completely renegotiate your way through the day, through the week, through the year, you know. And, so, the impact of those things redesigns a lot of things inside you.* (John*)

Some relatives described having *"two faces"* one which allowed them to address and feel the *"awful"* pain of grief and another where they had to stay strong for others in their role as *"parent," "carer"* or both. Having dual roles either buffered participants from connecting to their pain, or heightened it leading to feelings that they *"could not cope."*

Findings for the second superordinate theme suggest that the unnatural process of losing a child creates an unsettled state in relatives, leaving them in a state of crisis. The initial stages of moving past this grief appeared to be consumed by piecing together information from others, or memories of the past to make sense of the death. For participants the psychological and emotional impact of this appeared to be complex and heightened by guilt and blame directed at the self and others.

3. Building a new foundation: *"Redesigning the landscape"* (John*)

In the context of participants' experiences of the earthquake and aftermath described previously, this superordinate theme represents discussions of how relatives adapted and moved forward in their new world. Participants shared the challenges they faced and the strategies they used in building new foundations. This journey was individual with each describing varying routes and time periods taken to feel more secure and familiar with their surroundings. However, fundamental to all family members during this period was the need to remain connected to the old world where the deceased relative existed through storytelling, talking to the deceased, looking at photographs or possessions belonging to those lost. This appeared to be important in helping them adapt and transition between the old and new world.

3.1 *"Comes in Waves"* (Linda*)

This theme relates to participants' discussions of strategies that helped them move forward in their battle with grief. Taking control is seen to be essential and involved developing an acceptance that the sadness of the loss will never entirely disappear. In moving forward it was important to keep connected to the deceased through photographs and sharing stories.

3.1.1 *"To move forward, to take control"* (John*)

This subtheme relates to all participants' reflections on strategies used and challenges faced when attempting to accept the loss and move forward. From participants' accounts there was a sense that grief was seen as something that in the early stages was overpowering, strong and almost all consuming. Accounts suggest they were only able to move past this stage by developing strategies to regain control over their lives. The power of grief is illustrated by John* who parallels his experience to his son's struggle with addiction:

> *"I think it's, it's a bit like... the addiction – you know, who's got control? Heroin had control. And Dylan* was trying to move over to here to where he had control. You know, I kind of feel that bereavement and grieving is like that; who has control? Grief has control. And are you going to let that control the rest of your life? How are you going to move from there to there? " (John*)*

Relatives cited a range of different ways they were able to *"take control"* and better cope with grief. Strategies for good coping described by some were rooted in support received from generic or bereavement counselling and for others through their faith (spiritualism and Christianity were commonly cited). More frequently participants described developing ideas or approaches through reading books or talking to others that had been through a similar experience; this appeared to instil *"hope"* particularly in the early stages that participants would *"get past this."* Examples are summarised in Table 2.6:

Table 2.6

Quotes from FMs describing ways they took control of grief

Participant	**Quote**
Sandra*	*I did have a bit of counseling; He did probably make me look at things differently, erm didn't handle death necessarily just sort of handled my way of handling things so that probably did help me.; It might be sort of in their mind and not in my mind* [laughs].
Patricia*	*some friends put another book into my hands. They said, 'You might find this helpful;' an unbelievably big help to me, and I read and reread that book several times; engaged in a different way, from a different perspective*
Linda*	*some years ago I went to a spiritualist, and she said… she told me that Matthew* was sorry, he didn't mean it to happen, erm, but don't blame yourself. ; yeah, peace…*

An important part of regaining control and moving forward involved acceptance of the *"grey:"*

> *"I can live with grey, not black and white, and that's where I've learnt to live, and, to a very large extent, I've stopped asking the 'why' questions, you know" (Patricia*)*

Others echoed Patricia's* experience in that they no longer searched for answers, but accepted they may never know *"why"* the deceased relative either chose to use drugs or the circumstances of the death. In contrast, Sandra* spoke about how she had blocked the addiction out of her mind in trying to cope with her grief. Daniel* took a different approach to his wife; he described how he actively worked towards changing national guidance to prevent rehabilitation facilities discharging patients without further support in place; which he felt was a major shortcoming and contributed to his son's death. He described how this was his *"release"* and important in keeping his son's *"legacy"* alive.

Participants also discussed challenges to regaining control, including limited self and professional knowledge at the time, of support services specific to addiction related bereavement. Few described reaching out to their doctors but felt dismissed by either being ignored or offered *"antidepressants."* For few there was a sense of shame or unworthiness in accessing support from generic support services due to circumstances of the death:

> *"I felt… too guilty and that they wouldn't… I thought that, I think I was afraid that people would think, 'Well, you're not really worth, worth this service, because we're for people who've had tragic losses, like a car accident or cancer or something,' not for, not, you know, I'm putting, making up words here, really, but not for worthless drug users."* (Patricia*)

3.1.2 Storytelling: *"I found it very therapeutic"* (Linda*)

All participants highlighted the value of sharing their own stories about the deceased relative and that this was an important part of the healing process. It was acknowledged by many as a thread that pulled the deceased from the old world into the new. In this way, participants reflected that they remained connected to what they lost, which appeared to be important in helping them move forward. For most, this involved a reflection of the deceased relative's life as a whole; remembering positive and difficult experiences across their lifespan. This was illustrated by Linda's* experience of specialised bereavement support:

> *"They came to visit us at home. Erm, Ian* [Linda's* son] *didn't want to get involved, but I found it very therapeutic, to come and talk about Matthew*, about what a little shit he could be, but he was my little shit, and, erm, but how loving he could be, erm… you know, when he was a child, but then how he grew up, and all. I talked about all the places I'd had, supported him" (Linda*)*

Linda*'s account suggests the flexibility and comfort in being able to tell these stories at *"home,"* was important. Her extract signifies that although storytelling was *"therapeutic"* for her this was not true for everyone as it was not something her son wanted *"to get involved in."*

Storytelling was experienced in all interviews; all participants shared photographs and stories of the deceased depicting interactions with them in the old world. It appeared important the interviewer had a sense of the person behind the label of an *"addict*." A rounded representation and almost *"celebration"* of the person they knew and lived amongst. John*'s excerpt demonstrates an example:

> *"His hands created that picture behind you. There he is, sitting up there, this beautiful handsome boy, that he made that picture there, you know. Erm, that belongs to him out there in the hall. The whole place is just scattered with things that he created. Erm… they, they have to be celebrated."* (John*)

Storytelling extended to discussing the value of sharing experiences with other family members facing a similar situation, as many expressed *"no one else"* could identify with their *"pain."* Participants spoke about how such interactions provided a useful learning resource to share strategies to move forward. Others were often considered to be *"inspiring"* and experiences were accessed through face to face contact, reading books or listening to radio programmes. John's extract exemplifies the 'power' in moving forward by learning from others:

> *"I read her book and I thought, 'Wow* [amazed]! *What a powerful person you are! You know, you're doing this all on your own, you've lost, not just your child, but a really deep friend, and you are taking control. You're* <u>*fighting*</u> *your way through this.' And, I said, if she could do it, why can't I?"* (John*)

The value of shared experience was clear as the majority of relatives described how they had been involved in or part of organisations supporting other families bereaved by addiction.

3.1.3 Aftershocks: *"That still gets to me"* (Becky*)

All participants described how, whilst they were able to move forward with their grief, there were still times when the raw *"pain"* and *"sadness"* of the loss and absence of the deceased relative struck them like aftershocks. All spoke of anniversaries of the death, birthdays and/or major holidays as particularly difficult periods evoking high levels of emotion, through which there was a strong need to feel connected to the deceased. Seren* emphasised how important this connection was for her, as differences in ways to commemorate her nephew's anniversary created family discord. She expressed difficulty accepting her sister's decisions as she felt they were not connected to her nephew and the life he lived:

> *"And you've had a number of rows over Luke's** *anniversary, the last two years' running. It's a really difficult time, because everybody wants to do that which my sister, Laura, wants to do; she calls the shots overall. And, erm, I find that quite difficult."* (Seren*)

Seren's* statement *'she calls the shots overall'* reflects her frustration at the lack of acknowledgment by others of her relationship with Luke,* who she described being more *"like a mother"* too. Seren* felt the label of mother *"trumps"* over auntie, and the associated lack of ownership this gave her with regards to important decisions about Luke* heightens during anniversaries when they are made more prominent. This lack of validation of her relationship with Luke* appeared to complicate her grief. Despite this, most participants described celebrating the deceased relative by gathering friends and family, engaging in activities or displaying objects connected to the deceased when they existed in the old world, as illustrated by John*:

> *"Anna* [Dylan's* sister] *did this wonderful memorial, arranged this wonderful memorial .... it's a place where the band* [Dylan's* band] *used to rehearse, erm......put up an exhibition of all his pictures. We played music for him. Some very good friends of ours, they just* [half-laugh]*, God bless them, provided all this food that came in, had all, the band played upstairs, people spoke, Anna sang, I played the banjo while she sang. It was a wonderful, wonderful evening* [enthusiastically]. *We celebrated him." (*John*)

In what appeared to be a natural curiosity, five participants described imagining what the deceased would be doing if they were still alive and living in their new world. There was a tone of sadness in relatives' accounts. One mother who lost her only daughter talked about her difficulty in seeing other mothers and daughters, as this triggered a curiosity in what their relationship would have been like if her daughter was still alive:

> *I still get sad and, you know, yeah, 'cos it's like, oh, I wonder what she'd be doing now* [curiously]? *She'd be 35 years old… I wonder if I'd be a granny or… I'm sure we'd be best friends"* (Becky*)

3.2 ***"Makes you a better person"*** (John*)

Four participants reflected how the challenges of the death had led to a re-evaluation of themselves, the world and how they relate to others; akin to viewing the world with a different set of lenses.

> *"All the things that were up here before, they don't look exactly the same anymore. God, that's really beautiful, but it wasn't before* […] *don't take so many things for granted anymore* […] *I think it's just made you realise the value… of things more, of life, of the way, how you interact with people."* (John*)

As illustrated by John's account, constant comparisons were made in participants' narratives with changes in the way in which the world was viewed 'before' and after the death. This appeared to lead to positive psychological changes in participants' sense of self and functioning in their new world, including a greater appreciation and involvement in charitable work.

3.3 ***Advice "What I wanted"*** (Becky*)

A prominent feature in all participants' discussions was a reflection on their own experiences and advice shared for individuals going through a similar situation, and/or for services providing support. The majority emphasised the importance that services or individuals offering support *"would have to know about addiction"* (Daniel*), more so than bereavement. Many felt a stigma around drug use remains and *"subjective opinions"* may emerge in those with a lack of knowledge/awareness where they *"say precisely the wrong thing"* (Daniel*) which has the potential to complicate grief even further.

