Neonatal Death: Grief and Support Experiences of Fathers in the Australian Context

Student ID: a1645114

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School of Psychology

University of Adelaide

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Abstract

The death of a baby in the neonatal period has significant adverse physical and psychological impacts on parents. Research concerning neonatal death primarily focuses on the experiences of mothers, with limited research available examining the grief and support experiences of fathers. To fill this gap in the literature, using a qualitative research design, nine fathers were interviewed regarding their experiences of grief and support, including any barriers or facilitators in accessing support, following the death of their baby in the neonatal period. Thematic analysis resulted in four overarching themes. Findings indicated that neonatal death is an intense emotional experience that can impact all aspects of a father's life. Fathers who could access the support they required found these supports to be helpful in coping with their grief. Overall however, supports were perceived to be inadequate in both variety and availability, with greater follow-up support from the hospital desired. Fathers highlighted limited opportunities to make emotional connections with others and a strong desire to talk about their baby. Future research can expand on the current knowledge by examining the experiences of fathers in culturally diverse samples, and gender and sexuality diverse samples. The results of this study contribute to developing a better understanding of how healthcare professionals and support organisations can effectively assist fathers in coping with grief after the death of their baby, by increasing the variety of supports available and facilitating referrals to sources of support after leaving the hospital setting.

Keywords: fathers; grief; neonatal death; supports; loss

Declaration

This thesis contains no material which has been accepted for the award of any other degree of diploma in any University, and, to the best of my knowledge, this thesis contains no material previously published except where due reference is made. I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digital thesis repository, the Library Search and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

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September 2020

Contribution Statement

In writing this thesis, my supervisors and I collaborated to generate research questions of interest and design the appropriate methodology. As this research is part of an existing program of research, the ethics application was amended by my primary supervisor to include myself as the student researcher and any neonatal death specific questions that may be included in the interview schedule. I conducted the literature search and submitted the ethics application. My supervisors and I collaborated in creating the interview schedule, and my primary supervisor attended the pilot interview to ensure the appropriateness of interview questions and to highlight any necessary changes. I recruited participants from a group of fathers who had previously expressed interest in the larger research program. I arranged and conducted all interviews and completed the analysis with corroboration from supervisors for the final themes (as is standard in qualitative research). I selected all extracts and also wrote up all aspects of the thesis.

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CHAPTER ONE

Introduction

1.1 Overview

The death of a baby in the neonatal period is an unexpected outcome of pregnancy that results in profound effects on parents (Flenady et al., 2014), including adverse impacts on physical and psychological wellbeing (Banerjee et al., 2016; Lang et al. 2011). Neonatal death has been frequently researched alongside miscarriage and stillbirth, but very few studies have focused on neonatal death in isolation despite potential differences in experience, grief outcomes and support needs (Woodroffe, 2013). Existing research concerning neonatal death has also focused mostly on the experiences of mothers (Martinez et al., 2019), finding high levels of distress and grief (Vance et al., 2002). Recent studies have acknowledged a gap in men's experiences of pregnancy loss, and researchers have sought to expand the literature available (Jones et al., 2019; Martinez et al., 2019; Nguyen et al., 2019; Obst et al., 2020). However, the same level of research has not occurred for neonatal death. As such, this study aimed to address this gap by exploring Australian fathers' grief and support experiences after the death of their baby in the neonatal period.

1.2 Definitions and terminology

1.2.1 Pregnancy loss and neonatal death

In Australia, neonatal death is defined as the death of a baby within the first 28 days after birth (Australian Bureau of Statistics, 2018), occurring in approximately 2.5 of every 1000 pregnancies (Australian Institute of Health and Welfare, 2020). Due to the limited availability of research on men's experiences of neonatal death, the literature review for this thesis has also encompassed pregnancy loss experiences for both mothers and fathers. The term 'pregnancy loss' will be used to refer to any death in-utero, including miscarriages and stillbirths, with the specific terms miscarriage and stillbirth used when required. Miscarriage is defined in Australia as a loss occurring at less than 20 weeks' gestation, and stillbirth is defined as a death in-utero from at least 20 weeks' gestation or over 400 grams in weight (Australian Bureau of Statistics, 2018).

1.2.2 Men in heterosexual relationships

Pregnancy loss and neonatal death have historically been considered 'women's issues', with limited literature available on the impacts of this loss on the health and wellbeing of fathers (Due et al., 2017). Much of the literature available on men's grief experiences, and the focus of this thesis, is on heterosexual men, and does not include the experiences of gay, transgender or non-binary parents. Throughout this thesis, the term 'father/s' refers to heterosexual men and will also be used to refer to the male participants of this research.