Those participants either unaware of drug use or who had limited understanding of drugs prior to loss, highlighted how greater knowledge of addiction was an important component in them working through their grief. Linda described how a service she was put into contact with through the coroner's court, arranged meetings with addiction counsellors where she had the opportunity to sit, talk, ask questions and develop a better understanding of addiction, which was highly valued:

> *"*[Name of organisation] *orchestrated meetings with the, erm, counsellor, so I could understand about drugs, because, literally, I knew nothing"* (Linda*)

For others such as Patricia* access to support was not as readily available. Participants highlighted the need for better knowledge amongst professionals of services offering support and clearer pathways in connecting families to these. As in Linda's* case it was suggested this could be facilitated by increasing awareness of organisations offering support in services individuals come into contact with at the time, such as coroner's court, mortuary and funeral directors.

Becky* reflected on the value of learning from her own negative experiences in her attempts to access support, and how these shaped and contributed to the development of the services provided by a charity she established for families bereaved by addiction, following her daughter's death. As illustrated by the excerpt below it was important for Becky* to provide others with what she felt she never had, with particular attention to providing a comfortable and *"homely"* environment free of prejudice and shame.

> *"It was a scruffy, horrible, everything was torn, and it smelt, and it, and I just thought, 'Oh, I could not sit in a place like this [horrified],' you know, going through what I was going through, which is why, when I started* [Name], *I made the conscious decision that it was going to look like it does – homely – erm, because there's nothing to be ashamed of. Society is the way it is, unfortunately, today. You know, we see them from the poorest backgrounds to the richest backgrounds."* (Becky*)

An issue raised by some participants was the need for professionals involved in official processes associated with the death (funeral directors, police, coroner's court), to be more understaning and use *"simplified language"* to fully explain procedures as relatives *"need to know everything"* (Becky*). The most commonly cited difficulty was relatives being told they were not allowed to touch or embalm the body of the deceased relative because of concern around infection, although reasons for this were not explained.

A prominent feature across all participants' accounts that accessed counselling/talking therapy was the value they placed in being able to sit and talk openly about the deceased relative, reflecting on the person that lived and the bond they shared. They felt this should be widely available to others. Seren* highlighted the significance this had for her in validating her relationship with Luke*, which was not acknowledged by family and wider society due to the *"label"* of aunt as opposed to mother. The excerpt below highlights the importance of services acknowledging this:

> *"Chuck out the labels, don't think automatically that this person is only… you know, a nephew, only a, whatever, and take time to find out what that relationship… to, to both parties, and what was special about it, and, then, whatever support is provided, is provided on the basis of that relationship."* (Seren*)

John made a distinction between what he felt was helpful in the early and later stages of grief, moving from talking about the deceased relative in the early stages to *"constructive"* advice and suggestions to *"control"* the *"destructive sadness."* Others such as Daniel* emphasised that the process of grief is individual where one size does not fit all; despite his wife accessing support this was something he felt he did not need.

In summary, there was an overall shared consensus amongst participants that feeling emotionally connected to the deceased relative through storytelling, photographs or possessions, was pivotal in their transition from the old world into the new. Shared experiences provided a valuable resource in instilling hope and developing strategies to move forward. New foundations appeared to be built by participants redesigning themselves, accepting their pain and supporting others in their grief journeys.

Discussion

The present study set out to develop an in-depth understanding and exploration of the lived experience of family members bereaved following heroin overdose. It was the first to give voice beyond the initial impact of loss, to highlight the existential challenges faced by family members and the processes/strategies used to adapt to loss over time. The complexity and diversity of participants' experiences were captured and reported using an earthquake metaphor. Metaphors have been identified as a useful tool in capturing depth, intensity and emotion of painful experiences for readers, particularly those unlikely to be shared (Lakoff & Johnson, 1980; Shinebourne & Smith, 2010).

Experiences across individual participants' narratives illustrated the death of a close relative (mainly children), through heroin overdose constituted a major and devastating life event. The psychological impact was perceived to parallel an earthquake, shattering participants' sense of self-identity, reality and confidence in a familiar and secure world. Sense making appeared to be central when coping with initial grief; participants described being consumed by attempts to piece together information to give meaning to, and understand the trajectory of events leading to the death. This either protected against or exacerbated feelings of guilt and blame directed at the self, family and/or professionals, all felt to have failed the deceased in some way. Grief processes were complicated by stigma, isolation through poor awareness of support amongst participants and professionals, and differences in coping styles within families themselves. Commonalities were reported in strategies felt to help participants develop greater control, adapt and move forward with their grief, including acceptance of the loss, sharing experiences with counsellors or others affected by similar experiences. The findings are discussed below in the context of relevant psychological research literature and bereavement theories.

The applicability of contemporary psychological models to those bereaved by illicit drug deaths has not been previously evaluated using empirical findings, despite these approaches being widely used to develop generic and specialised bereavement interventions (Wright & Hogan, 2008). Parkes (1998) suggests certain bereavement types including losing a child put those affected at greater risk of mental health difficulties. The sample consisted of six parents and an aunt (who identified her relationship with her nephew more like mother-son); the findings could therefore be interpreted as extending this evaluation to parental bereavement experiences.

The findings support contemporary theories which posit grief responses and coping are intensified by social processes resulting from the circumstances surrounding the death that deem it ‘unspeakable’ (Lazare, 1979). Despite differences in the specific circumstances of the death and how participants were informed, all experienced extreme shock and intense levels of psychological and emotional grief. The impact was just as intense in participants aware of drug use and ‘semi prepared’ through foreshocks, to those who were unaware prior to death; mirroring existing drug bereavement literature (DaSilva et al, 2007; Guy, 2004; Templeton 2016b). Participants highlighted how they faced additional challenges in their experience of losing a child, due to the sudden, *traumatic* nature of the death, and associated negative societal connotations. This left many exposed to *stigma*, insensitive comments from family and professionals and *disenfranchised* in their grief. Such features (*italicized*) identify with what is also commonly referred to as ‘special deaths’ in the wider substance related bereavement literature (Guy & Holloway, 2007). However participants described additional processes in the immediate aftermath of the death that appeared to further impact their grief, which have not been identified within bereavement theory/models. These included greater involvement in official procedures such as inquests, not fully knowing the events/circumstances of the death and being unable to touch the deceased when seeing the body, reasons for which were not explained by professionals. Such findings parallel key features identified by Templeton et al. (2016b) as setting drug overdose deaths *apart* from other drug deaths as they evoke stronger feelings and wider societal exposure to shame and guilt.

Models acknowledge grief responses are distinctively more complicated in those who experience trauma, particularly intrusions associated with the death (Horowitz, 1986; Stroebe & Schut, 1999). The ‘difficult experience’ of finding a body and revealing a drug/alcohol related death of a relative/friend has been described previously (Templeton et al., 2016a). However, the present findings highlight in greater detail the potential this has for psychological impact on grief responses, providing support to the application of bereavement models to this population. One of the two participants who found the decomposed body of her deceased relative described experiencing flashbacks, which significantly heightened her distress. Similar symptoms have been reported in individuals who have witnessed suicide. The associated stress has been found to complicate grief by supressing activation of brain areas important in emotional regulation that facilitate normal grieving processes (Nakajima, Ito, Shirai &Konishi, 2012; Young et al., 2012). Participants also spoke about concern for professionals who found the body. The importance of debriefing police officers following traumatic experiences has been publicised (Karlsson & Christianson, 2003), however participants' appeared to have no knowledge or exposure to such support.

What was striking in participants' accounts was the 'surreal' experience of the death in ripping apart the core foundations (beliefs/assumptions) central to their identity, and ways of making sense of the world. Bereavement approaches conceive this as a natural response to loss, and core to the emotional pain experienced. Parkes (1988) labelled this as a loss of one's 'assumptive world,' Yalom (1980) as an existential crisis and constructivists as the loss of the coherent narrative that guide one's actions in the world (Neimeyer, 2004). The findings provide empirical evidence of their applicability to those bereaved following drug overdoses. In line with the models the findings suggest healthy bereavement processes involve adapting and making sense of these changes (Valentine et al., 2016). The results indicate this is not a dynamic and straightforward process as suggested by older grief stage based models, with participants often oscillating between crises, sense making and adaptation over asymmetrical time periods in comparison to other family members. The findings best complement Stroebe and Schut's (1999) Dual Processing Model (DPM), which recognises the individualistic nature of coping with bereavement.

The DPM postulates that individuals oscillate between the past (to emotionally process the loss, including the circumstances and relationship/bond lost using memories and photographs; 'loss orientation'), and the present (to adjust to life changes as a consequence of the death; 'restoration orientation;' Stroebe & Schut, 1999). Despite the findings mirroring these processes they also highlight idiosyncratic complexities in the cognitions and behavioural responses associated with both orientations, specific to those bereaved by heroin overdose. Whilst all participants experienced high levels of guilt and self-blame in 'loss orientation' those unaware of drug use prior to death expressed greater confusion and preoccupation with thoughts of whether the deceased wanted to die, whether they really knew the person, and if they could have prevented the death. Similar findings have been reported in parents bereaved through suicide (Wertheimer, 2013) and in the wider family following cocaine overdose (DaSilva et al., 2007). In contrast, those aware expressed greater confidence the death was an 'accident,' and two participants and siblings in other families described feeling some form of *'relief'* from the pressures associated with a living close relative with a drug problem. Such differences have been noted previously (DaSilva et al., 2007; Templeton 2016b), although not considered in relation to bereavement theories.

In terms of behavioural responses participants aware of drug use were more likely to be open with others about the nature of the death, as many were aware of the deceased's drug use whilst they were alive. Many described challenging societal stigma by being open about the death voicing this could happen to anyone; echoing recent findings in those bereaved following drug and alcohol deaths (Templeton et al., 2016a). Conversely, those unaware of drug use prior to death expressed greater ambivalence than those aware of use, about telling others the circumstances surrounding the death. This may have been to protect the deceased relative's identity for themselves or in the eyes of others. Kauffman (2002) has suggested in such cases individuals can internalise negative cultural scripts associated with drugs, which can influence their behaviour often leading to social isolation. Similar to previous studies the findings suggest such stigma can act as a barrier in help seeking, as some participants felt 'unworthy' in accessing generic bereavement counselling (Templeton et al, 2016a). The DPM acknowledges stigmatised deaths isolate those affected and whilst the findings support this, they also highlight many family members are open to challenging stigma and are supported by their networks.

Maintaining a connection with the deceased was important throughout the grieving process ('loss orientation'). This initially appeared to create sadness although overtime was assimilated as part of adaptation ('restoration') by keeping the deceased alive in the new world. The need for a 'continuing bond' with the deceased is recognised as an adaptive component of grief by contemporary bereavement models, including the DPM (Klass, 2006; Stoebe & Schut, 1999). Sharing stories with others particularly with those who had experienced similar losses was labelled as important in continuing this bond and helping participants heal and move forward. 'Storying' grief has been acknowledged as critical to re-adaptation following loss (Neimeyer, 2002). Shared stories reflected on the deceased as a whole, including positive and negative experiences that included their drug use, suggesting representations of the deceased were not influenced by stigma or stereotypes, a finding that has not been reported previously. More research would need to be conducted to establish if this holds true throughout the bereavement process, as all participants appeared to have adapted to their new world. Other strategies to regain control included acceptance of the unknown with regards to circumstances of the death or choices around drug use; to sense making through faith, adopting approaches successfully used by others with shared experience, and in more practical ways by changing national guidance. Despite commonalities in some approaches adopted, others were individualistic emphasising ‘no one size fits all.’ The findings fit with models that emphasise the individualistic process of grief, however are the first to allude to coping mechanisms specific to those bereaved by heroin overdose that may be beneficial to those providing support.

The DPM posits grief processes are embedded in everyday experiences including other roles. The findings provide support to how this has the potential to complicate grief, which occurs at an individual and wider familial level. Participants that were parents and/or carers described putting the grief/care of others first, making it difficult for them to address intrapersonal grief processes. Support or guidance in sharing strategies to aid initial coping of self and others may be beneficial.

This is the first study within addiction bereavement literature to describe personal growth or positive psychological changes in self-identity and functioning, following loss. Also referred to as ‘posttraumatic growth;’ this construct is recognised by contemporary bereavement theory (Stroebe & Schut, 1999: Worden, 2008) and the findings suggest apply to individuals bereaved following heroin overdose.

Limitations

The sample size is small however IPA is more concerned with depth, than breadth or generalisability of experiences (Smith & Osborn, 2003). All participants were White British and recruited through organisations supporting families bereaved by addiction, and therefore had access to some type of support following loss. The grief processes and needs of more ‘hidden families’ affected, who are not accessing support remain unclear. Despite the need for research to understand these further, this can be a difficult population to identify and recruit, even through organisations (Dyregrov, 2004). Furthermore, there remains very limited understanding in the area of grief experiences across more diverse ethnic groups affected. Cultural conditions in how such deaths are received could potentially be different, resulting in different needs and grief processes. Future research may need to consider these factors, including the use of email to reach a broader audience. This approach has been applied to IPA research and shown to be effective in exploring emotive topics leaving time for reflection between communications (Üstündağ–Budak, Larkin, Harris & Blissett, 2015)

Finally, finding credibility was strengthened through steps taken to reduce potential researcher bias upon data analysis and interpretation (see ‘reflexivity’ in method). However credibility checks with participants could have added increased validity.

Clinical implications

The findings, particularly the theme *“what I would have wanted”* highlight useful considerations for clinicians supporting family members in navigating through and adjusting to the bereavement challenges they face. Maintaining a connection with the deceased appeared most significant, with the findings suggesting clinicians should encourage family members to talk about the deceased as a whole person, reflecting on good and bad experiences. This may serve a dual purpose in validating a widely stigmatised loss and the relationship they shared with the deceased. It may be helpful to elicit other strategies used to maintain this bond and where absent suggest others highlighted within the findings, such as through writing, talking to, and engaging in activities previously shared with the deceased. Clinicians where possible would benefit from creating a comfortable, inviting environment and have an awareness of drugs and the challenges associated with living and being bereaved by heroin overdose. This awareness may facilitate sense making and adaptation as well as normalising experiences. Furthermore, as demonstrated by the results, metaphors may be a way of communicating difficult emotions/experiences and could be used for such purposes. Individual differences in factors influencing grief processes and adaptation raised in the findings, including awareness of drug use prior to death, finding the body and/or competing roles highlight the importance of clinicians in using a person centred approach, tailored to the individual. Greater awareness of support organisations within services/professionals those affected may come into contact with (e.g., police, funeral directors, courts) may facilitate access to support.

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Chapter Three – Public Dissemination Document: Developing a psychological understanding of complex loss

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Public Dissemination Document

This document summarises two research studies that include (i) a review of published research (meta-ethnography) and (ii) an empirical study, both completed as part of the Clinical Psychology Doctorate at The University of Birmingham.

Developing a psychological understanding of complex loss

The research described was an attempt to develop a deeper understanding of the psychological experiences of two groups of people following difficult grief experiences, as a result of losing a relative in traumatic situations. The first was a review of published research studies on the impacts of the loss of a child on parents. The second research study focused on the impacts on family members who experienced the death of a relative as a result of heroin overdose. Each part is described in more detail below.

Review of published research studies: The experience of subsequent pregnancy and parenting following miscarriage, stillbirth and neonatal death: A Meta-ethnography.

Background: Miscarriage, stillbirth and/or neonatal deaths are losses that occur in pregnancy or shortly after birth. Such devastating losses have been found to have negative impacts on the physical and emotional wellbeing of parental couples affected. The consequences are likely to carry forward and create high levels of anxiety in a next pregnancy, and in the experience of parenting.

The Aim and Methods used: A meta-ethnography summarises qualitative research in a given area and in doing so, offers fresh perspectives and learning through the author's interpretation. The aim of the meta-ethnography was to improve our understanding of the emotional experiences of pregnancy and parenting after a miscarriage, stillbirth and/or neonatal death, by reviewing all qualitative research in the area. Research databases were searched for related studies, and 18 published studies were found in total. The methodology used within studies included gathering detailed information of experiences of women, men or couples using interviews, questionnaires or calendar entries (a form of diary keeping). The quality of these studies was assessed using a well-known evaluation framework.

The Results: The findings of the meta-ethnography were described using three categories important in understanding the experiences of a next pregnancy and/or parenting. These included:

1. **The dark cloud** – The previous experience of a loss had led to a new awareness in couples that having a healthy live born baby was not always the guaranteed result of a pregnancy. Parents felt that this knowledge was a dark cloud that hung over them in the next pregnancy, creating high levels of anxiety.
2. **Weathering the storm of uncertainty –** described the worries and concerns couples had in their next pregnancy and ways in which they tried to cope, up until the birth.
3. **Parenting –** less than half of studies included commented on parenting, although where this was reported couples described how they still experienced anxiety once the child was born. During this period it was important to recognise both the next child and the one lost, and maintain separate bonds with each.

The Conclusions: The findings highlight a need for additional emotional support for couples, to be provided as early as when they are attempting to conceive, throughout pregnancy and up to the first year of parenting. Recommendations for professionals looking after those who experienced the loss include the need for greater acknowledgment, awareness and understanding of the anxieties expressed by couples and the strategies used to cope. This includes possible delayed attachment behaviours in pregnancy so they are not inaccurately raised as potential risk issues. Furthermore, couples would benefit if professionals were aware of obstetric histories prior to appointments, and recognised the live newborn and lost child as distinct beings with their own identity.

Empirical Study: Family members' lived experience of bereavement following the loss of a close relative to heroin overdose

The Background: The negative impact of addiction on the family members' wellbeing is well understood and documented. Little is known however about the impact and grief experiences that follow when losing a close relative to an illicit drug related death, particularly heroin overdose. The circumstances of the death make it likely that the experience of grief may be more complicated than when other less traumatic deaths occur, in that the deceased is likely to be young, the death unexpected and the circumstances traumatic particularly if the deceased relative was found by family members' themselves. Societal views of heroin use and associated lifestyles as negative means such deaths are often viewed as self-inflicted and associated with high levels of stigma, leaving family members isolated in their grief.

The Aims and Methods: This study aimed to develop a detailed understanding of family members lived experience of grief (meaning ascribed to loss and impact over time), following the loss of a close relative to heroin overdose. Seven participants were interviewed and transcripts of the interviews were analysed using a qualitative method called Interpretative Phenomenological Analysis (IPA), which focuses on the personal meaning those interviewed attribute to a particular experience.

The Results: Shared descriptions and language used by family members when describing their experiences created the sense that grief was experienced like a natural disaster, leading to the development and use of an earthquake metaphor to capture the depth and power of emotions behind family members experiences. These experiences were expressed through three main themes:

(1) **The earthquake hits** described the family members' descriptions of how news of the death had led to their whole world falling apart, leaving them shaken and severely distressed.

(2) **Standing in the rubble** represented the early stages of family members trying to make sense of their grief through the realisation that their world had changed forever. Films were referenced as the only tangible source of comparison to the pain, devastation and heartache experienced. Many described feeling lost in their new world, and preoccupied with making sense of how the earthquake came to be.

(3) **Building a new foundation** described how family members move forward in their new world; strategies that they used to adjust and build new foundations in a world without the physical presence of the deceased relative.

Maintaining a connection with the deceased as they existed in the old world through physical possessions (photographs, possessions) or mentally (memories, sharing stories) was important for family members throughout every part of their bereavement journey.

The Conclusions: The findings bought to light the unique challenges faced by family members bereaved following heroin overdose of a close relative, and how these differ from those bereaved from other deaths. The specific features of these differences are highlighted in detail, but include high levels of societal stigma and not fully knowing/understanding the circumstances of the death, greater involvement with legal processes and the possibility of trauma or shock from finding the body. The need for professionals to be trained to understand these in order to provide more targeted and compassionate help is highlighted.

Both studies of grief following traumatic and complex death showed new insights and the need for specific help for those affected.

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Appendices

Appendix One: Definitions and prevalence rates across countries of miscarriage, stillbirth and neonatal death

Definition
Miscarriage also commonly referred to as ‘spontaneous abortion,’ is in the United Kingdom (UK) defined as unplanned loss of a pregnancy anytime up to 24 weeks gestation. In the United States (US) a miscarriage is recognised as occurring before 20 weeks gestation
Stillbirth is legally defined in the UK as a child that is born after 24 weeks gestation and does not breathe or show any signs of life before birth. The birth and death has to be legally registered. In the US there is no universally accepted definition of stillbirth across states, however it is most commonly seen as a loss at 20 weeks gestation to full-term In Australia, similar to the United States stillbirth is defined as no sign of life after 20 weeks gestation, or weighing more than 400g if the weeks of gestation are unknown.
Neonatal death is defined as the loss of a baby within the first 28 days of life. Deaths that occur within the first seven days of life are labelled as early neonatal deaths, and those that occur after the seventh day but before the twenty eighth day post birth as late neonatal deaths.