1.3 Models of grief

1.3.1 Grief styles

Grief is a normal but complex response to the death of a loved one, unique to each individual (Aho et al., 2006), however, general patterns have been identified. Doka and Martin (2011) differentiated between intuitive and instrumental grief styles; the former characterised by expression of the grief experience, such as talking about painful feelings and crying, and the latter characterised by channelling energy into activity and attending to practical responsibilities. Within many cultures, including those considered 'Western', intuitive styles are considered to be more 'feminine' and instrumental styles are considered to be more 'masculine'. However, Doka and Martin (2011) have emphasised that these two styles are at opposing ends of a continuum, rather than concrete. Individuals can fall at any point on this continuum as well as exhibit a blended style.

Similarly, the dual-process model (DPM) of coping with bereavement also differentiates between two methods of coping: loss-oriented strategies and restoration-oriented strategies (Shannon & Wilkinson, 2020). Again, while within many Western cultures loss-oriented strategies are considered to be 'feminine', and restoration-oriented strategies are considered 'masculine' (Shannon & Wilkinson, 2020), the DPM proposes that individuals can oscillate between the two types of strategies (Schut & Stroebe, 1999; Stroebe & Schut, 2010). This approach is consistent with neonatal death research, where bereaved parents have reported to alternate between focusing on their grief and trying to adjust to a world without their baby (Currie et al., 2019).

1.3.2 Men's grief

While gender does not define grief styles, the grief experience is strongly influenced by gender role socialisation, personality and culture (Doka & Martin, 2011). In Western societies, gender roles have typically led to outward emotional expressions from women, and expectations that men are to remain "strong" (Fisher et al., 2018, p309). Recurring themes in men's grief research in general, for any form of loss, frequently include descriptions of men as practical, emotionally stoic and as problem solvers (Martinez et al., 2019). Additionally, Western formal supports (such as counselling) typically focus on affective expression (Doka & Martin, 2011), which directly conflicts with the expectations assigned to men (Addis & Mahalik, 2003). Effective support strategies would therefore ideally acknowledge potential differences in how men and women grieve and validate individualised grief experiences (Doka & Martin, 2011; Michon et al., 2003).

1.3.3 Disenfranchised grief

Disenfranchised grief occurs when a death is not publicly acknowledged or socially supported (Lang et al., 2011). The unanticipated and ambiguous nature of pregnancy loss and neonatal death has been associated with high levels of disenfranchised grief (Shannon & Wilkinson, 2020). When neonatal death occurs, parents often face ambiguity regarding funeral arrangements and sharing news of the death (Lang et al., 2011). Since neonatal death is not a common occurrence, parents are also likely to be faced with a lack of social recognition for their grief (Badenhorst et al., 2006). Also, stillbirth research indicates that due to the 'hidden' nature of stillbirth, parents have limited understanding of societal norms and expectations that help guide the mourning of their baby (Due et al., 2018). As reflected in pregnancy loss research, parents who experience a neonatal death may similarly feel as though their loss is dismissed by society, due to a lack of prescribed norms and social or cultural rituals concerning grief (Shannon & Wilkinson, 2020).

Disenfranchised grief is particularly salient for men experiencing pregnancy loss (Due et al., 2017) and highly likely for those experiencing a neonatal death, as they are perceived to fulfil more of a supportive role for their female partner. This supportive role is consistent with male gender role socialisation in Western cultures, where men anticipated to exhibit emotional control (Fisher et al., 2018). Bereaved fathers are, therefore, likely to experience a double-bind, where they are expected to support their family and also adequately cope with their grief (Cholette, 2012; Cook, 1988). No studies on disenfranchised grief specific to neonatal death were found during this literature review.

1.4 Current research and understanding of neonatal death

Most research on neonatal death does not represent the experiences of fathers, reflected in a recent review of 27 studies where 64.5% of studies on neonatal death and pregnancy loss were based on mothers, only 6.5% on fathers, and the remaining on couples (Jones et al., 2019). Research focusing exclusively on neonatal death is also scarce, with most studies combining stillbirth and neonatal death, or examining pregnancy loss in general (Badenhorst et al., 2006; Barr, 2012; Flenady et al., 2014). Indeed, only one study specific to fathers' experiences of neonatal death was found (Kimble, 1991). As such, to gain an understanding of fathers' grief after neonatal death, this literature review drew upon: studies that examined pregnancy loss and neonatal death in combination; studies of neonatal death experiences of mothers as well as fathers (including studies that focused solely on mothers' experiences of neonatal death); and studies that discussed fathers' experiences in Neonatal Intensive Care Units (NICUs).