Appendix Two: Details of search strategies conducted in individual databases

PsychINFO search strategy (1967 to April week 3 2016)

	Searches	Results
1	stillbirth* or stillborn* or still-birth* or still-born* (keyword Search)	704
2	miscarriage* (keyword Search)	929
3	spontaneous abortion (subject heading search)	713
4	2 OR 3	1242
5	neonatal death* or neonatal loss* or neonatal mortalit* or perinatal death* or perinatal loss* or perinatal mortalit* or antepartum loss* or antepartum mortalit* or antepartum death* or fetus death* foetus death* or fetus loss* foetus loss* or fetus mortalit* or foetus mortalit* or fetal death* foetal death*or fetal loss* foetal loss* or fetal mortalit* or foetal mortalit* (keyword search)	1156
6	1 OR 4 OR 5	2583
7	mom* or mum* or dad* or mother* or father* or parent* or maternal* or paternal* (keyword search)	341111
8	family* or relation* or relational* or uncle* or aunt* grandparent* or grandmother* or grandfather* or sister* or brother* or sibling* or grandma* or grandpa* (keyword search)	1000904
9	parents/ or adoptive parents/ or exp fathers/ or foster parents/ or homosexual parents/ or exp mothers/ or exp single parents/ or stepparents (subject heading search)	76900
10	family (subject heading search - explode)	42107
11	grandparents/ (subject heading search)	2160
12	siblings (subject heading search – explode)	12069
13	7 OR 8 OR 9 OR 10 OR 11 OR 12	1154680
14	parenting* or subsequent children* or subsequent child* or child rearing* or parenthood* or subsequent pregnanc* (keyword search)	41930
15	Parenting (subject heading search – explode)	79615
16	parenting skills (subject heading search)	2463
17	parenting style (subject heading search – explode)	5369
18	Parenting attitudes (subject heading search – explode)	15716
19	14 OR 15 OR 16 OR 17 OR 18	99638
20	experience* or impact* or perspective* or exploration* or narrative* or phenomenolog* or qualitative* (Keyword search)	983081
21	6 AND 13 AND 19	240
22	20 AND 21	166

Appendix Two: Details of search strategies conducted in individual databases

Embase Search Strategy (1974 to 2016 April 04)

	Searches	Results
1	stillbirth* or stillborn* or still-birth* or still-born* (keyword Search)	19150
2	miscarriage* (keyword Search)	16161
3	spontaneous abortion (subject heading search)	31778
4	2 OR 3	36264
5	neonatal death* or neonatal loss* or neonatal mortalit* or perinatal death* or perinatal loss* or perinatal mortalit* or antepartum loss* or antepartum mortalit* or antepartum death* or fetus death* foetus death* or fetus loss* foetus loss* or fetus mortalit* or foetus mortalit* or fetal death* foetal death*or fetal loss* foetal loss* or fetal mortalit* or foetal mortalit* (keyword search)	51841
6	1 OR 4 OR 5	95024
7	mom* or mum* or dad* or mother* or father* or parent* or maternal* or paternal* (keyword search)	1412388
8	family* or relation* or relational* or uncle* or aunt* grandparent* or grandmother* or grandfather* or sister* or brother* or sibling* or grandma* or grandpa* (keyword search)	3188291
9	parent/ or adoptive parent/ or divorced parent/ or exp father/ or exp mother/ or separated parent/ or single parent/ (subject heading search)	190148
10	family/ or extended family/ or family relation/ or grandparent/ (subject heading search - explode)	90184
11	sibling relation or sibling (subject heading search - explode)	33146
12	7 OR 8 OR 9 OR 10 OR 11	4267072
13	parenting* or subsequent children* or subsequent child* or child rearing* or parenthood* or subsequent pregnanc* (keyword search)	31652
14	child parent relation (subject heading search – explode)	72120
15	14 OR 15	90167
16	experience* or impact* or perspective* or exploration* or narrative* or phenomenolog* or qualitative* (keyword search)	2461030
17	6 AND 12 AND 15	1472
18	17 AND 16	425

Appendix Two: Details of search strategies conducted in individual databases

Search Strategy MEDLINE 1946 to April week 3 2016

	Searches	results
1	stillbirth* or stillborn* or still-birth* or still-born* (keyword search)	12309
2	fetal death/ or stillbirth (subject heading)	26271
3	miscarriage* (keyword Search)	9053
4	Abortion, Spontaneous/(subject heading search - explode)	33105
5	neonatal death* or neonatal loss* or neonatal mortalit* or perinatal death* or perinatal loss* or perinatal mortalit* or antepartum loss* or antepartum mortalit* or antepartum death* or fetus death* foetus death* or fetus loss* foetus loss* or fetus mortalit* or foetus mortalit* or fetal death* foetal death*or fetal loss* foetal loss* or fetal mortalit* or foetal mortalit* (keyword search)	42865
6	1 OR 2 OR 3 OR 4 OR 5	81946
7	mom* or mum* or dad* or mother* or father* or parent* or maternal* or paternal* (keyword search)	849476
8	family* or relation* or relational* or uncle* or aunt* grandparent* or grandmother* or grandfather* or sister* or brother* or sibling* or grandma* or grandpa* (keyword search)	2824904
9	family/ or grandparents/ or exp parents/ or siblings/ or single-parent family (subject heading)	153825
10	7 OR 8 OR 9	3431465
11	parenting* or subsequent children* or subsequent child* or child rearing* or parenthood* or subsequent pregnanc* (keyword search)	28488
12	parent-child relations/ or parenting (subject heading search – explode)	55624
13	11 OR 12	68702
14	experience* or impact* or perspective* or exploration* or narrative* or phenomenolog* or qualitative* (keyword search)	1601900
15	6 OR 10 OR 13	833
16	15 AND 14	244

Appendix Two: Details of search strategies conducted in individual databases

ASSIA Search 25th April 2016

	Searches
1	"stillbirth*" OR "stillborn*" OR "still-birth*" OR "still-born*" OR miscarriage* OR "neonatal death*" OR "neonatal loss*" OR "neonatal mortalit*" OR "perinatal death*" OR "perinatal loss*" OR "perinatal mortalit*" OR "antepartum loss*" OR "antepartum mortalit*" OR "antepartum death*" OR "fetus death*" OR foetus death* OR "fetus loss*" OR foetus loss* OR "fetus mortalit*" OR foetal mortalit* OR "fetal death*" OR foetal death* OR "fetal loss*" OR foetal loss* OR "fetal mortalit*" OR foetal mortali* (keyword search)
2	**AND**
3	family* or relation* or relational* or uncle* or aunt* grandparent* or grandmother* or grandfather* or sister* or brother* or sibling* or grandma* or grandpa* OR mom* or mum* or dad* or mother* or father* or parent* or maternal* or paternal* (keyword search)
4	**AND**
5	family* or relation* or relational* or uncle* or aunt* grandparent* or grandmother* or grandfather* or sister* or brother* or sibling* or grandma* or grandpa* or mom* or mum* or dad* or mother* or father* or parent* or maternal* or paternal* (keyword search)
6	**AND**
7	parenting* OR "subsequent children*" OR "subsequent child*" OR "child rearing*" OR parenthood* OR "subsequent pregnancy*" (keyword search)
8	**AND**
9	experience* OR impact* OR perspective* OR exploration* OR narrative* OR phenomenology* OR qualitative* (keyword search)

Results: 26 papers

Appendix Two: Details of search strategies conducted in individual databases

CINAHL Search Strategy 25th April 2016

	Search Term	**Results**
1	MM "Perinatal Death	2876
2	neonatal loss	24
3	neonatal mortali*	1048
4	perinatal loss	277
5	perinatal mortalit	985
6	antepartum loss	1
7	antepartum mortalit*	1
8	antepartum death	7
9	fetus death	1
10	fetus loss*	2
11	fetus mortalit*	0
12	Foetus mortalit*	0
13	Foetal loss*	8
14	Foetal mortalit*	5
15	MM "Abortion, Spontaneous (subject heading search)	1710
16	fetal loss	358
17	fetal mortalit*	164
18	1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17	6635
19	(MH "Family+") OR (MH "Extended Family+") (subject heading explode)	153264
20	relation*	424586
21	uncle*	20838
22	aunt*	218
23	sibling*	7401
24	brother	666
25	sister*	2895
26	MM "Grandparents	970
27	grandma*	166
28	grandpa*	2063
29	mother*	58161
30	father*	11327
31	Parent*	107843
32	Maternal*	54178
33	Paternal*	4624
34	Mom*	1325
35	Mum*	4194
36	Dad*	1608
37	19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36	633429
38	experience	223613

39	impact*	156401
40	perspective*	76754
41	exploration*	11212
42	narrative*	19034
43	phenomenolog	15647
44	qualitative*	96460
45	38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44	483213
46	Parenting (Subject heading search)	11115
47	subsequent children*	26
48	subsequent child*	116
49	parenthood*	2006
50	subsequent pregnanc*	652
51	46 OR 47 OR 48 OR 49 OR 50	13563
49	18 AND 37 AND 45 AND 51	66

Appendix Three: CASP Tool and numerical rating guidelines

CASP Criteria	Numerical rating guidelines
1. Was there a clear statement of the aims of the research? *HINT: Consider* a) What was the goal of the research? b) Why it was thought important? c) Its relevance	2 – The relevant literature is covered sufficiently (hint b and c) 1 – Hint (a) is detailed - It is clear what the research is setting out to achieve. 0 – none of the hints are covered
2. Is a qualitative methodology appropriate? *HINT: Consider* a) If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants. b) Is qualitative research the right methodology for addressing the research goal?	2 – Covers hints (a) and (b) 1- Covers hint (a) it is clear that qualitative methods were used and that they are suitable **OR** hint (b) if the researcher states that they are trying to illuminate experiences/actions of individuals in relation to the topic of interest 0 - none of the hints are covered
3. Was the research design appropriate to address the aims of the research? *HINT: Consider* a) If the researcher has justified the research design b) Have they discussed how they decided which method to use?	2 – Covers hint (a) and (b) A rationale is provided why this method has been selected over other research methods/designs 1- The design is justified; covers hint (a) 0 - none of the hints are covered
4. Was the recruitment strategy appropriate to the aims of the research? *HINT: Consider* a) If the researcher has explained how the participants were selected	2 – Covers hint (c) as to why some people did not take part, well as (a) and (b) 1 – covers both hints (a) and (b) – it is clear how participants were chosen and why they are appropriate

b) If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study c) If there are any discussions around recruitment (e.g. why some people chose not to take part)	0 – none of the hints are covered
5. Was the data collected in a way that addressed the research issue? *HINT: Consider* a) If the setting for data collection was justified. b) If it is clear how data were collected (e.g. focus group, semi-structured interview etc.) c) 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)? d) If methods were modified during the study. If so, has the researcher explained how and why? e) If the form of data is clear (e.g. tape recordings, video material, notes etc) f) If the researcher has justified the methods chosen g) If the researcher has discussed saturation of data (if relevant to method of analysis e.g. grounded theory)	2 – In addition to below (point 1) hint (e) and if relevant hint (f) are discussed. 1 – Any three hints between (a) and (e) are addressed – methods of data collection need to be clear. 0 – none of the hints are covered
6. Has the relationship between researcher and participants been adequately considered? *HINT: Consider* a) If the researcher critically examined their own role, potential bias and influence during (i) Formulation of the research questions (ii) Data collection, including sample	2 – Covers hint (a – i or ii) and (b). For b) there is evidence that the researcher has considered the impact of their background on any part of the study. 1 – covers hint (a) either (i) or (ii)– there is evidence of some reflection of the researchers background 0 – none of the hints are covered

recruitment and choice of location b) How the researcher responded to events during the study and whether they considered the implications of any changes in the research design	
Have ethical issues been taken into consideration? *HINT: Consider* a) If approval has been sought from the ethics committee b) If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained c) 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)	2 – Covers hint (a) in addition to one or both hints (b) and (c) 1 – If only hint (a) is covered where details of gaining ethical approval are clear **OR** just one between hint (b) or (c) is described – if there is an understanding that ethical procedures were clearly explained to participants or were considered. 0 – none of the hints are covered
8. Was the data analysis sufficiently rigorous? *HINT: Consider* a) If there is an in-depth description of the analysis process. b) If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? c) If sufficient data are presented to support the findings d) To what extent contradictory data are taken into account e) Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation f) Whether the researcher explains how the data presented were	2 – In addition to coverage of three hints between (a) – (d), either hint (e) or (f) is also discussed which provides an indication of come level of bias or how it was addressed. 1 – If three of the hints (a) – (d) are covered – so that the methods of analysis are clear and substantiated with sufficient data. 0 – none of the hints are covered

selected from the original sample to demonstrate the analysis process.	
9. Is there a clear statement of findings? *HINT: Consider* a) If the findings are explicit b) If the findings are discussed in relation to the original research question c) If there is adequate discussion of the evidence both for and against the researchers arguments d) If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst).	2 – In addition to below (point 1) the paper covers either or both hint (c) and (d) so there is adequate discussion of the findings. 1 – If hint (a) and (b) is covered – the findings are clear in relation to the original questions 0 - none of the hints are covered
10. How valuable is the research? *HINT: Consider* a) 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? b) If they identify new areas where research is necessary c) 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	2 – If all three hints are covered 1 – If any two of the three hints are covered 0 – none of the points are covered

Appendix Four: Application of CASP and numerical framework to one study

Quality Criteria (Phipps, 1985)	**Comments**		**Rating (yes=2, partial=1, no=0)**
	Strengths	**Weaknesses**	
Was there a clear statement of the aims of the research?	The author provides an overview of relevant literature and makes it clear that there is a paucity of research beyond single case reports, even these do not look at how individuals that have lost a child in pregnancy and have healthy behavioural outcomes cope.		2
Is a qualitative methodology appropriate?	Yes a qualitative enquiry is appropriate as the author aims to conduct an exploration of the topic under interest.		2
Was the research design appropriate to address the aims of the research?	Yes, the researcher justifies why a qualitative approach is most appropriate. The author details the topics covered by the interview schedule.	The author does not justify why they chose to use interviews	1
Was the recruitment strategy appropriate to the aims of the research?	The researcher details how the participants were selected and where they were recruited from.	The researcher does not provide details of the recruitment process itself; how the study was explained, whether some people decided not to take part. It may have been beneficial to have added information about how many participants were approached and the number and reason for those not wishing to	1

		take part.	
Was the data collected in a way that addressed the research issue?	The author details that the interviews were conducted in participant’s homes, together with couples and the length of interviews. It is clear that an interview guide was used and the topics that were covered by the questions. The author details that the interviews were tape recorded. There is no indication/detail whether any modifications were made during the study suggesting none were made.	The researcher does not justify why interviews. Details to how the author reached saturation in terms of data collection is not provided (particularly important because it is grounded theory).	1
Has the relationship between researcher and participants been adequately considered?		There is no reflection at all of the researchers background and potential implications for biasing the study.	0
Have ethical issues been taken into consideration?		The author does not mention ethics approval or issues such as informed consent. Furthermore no information is included as to how the author handled the effects of the study.	0
Was the data analysis sufficiently rigorous?	There are however sufficient quotes presented to support the findings and contradictory data are taken into account.	Saturation? The author does not provide a step-by-step description of analysis method. The findings are presented under topic headings used for the interview schedule – not good as she is using grounded theory. The author does not examine their own role in the analysis process.	1

Is there a clear statement of findings?	The author clearly describes the findings and discusses them in relation to the original research questions.	The author does not discuss the credibility of the finding in terms of methods to ensure trustworthiness of the data. There is no discussion of evidence for and against the researchers arguments.	1
How valuable is the research?	The researcher acknowledges limitations in the research – including limits to the method. The researcher considers in depth the contribution of the findings to the literature, makes suggestions for future research and provides a comprehensive list of suggestions with regards to implications of the research findings.		2

Appendix Five: Main ethical considerations for bereavement related research incorporated into the research design

Recommendations for researchers in minimising distress, made by parents in the Dyregov study (2004) have been considered. Precautions to be taken include:

1. Family members that have experienced the recent death of a close relative may find it difficult or stressful to talk at length about the death in a qualitative interview. Therefore to minimise the potential for this, those family members that have experienced a loss in the previous six months will be excluded from the study.

2. Participants will be given details of the interviewer on the information sheet, and will have the opportunity to ask any questions.

3. To maximise comfort participants' will be able to decide whether the interview will take place in their home or in a private room at the University.

4. Participants will also be provided with a copy of the interview schedule prior to obtaining consent, so that they are able to review the topics to be covered and identify if there are areas they do not want to explore if they were to participate.

5. Participants' will be given the opportunity to take part in one or several short interviews; this does not need to be decided prior to the first interview. Furthermore, they will be offered to take breaks during the interview(s), if needed.

6. Prior to the interview they will be assured of their right to ask for the audio recorder to be turned off at any time during the interview.

7. Information on local and national bereavement support services will be provided at the end of the interview.

8. The interview schedule has been structured to start with less distressing topics, before asking the participant about the actual loss, in order to minimise the potential for distress.

9. All interviews will be conducted by a researcher that is currently training to be a clinical psychologist and has knowledge and experience of working with individuals that have experienced bereavement. Therefore, if needed they will use their skills to offer emotional support and manage distress during the interview, but also be mindful of their primary role in this instance (as researcher not therapist) and if needed, provide the participant with information of additional sources of support.

10. Participants will be debriefed at the end of the study and have the opportunity to ask questions.

11. Contact details of the academic supervisor and someone independent from the research but affiliated with the University will be provided on the information sheet, if participants wish to make a complaint.

Appendix Six: Interview schedule

Title of Project: **Family Members (FMs) lived experience of bereavement following the loss of a close relative to illicit substance misuse.**

Remind family members of their right to withdraw, everything annonymised, stop recording, stop/breaks anytime

Interview Style
The interviewer should ensure that the participant is at ease and start with a broad question about the deceased that allows a gentle introduction to the difficult topic that is the focus of the interview. Each area starts with an open question with possible prompts however these should only be used if and when relevant, as the participant may provide the necessary information without being promoted.

Possible prompts and probes to aid exploration of topics

- Could you please provide an example of that?
- Could you tell me a bit more about that?
- What do you mean by X?

Areas to be covered as part of the interview include:
1. Reflections on relationship with the deceased relative
2. Circumstances and reaction to the death
3. Aftermath of the death: (social reactions, changes in relationships, coping strategies, support)
4. Impact and meaning (then vs now) – Assumptions about themselves, world and others. Experience of/need for professional help.

The interview is divided into two broad sections that cover all four areas outlined above. Each section and the associated initial questions and prompts are detailed below:

Reflections on relationship with the deceased

1) Can you please tell me about X (name of the deceased relative)?
   Possible prompts: *What were they like as a person? How were you related? How was your relationship with them? Did this change over time?*

2) Were you aware of any difficulties X was having? If Yes, do you think this impacted on your relationship?
   Possible prompts: *Mood, day to day living, were you aware of the drug use prior to the death? If yes, how did you make sense of the drug use? Your partner? Significant Others?*

Circumstances, reactions and impact of the death

3) Could you please tell me about how you came to learn of the death? What were the circumstances around the death?
Possible prompts: *Were you with X? If not, who told you? Were you alone?*

4) Could you please tell me about what happened when X died? Can you tell me how you reacted?
Possible prompts: *What went through your mind? How did you feel? What were your thoughts? Was this influenced by the nature of the death? Has this changed overtime? What meaning, if any, do you make of the death now?*

5) Could you please tell me about any changes you experienced to your physical and psychological health in the months following the death? Has this changed overtime?
Possible prompts: *Can you describe what felt different, what felt the same? Has this changed overtime? Check possible symptoms; sleep, appetite, concentration, mood, engagement in day to day and social activities? Confidence in roles.*

6) How did other people (family, wider community) react to the death?
Possible prompts: *Were they aware of the circumstances? Did you talk to them about the death? Was there anyone you could talk to about the death? How do you think they saw you? Did your relationships with these people change in anyway?*

7) Could you describe times after the death that were particularly difficult?
Possible prompts: *Could you describe things that helped you to cope after the death? Were there particular sources of comfort/support? Did you seek any professional help or support at this time?*

8) Has the death changed the way you think about yourself, others or the world?
Possible prompts: *How do you feel your hobbies/occupation/role has been affected by the death?*

9) What kind of things have you learnt from your experience that you feel would be helpful to other people going through the same thing? Or to services supporting people affected by death following substance misuse?
Possible prompts: *What type of support, if any, following the death would have been helpful for you? At what point following the death would this have been most beneficial? Were you aware of any professional support services?*

Appendix Seven: Demographic Information for Family Members

Demographic Information

Participant Identification Code:

Family Member

Age:

Gender:
Male ☐ Female ☐

Ethnicity:

White
British☐ Irish ☐ Other ☐

Mixed
White & Black Caribbean ☐ White & Black African ☐ White & Asian ☐ Other ☐

Asian or British Asian
Indian ☐ Pakistani ☐ Bangladeshi ☐ Other ☐

Chinese ☐ **Other** ☐

Occupation:

Employed ☐ Unemployed ☐ Student ☐

Relationship with the deceased: ☐

Number of years since the loss: ☐

Substance Implicated in the death:

Heroin ☐ Crack Cocaine ☐ Ecstasy ☐ Other ☐
Please specify:

Appendix Eight: Demographic Information Sheet Deceased Relative

Demographic Information of the deceased at the time of the death:

Age:

Gender:
Male ☐ Female ☐

Ethnicity:

White
British ☐ Irish ☐ Other ☐

Mixed
White & Black Caribbean ☐ White & Black African ☐ White & Asian ☐ Other ☐

Asian or British Asian
Indian ☐ Pakistani ☐ Bangladeshi ☐ Other ☐

Chinese ☐ **Other** ☐

Occupation:

Employed ☐ Unemployed ☐ Student ☐

Appendix Nine: Ethical Approval

[redacted]

Appendix Ten: Participant Information Sheet

Title of Project: Family Members (FMs) lived experience of bereavement following the loss of a close relative to illicit substance misuse.