1.4.1 Pregnancy loss research

In pregnancy loss literature, high levels of enduring psychological distress are reported for approximately one in five bereaved parents (Obst & Due, 2019). The supporter role played by fathers is consistently conveyed in the pregnancy loss literature (Bonnette & Broom, 2012) and some fathers have reflected that this role provided some distraction and relief from the intensity of their grief (Jones et al., 2019). Pregnancy loss research also describes the importance of fathers having a positive relationship with their partner to help minimise feelings of isolation which may result from limited validation of their grief (Nguyen et al., 2019). A scoping review on stillbirth and neonatal death in the United Kingdom (UK) found that fathers reported less intense levels of distress than mothers (Jones et al., 2019). However, researchers have questioned the extent to which measurements of grief are sensitive to male forms of expression or instrumental styles of grief (Jones et al., 2019; Obst et al., 2020).

1.4.2 Parent experiences of neonatal death

Most research on neonatal death has been conducted in the UK or the United States (US) and primarily consists of qualitative studies on the experiences of families, mothers or parents generally (Clyman et al., 1980; Currie et al., 2019; Redshaw & Henderson, 2018; Waugh et al., 2018). Of the few studies that report parents' experiences of neonatal death, anxiety, depression and sleep difficulties are common among both mothers and fathers (Vance et al., 2002). A qualitative study on 10 UK mothers' experiences found that mothers experienced enduring symptoms of post-traumatic stress disorder and complex grief (Waugh et al., 2018). A review study of parental grief after the death of a baby in the NICU described the experience of neonatal death as overwhelming and traumatic for parents, resulting in diminished capacity to absorb and retain new information (Woodroffe, 2013). Also in the UK, a quantitative study of 249 mothers found that mothers are often included in the decision to withdraw life support for a struggling baby, however an inability to process information from healthcare providers may hinder parents' capability for decision-making (Redshaw & Henderson, 2018).

As noted, only one study (Kimble, 1991) was identified as focusing exclusively on fathers' experiences of neonatal death. This qualitative study on eight US fathers' experiences of neonatal death found common emotional reactions for fathers included anger, guilt, irritability and sadness. Fathers in this study also reported experiencing sleep difficulties, loss of appetite and restlessness.

1.4.3 Fathers and the NICU

Several studies have focused on fathers' experiences within the NICU (Archibald et al., 2019; Fisher et al., 2018; Hearn et al., 2020; Ireland et al., 2019; Stefana et al., 2018). In a review of fathers' engagement in NICUs, the emotional experience of having a baby in the NICU was described as "a rollercoaster of closeness and separation" (Fisher et al., 2018, p308), with parents feeling overwhelmed at seeing their baby in an incubator surrounded by equipment (Stefana et al., 2018). An Australian qualitative study on the NICU experiences of 17 mothers and six fathers found that in addition to commonly reported symptoms of anxiety and depression, stress and trauma have also been described by parents who have a baby in a NICU (Ireland et al., 2019). Another US qualitative study found that many fathers experienced added pressure from a need to return to work due to financial responsibilities or to care for other children (Hearn et al., 2020).

1.4.4 Australian studies on neonatal death

In Australia, a series of studies by Vance et al. (2002, 1995, 1994, 1991) examined anxiety, depression and alcohol consumption in bereaved parents after a neonatal death, stillbirth, or infant death. For example, Vance et al.'s (2002) 30-month follow-up study using self-report questionnaires to examine the experiences of 138 bereaved parents who remained in a relationship with their partner, found that fathers' distress varied across time and peaked at the 30-month point. In addition to the studies by Vance et al., one correlational study (Barr, 2012) has been identified in the Australian context within the past decade. Barr (2012) found that fathers were more likely to experience shame and guilt after experiencing stillbirth or neonatal death than mothers. Recent systematic reviews have highlighted a need for updated research on fathers' experiences of grief and support experiences following neonatal death (Jones et al., 2019; Obst et al., 2020), particularly within the Australian context.