Invitation

Thank you for expressing an interest in my research study.

My name is Gagandeep Chohan and I am a trainee Clinical Psychologist at The University of Birmingham, and I am carrying out this research project as part of my doctoral qualification in Clinical Psychology. My interest in carrying out this project stems from my previous experience of working in Addiction; I have worked closely with substance misusers and with families affected by substance misuse.

Before you decide whether you would like to participate it is important to understand why the research is being done and what it will involve. Please take time to read the following information carefully, it may address any of the questions you may have. Feel free to discuss with others if you wish.

What is the purpose of the study?

Little is known about the impact of losing a close relative to substance misuse on family member’s wellbeing, which is surprising given the high number of people that lose their lives to substance misuse each year. Within the research field there is little understanding of the bereavement process for family members, and how this impacts on their health and wellbeing.

The purpose of this study is to conduct interviews to gain a detailed understanding of family members experiences of losing a relative to substance misuse. We are interested in identifying some of the challenges you may have faced or continue to face, sources of support that were or would have been beneficial at the time and an understanding of the bereavement process. Your views may improve our understanding of grief processes of family members, the challenges you face, access and barriers to support services. This information may help to improve knowledge of needs amongst clinicians as well as provisions or accessibility of professional services.

Why have I been invited to take part?

You have been invited to take part in the study because you have experienced the death of a close relative following illicit substance misuse. In total, we are hoping to recruit between six to eight participants to take part in the study.

Do I have to take part?

No, participation in the study is completely voluntary; it is up to you to decide whether or not you want to take part in the study. If you do, the researcher will go through this information sheet with you and answer any further questions you may have. You will be provided with a copy of the information sheet and asked to sign a consent form showing that you have agreed to take part. You are still free to withdraw from the study at any time before the interview, if you decide to withdraw during or after the interview is completed, you have up to one month to withdraw your data (the interview transcript), after which data analysis will begin. You do not need to provide a reason if you decide not to take part or if you withdraw at any time. Furthermore, there will be no repercussions should you decide not to take part or to withdraw.

What will happen to me if I take part?

If you decide to participate, you will be invited to take part in either one or a few shorter interviews (depending on your preference) to talk about your experience and the impact of the death of your relative following illicit substance misuse. In total the interview(s) is/are expected to last approximately 1hour although it is possible that interviews could last longer if regular breaks are required, and this could extend to a maximum of 3 hours if necessary.

You will be asked to either contact the researcher directly, whose information is provided at the end of the sheet or leave your details with the organisation, so the researcher can contact you directly, to arrange the best date, time and place to carry out the interview. The interview can be held in your home or in a private room at The University of Birmingham.

The researcher will then meet you at your preferred location and time. The interview is likely to last anywhere between one to one and a half hours although this will be flexible depending on whether you would prefer one or several shorter interviews. You do not need to indicate a preference for one or the other prior to the interview; this can be decided once the interview has started. The interview will involve an open discussion about your experiences following the death of your close relative through substance misuse. You have the opportunity to see the interview questions before the interview and let the researcher know if you have any concerns. There are no right or wrong answers to the questions asked in the interview, the main aim is to get an understanding of your experience. I understand that it is an emotional topic therefore if needed you will have the opportunity to take breaks during the interview. With your consent the interview will be recorded on audiotape, so that the discussion can be analysed in greater detail without the researcher forgetting important details. You are able to request for the recording to be stopped at any time during the interview. The recording will be coded with a unique identification code and any detailed information will be omitted in the transcript in order to prevent the possibility of you being recognised.

What will happen after the interview?

After the interview the researcher will generate a transcript of the interview; type out a word to word document of the discussion from the interview. You will be sent a copy of the transcript to review within the one-month reflection period after the interview, to ensure you are happy with the content as direct quotes are likely to be used from your transcript to describe particular experiences when writing up the final report for the study. You will have the opportunity to discuss any concerns with the researcher in person or over the telephone.

What will happen to me if I decide I do not want to carry on with the study?

If you agreed to take part in the study and then change your mind before the interview has taken place, any data collected from you will be destroyed e.g. consent forms. If you wish to withdraw during the interview, or once it has been completed you have a period of one month to withdraw your data, after which data analysis will begin. You do not need to provide a reason if you decide not to carry on with the study and there will be no repercussions.

What will happen to the data collected in the study??

After the interview the recording will be uploaded on a password protected computer at The University of Birmingham and allocated a unique identification code that will be used to identify all information collected by you, so only the researcher will be able to recognise you. Once uploaded onto a computer the recording will be deleted off the audiotape. All other information collected (including demographic information, transcripts) will also be assigned the same unique identification code and be stored in locked filing cabinets at The University of Birmingham. Consent forms will be stored in a separate filing cabinet, as you will be asked to provide your contact details if you would like to see a copy of your interview transcript in the one month reflection period or receive a copy of the findings once the study has finished. No-one but the research team will have access to the data; they are all trained to manage this information in accordance with University, national and local guidelines on confidentiality and data protection. In line with the University's code of practice for research data, all data collected for the study will be preserved and accessible for ten years by the research team, after which it will be destroyed.

Direct quotes from the interviews are likely to be used in final reports; however this will not include any participant identifiable information. You will have the opportunity to read your interview transcript before any quotes are used in reports, to ensure you are happy with the interview content.

What are the possible disadvantages and risks of taking part?

It is possible, given the sensitive nature of the topics to be discussed during the interview that people may feel upset. A number of steps will be taken to minimise any distress you may experience, including the opportunity to see the interview questions before the interview takes place. Furthermore, if you feel yourself getting upset during the interview, please let the researcher know and you will be able to take as many breaks as you need, or if more suitable you can stop the interview to be continued at a later time. At the end of the interview you researcher will debrief you and if required can provide information of bereavement support services.

Are there any benefits from taking part?

There are no clear direct benefits in taking part however, some people find it helpful to talk and reflect on their experiences. However your views may be helpful in providing us with a better understanding of family members' experience of grief following the death of a loved one to illicit substance misuse. This may help us to understand some of the challenges you faced (or continue to face), sources of support that would be beneficial, improve knowledge of needs amongst professionals and access to support services.

What happens when the research study stops?

At the end of the study we will describe the findings in a report, which we hope to get published. You will be asked to indicate when you consent to take part in the study whether you would like to receive a copy of the research findings. If you wish to do so, a copy of the report will be sent to you.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with the researcher who will do their best to answer your questions (contact details are provided at the end of this sheet). If you remain unhappy or have any cause to complain about any aspect of the way in which you have been approached or treated during the course of the study, it will be addressed. The researcher is a clinical Psychology Trainee based at The University of Birmingham therefore any complaints should be addressed to the trainee's academic supervisor Prof. Alex Copello, who can be contacted on [redacted].

If you wish to speak to a person independent from the study you can contact Dr Sean Jennings who is the Research Ethics and Governance Manager at The University of Birmingham. His contact details are:

Address: Research Support Group,
University of Birmingham,
Room 119, Aston Webb Building,
Edgbaston,
Birmingham,
Post Code: B15 2TT
Telephone: [redacted]
E−mail: [redacted]

Who has reviewed the study?

The University of Birmingham is involved in the organisation and funding of this study. The school of Psychology has reviewed the study to ensure it meets the standards of scientific research. The study will also be reviewed by the University of Birmingham's ethics committee.

What do I do next?

Thank you for taking the time to read this information sheet. After reading this you do not need to make a decision straight away as to whether you would like to take part. We would encourage you to take at least 24 hours to make a decision. If you are interested in taking part in the study please either contact the researcher directly by telephone or email, details of which are provided below, or if you prefer the researcher to contact you please leave your details with someone from the organisation to pass on to the researcher. We can then arrange an appropriate date, time and place to meet and discuss any questions you may have.

Contact Details:

Researcher	**Academic Supervisor**
Gagandeep Chohan	Prof. Alex Copello
Trainee Clinical Psychologist	Professor in Addictions Research
Telephone:	Telephone: [redacted]
Email: [redacted]	Email : [redacted]

The University of Birmingham,
School of Psychology,
Edgbaston,
Birmingham,
B15 2TT

Thank you for your time.

UNIVERSITY OF
BIRMINGHAM

Appendix Eleven: CONSENT FORM

Research site: ....

Participant Identification Code:…… Name of Researcher…………………

Title of Project: Family Members (FMs) lived experience of bereavement following the loss of a close relative to illicit substance misuse.

Please initial box

1. I confirm that I have understood the information sheet dated .... (version ...) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time prior to and during the research interview, without giving any reason, and this will not impact on the care/support I receive from the organisation that informed me about the research. ☐
3. I understand that the research interview will be audio-recorded ☐
4. I understand that following the research interview I will have a one-month period for reflection. The researcher will then contact me at which point I may withdraw my interview entirely or in part, without giving any reason, without my care or legal rights being affected. ☐
5. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. ☐
6. I understand that I have the opportunity to review the interview transcript before any direct quotes are used in reports, in the one-month reflection period after the interview. ☐
7. I understand that direct quotes from my interview may be published in any write-up of the data, and used for training purposes, but that my name will not be attributed to any such quotes and that I will not be identifiable by my comments. ☐
8. I agree to take part in the above study. ☐

If you would like to receive a copy of your interview transcript in the one-month reflection period or a copy of the study findings once the research has been completed, please tick the appropriate box below and provide contact details and your preferred method of contact in the space provided:

I would like to receive a copy of my interview transcript. ☐

I would like to receive a copy of the study findings ☐

Contact Details:

Preferred method of contact:
Post: ☐ Email: ☐ Telephone: ☐

....	....	....
Name of participant	Date	Signature
....	....	....
Researcher	Date	Signature

Appendix Twelve: Sources of Support

Thank you very much for taking part in this study, the experiences that you have shared may help us to understand some of the difficulties, grief processes and areas of support that may be beneficial for family members affected by a similar experience. We appreciate that the nature of the interview involved discussing some sensitive topics, during which you may have experienced some distress. In the event that you feel that this distress is difficult to deal with, or you would like some additional support, a list of services that are available to provide this type of support (general and those specific to addiction) are provided below.

If you are experiencing problems with feelings of anxiety or depression, or feel you may be at risk of harming yourself, you could also approach and talk to your General Practitioner who may refer you for psychological support and help locally.

Services specific to addiction

DrugFAM

Offer support and advice to individuals/families affected by a loved one's use of drugs or alcohol. Ensure individuals/families are understood and supported, the service offers support groups, one-to-one support and befriending services, telephone and email support, bereavement support, education and awareness and signposting.

Telephone: 01494 442 777 or 0845 388 3853
Email: office@drugfam.co.uk
Text: 07725 908 399
Skype: drugfam.support (9am – 5pm, Mon – Fri)

GRASP

US based support service that offers online resources for family member affected by the death of a loved one through substance misuse including; other peoples stories, meditations and links to online support groups.

Web link: http://grasphelp.org/resources/

General services:

Samaritans

Provide 24 hour support 7 days a week; offer confidential support to people that are experiencing emotional distress. Support offered can include helping you to explore your options, understands your difficulties better or someone listening to your difficulties.
Telephone: 08457 90 90 90
Email: jo@samaritans.org
Find you local branch: http://www.samaritans.org/branches

CRUSE

Provide support to individuals that are experiencing grief following the death of a friend or relative. Support is provided in the form of information leaflets about grief, a national helpline with volunteers trained providing grief support.

Website: http://www.crusescotland.org.uk
Supportline: 0845 600 2227

The compassionate Friends

A charitable organisation of bereaved parents, siblings and grandparents dedicated to the support and care of other bereaved parents, siblings, and grandparents who have suffered the death of a child/children. Support is offered in the form of listening and sharing experiences, either over the phone or face-to-face if you request a befriender.

Telephone: 0845 123 2304 (10am – 4pm, 7pm-10pm)
Website: http://www.tcf.org.uk/#
Link to request support from a befriender: http://www.tcf.org.uk/local-support/

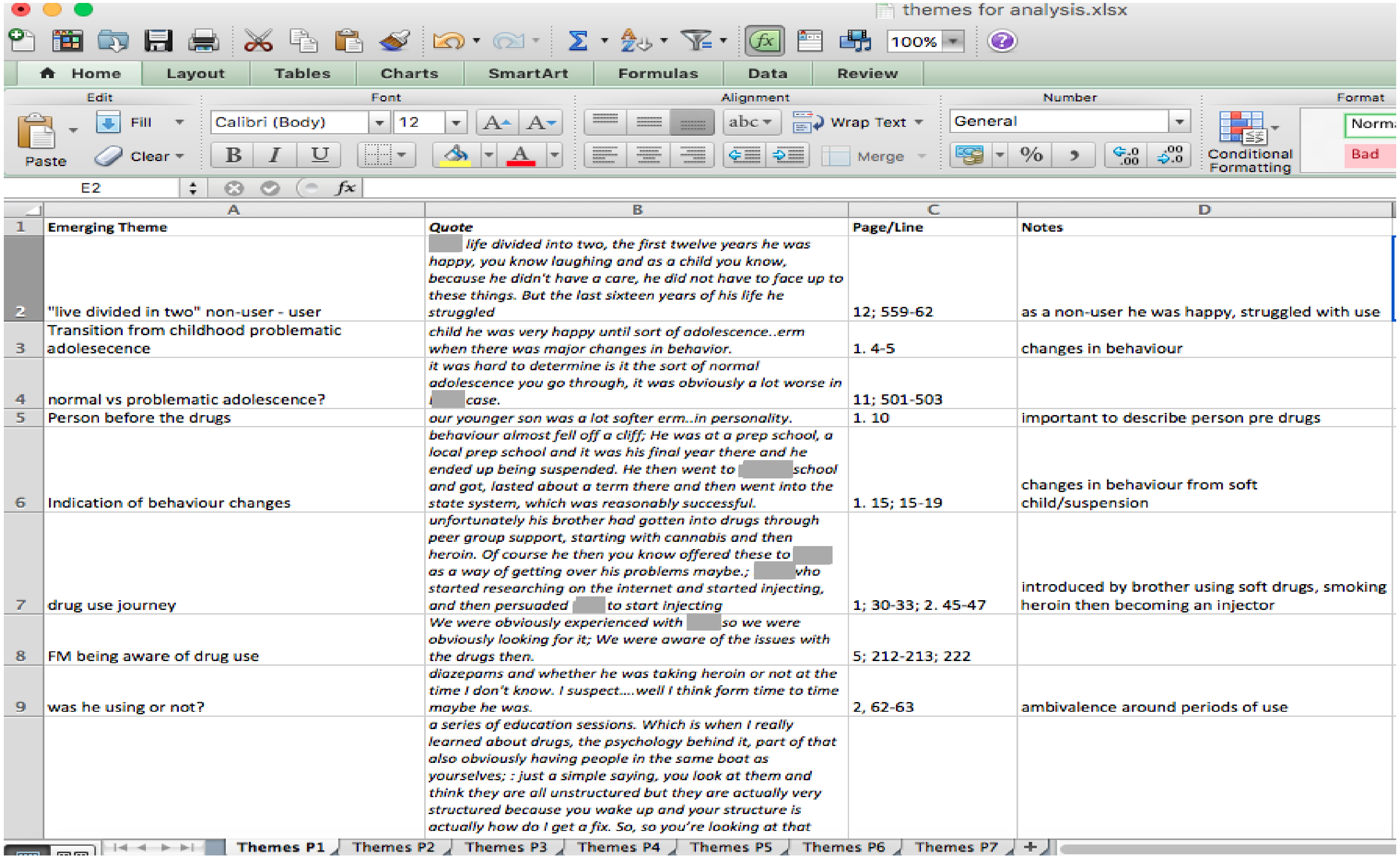
The Bereavement Trust

Provide free confidential and unlimited support in a number of different languages, to individuals struggling with bereavement.

Helpline: 0800 435 455 (6pm-10pm everyday)
Website: http://bereavement-trust.org.uk

Appendix Thirteen: *Example of stage four of analysis*

Example of stage four of analysis: listing emerging themes chronologically, alongside corresponding quotes and line/page numbers of text locations.



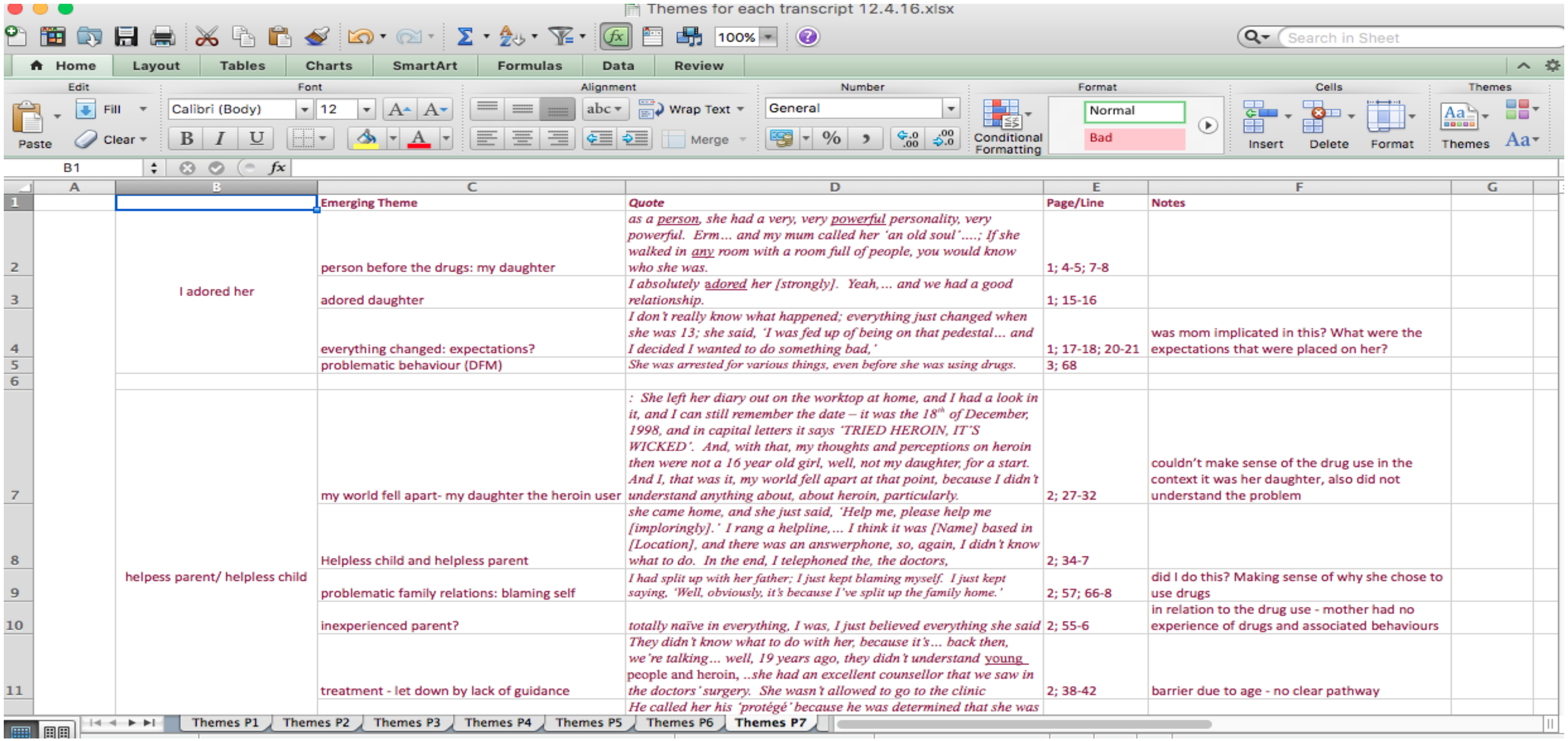
	A	B	C	D
1	**Emerging Theme**	***Quote***	**Page/Line**	**Notes**
2	"live divided in two" non-user - user	*[redacted] life divided into two, the first twelve years he was happy, you know laughing and as a child you know, because he didn't have a care, he did not have to face up to these things. But the last sixteen years of his life he struggled*	12; 559-62	as a non-user he was happy, struggled with use
3	Transition from childhood problematic adolesecence	*child he was very happy until sort of adolescence..erm when there was major changes in behavior.*	1. 4-5	changes in behaviour
4	normal vs problematic adolescence?	*it was hard to determine is it the sort of normal adolescence you go through, it was obviously a lot worse in [redacted] case.*	11; 501-503	
5	Person before the drugs	*our younger son was a lot softer erm..in personality.*	1. 10	important to describe person pre drugs
6	Indication of behaviour changes	*behaviour almost fell off a cliff; He was at a prep school, a local prep school and it was his final year there and he ended up being suspended. He then went to [redacted] school and got, lasted about a term there and then went into the state system, which was reasonably successful.*	1. 15; 15-19	changes in behaviour from soft child/suspension
7	drug use journey	*unfortunately his brother had gotten into drugs through peer group support, starting with cannabis and then heroin. Of course he then you know offered these to [redacted] as a way of getting over his problems maybe.; [redacted]vho started researching on the internet and started injecting, and then persuaded [redacted] to start injecting*	1; 30-33; 2. 45-47	introduced by brother using soft drugs, smoking heroin then becoming an injector
8	FM being aware of drug use	*We were obviously experienced with [redacted] so we were obviously looking for it; We were aware of the issues with the drugs then.*	5; 212-213; 222	
9	was he using or not?	*diazepams and whether he was taking heroin or not at the time I don't know. I suspect....well I think form time to time maybe he was.*	2, 62-63	ambivalence around periods of use
		a series of education sessions. Which is when I really learned about drugs, the psychology behind it, part of that also obviously having people in the same boat as yourselves; : just a simple saying, you look at them and think they are all unstructured but they are actually very structured because you wake up and your structure is actually how do I get a fix. So, so you're looking at that		

Appendix Fourteen: *Example of stage five of analysis*

Example of stage five of analysis: Connections/patterns (similarities and differences) between emerging themes were explored, and related themes were clustered together and given names to represent superordinate themes

Appendix Fifteen: *Example of stage six of analysis*

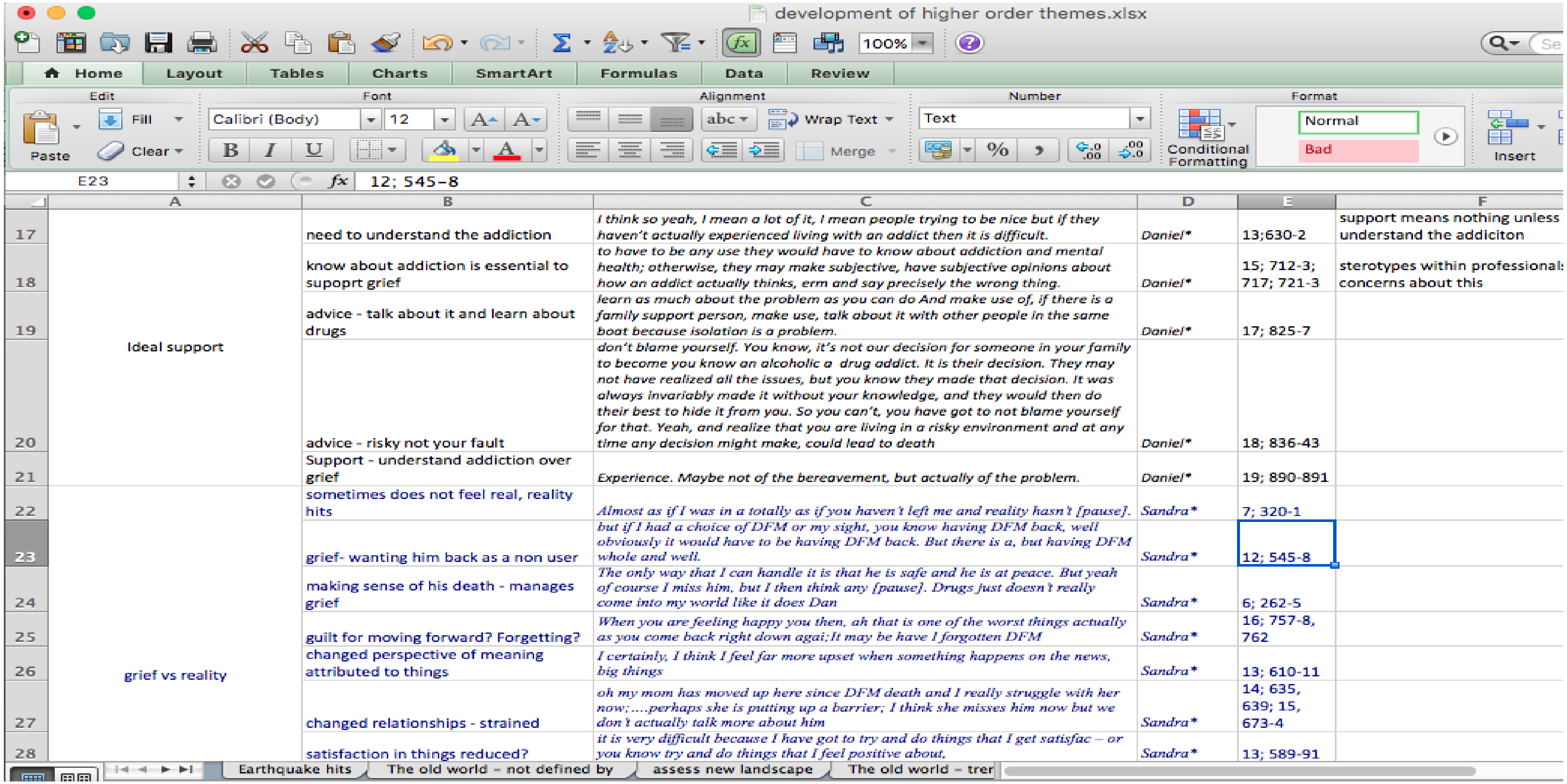
Example of stage six of analysis: Worked example of table developed to represent each superordinate theme was created that including a list of corresponding emerging themes, direct quotations from the transcript detailing line/pages they could be found.



	A	B	C	D	E	F	G
1			Emerging Theme	Quote	Page/Line	Notes	
2		I adored her	person before the drugs: my daughter	as a person, she had a very, very powerful personality, very powerful. Erm… and my mum called her 'an old soul'….; If she walked in any room with a room full of people, you would know who she was.	1; 4-5; 7-8		
3			adored daughter	I absolutely adored her [strongly]. Yeah,… and we had a good relationship.	1; 15-16		
4			everything changed: expectations?	I don't really know what happened; everything just changed when she was 13; she said, 'I was fed up of being on that pedestal… and I decided I wanted to do something bad,'	1; 17-18; 20-21	was mom implicated in this? What were the expectations that were placed on her?	
5			problematic behaviour (DFM)	She was arrested for various things, even before she was using drugs.	3; 68		
6							
7		helpess parent/ helpless child	my world fell apart- my daughter the heroin user	: She left her diary out on the worktop at home, and I had a look in it, and I can still remember the date – it was the 18th of December, 1998, and in capital letters it says 'TRIED HEROIN, IT'S WICKED'. And, with that, my thoughts and perceptions on heroin then were not a 16 year old girl, well, not my daughter, for a start. And I, that was it, my world fell apart at that point, because I didn't understand anything about, about heroin, particularly.	2; 27-32	couldn't make sense of the drug use in the context it was her daughter, also did not understand the problem	
8			Helpless child and helpless parent	she came home, and she just said, 'Help me, please help me [imploringly].' I rang a helpline,… I think it was [Name] based in [Location], and there was an answerphone, so, again, I didn't know what to do. In the end, I telephoned the, the doctors,	2; 34-7		
9			problematic family relations: blaming self	I had split up with her father; I just kept blaming myself. I just kept saying, 'Well, obviously, it's because I've split up the family home.'	2; 57; 66-8	did I do this? Making sense of why she chose to use drugs	
10			inexperienced parent?	totally naïve in everything, I was, I just believed everything she said	2; 55-6	in relation to the drug use - mother had no experience of drugs and associated behaviours	
11			treatment - let down by lack of guidance	They didn't know what to do with her, because it's… back then, we're talking… well, 19 years ago, they didn't understand young people and heroin, ..she had an excellent counsellor that we saw in the doctors' surgery. She wasn't allowed to go to the clinic	2; 38-42	barrier due to age - no clear pathway	
				He called her his 'protégé' because he was determined that she was			

Appendix Sixteen: *Stage seven of analysis*

Stage seven of analysis: Superordinate themes representing data from all participants (shown as different colours), listing corresponding emerging themes, quotes, line and page number.



E23 12; 545-8

	A	B	C	D	E	F
17	Ideal support	need to understand the addiction	*I think so yeah, I mean a lot of it, I mean people trying to be nice but if they haven't actually experienced living with an addict then it is difficult.*	*Daniel**	13;630-2	support means nothing unless understand the addiciton
18		know about addiction is essential to supoprt grief	*to have to be any use they would have to know about addiction and mental health; otherwise, they may make subjective, have subjective opinions about how an addict actually thinks, erm and say precisely the wrong thing.*	*Daniel**	15; 712-3; 717; 721-3	sterotypes within professional concerns about this
19		advice - talk about it and learn about drugs	*learn as much about the problem as you can do And make use of, if there is a family support person, make use, talk about it with other people in the same boat because isolation is a problem.*	*Daniel**	17; 825-7	
20		advice - risky not your fault	*don't blame yourself. You know, it's not our decision for someone in your family to become you know an alcoholic a drug addict. It is their decision. They may not have realized all the issues, but you know they made that decision. It was always invariably made it without your knowledge, and they would then do their best to hide it from you. So you can't, you have got to not blame yourself for that. Yeah, and realize that you are living in a risky environment and at any time any decision might make, could lead to death*	*Daniel**	18; 836-43	
21		Support - understand addiction over grief	*Experience. Maybe not of the bereavement, but actually of the problem.*	*Daniel**	19; 890-891	
22	grief vs reality	sometimes does not feel real, reality hits	*Almost as if I was in a totally as if you haven't left me and reality hasn't [pause].*	*Sandra**	7; 320-1	
23		grief- wanting him back as a non user	*but if I had a choice of DFM or my sight, you know having DFM back, well obviously it would have to be having DFM back. But there is a, but having DFM whole and well.*	*Sandra**	12; 545-8	
24		making sense of his death - manages grief	*The only way that I can handle it is that he is safe and he is at peace. But yeah of course I miss him, but I then think any [pause]. Drugs just doesn't really come into my world like it does Dan*	*Sandra**	6; 262-5	
25		guilt for moving forward? Forgetting?	*When you are feeling happy you then, ah that is one of the worst things actually as you come back right down agai;It may be have I forgotten DFM*	*Sandra**	16; 757-8, 762	
26		changed perspective of meaning attributed to things	*I certainly, I think I feel far more upset when something happens on the news, big things*	*Sandra**	13; 610-11	
27		changed relationships - strained	*oh my mom has moved up here since DFM death and I really struggle with her now;….perhaps she is putting up a barrier; I think she misses him now but we don't actually talk more about him*	*Sandra**	14; 635, 639; 15, 673-4	
28		satisfaction in things reduced?	*it is very difficult because I have got to try and do things that I get satisfac – or you know try and do things that I feel positive about,*	*Sandra**	13; 589-91	