1.6 Formal and informal support experiences

1.6.1 Experiences with hospitals and healthcare professionals

Within the hospital setting, mixed experiences have been reported following neonatal death. For example, Redshaw and Henderson's (2018) study found that limited private facilities were reported to be available, with some mothers being placed in a postnatal ward within sight and sound of mothers who had had live babies. Often, there was no space for fathers to stay in the hospital overnight (Redshaw & Henderson, 2018). Limited space for fathers following neonatal death was echoed in a study by Serlachius et al. (2018), with fathers in another study reporting minimal opportunities to discuss concerns privately with NICU staff (Fisher et al., 2018). Conflicting reports on the adequacy of information provision following neonatal death have been reflected in the literature, with some mothers conveying positive experiences (Redshaw & Henderson, 2018) and others reporting feelings of disempowerment as a result of being ill-informed (Serlachius et al., 2018). Overall, research into desired support in the hospital setting following neonatal death has highlighted a need for shared decision-making between healthcare professionals and parents of the baby in the NICU (Kendall & Guo, 2008). Finally, due to the disenfranchised grief that may be experienced by parents following neonatal death or pregnancy loss, previous research has advocated for a continuation of support services after hospital discharge (Cholette, 2012).

1.6.2 Experiences with formal and informal supports

Limited variety of formal support options for parents after neonatal death and pregnancy loss were reported in the literature, with primary supports including support groups and individual counselling (Archibald, 2019; Harvey et al., 2008; Obst & Due, 2019). Mothers have highlighted the importance of connecting with other parents who have experienced neonatal death, to form an emotional connection, feel understood and empathise (Waugh et al., 2018). Peer support groups, particularly for parents in the NICU, can offer a shared experience in which parents can relate to each other, foster a sense of safety and provide each other with comfort (Archibald, 2019). A qualitative study into a father's support group within the NICU showed that fathers may also benefit from this type of peer support (Thomson-Salo et al., 2017), however providers should consider that those with instrumental grief styles may be reluctant to openly share their grief in organised support groups (Doka & Martin, 2011). Broader pregnancy loss research has found that observing other men in a similar situation and talking about coping strategies helps to give fathers a comparative norm and can lessen grief (Addis & Mahalik, 2003).

In pregnancy loss literature, informal supports, such as the provision of information or emotional support from family and friends, is considered to be an important factor in coping after the death of a baby (Lasker & Toedter, 2000). In one qualitative study, mothers discussed the importance of acknowledgement for their baby's life from those around them (Waugh et al., 2018). However, research shows that friends and family of bereaved parents may feel unsure about how to best provide support (McCreight, 2004) and that disenfranchisement of parents' grief can further exacerbate feelings of isolation and adversely impact social relationships (Aho et al., 2011).

1.7 Current care and support guidelines

In Australia, the Perinatal Society of Australia and New Zealand (PSANZ) has developed guidelines to inform quality bereavement care practices after stillbirth and neonatal death (Boyle et al., 2019). These guidelines encompass four overarching goals of care: good communication, shared decision making, recognition of parenthood and effective support. These overarching goals are mirrored in neonatal death care guidelines internationally; in Ireland, Canada and the UK (Health Service Executive, 2019; Henderson & Davies, 2020; National Bereavement Care Pathway, 2020). Practical recommendations from PSANZ for hospitals advocate for a collaborative approach and allowing parents to bond with their baby. Once the family has been discharged from the hospital, it is recommended that parents have access to 24-hour follow-up support, written information about ongoing bereavement support services and a hospital review meeting within 12 weeks of their baby's death. It is important to note that the guidelines imposed by PSANZ are directed towards supporting the mother of the baby or both parents together. The guidelines acknowledge that healthcare professionals should include fathers in all communications regarding their baby, but no other bereavement support guidelines specific to fathers are provided.

1.8 Aims and research questions

As noted above, there have been minimal studies conducted concerning fathers' experiences after neonatal death, with most papers focusing on miscarriage and stillbirth, or the experiences of mothers. As the first study on father's experiences of neonatal death within the Australian context, this thesis aimed to address this gap in the literature, and explore fathers’ bereavement and support experiences following neonatal death, through the following research questions: 1) How do fathers experience grief following neonatal death? 2) What supports do fathers perceive are available to them following neonatal death, and are these considered to be adequate? 3) What are some of the barriers and facilitators that fathers experience in accessing supports, including future support options that they would like?

CHAPTER TWO

Method

2.1 Participants

This study formed part of a more extensive program of research exploring grief and support experiences for fathers after pregnancy loss or neonatal death. As part of this larger program of research, participants completed an online survey and provided contact details if they wished to participate in a follow-up interview to discuss their experiences in greater depth. Participants who had experienced a neonatal death and who indicated their interest in a follow-up interview were contacted for participation in the current study (a total of $N = 14$ participants).

Participants for this study were nine Australian men (64% of the sample who expressed interest in an interview), who had experienced a neonatal death. Men were eligible to participate if they were fluent in English, over the age of 18 years and had experienced a neonatal death at least six months earlier (to minimise distress). Ten interviews were conducted however one participant was subsequently excluded as it was revealed during the interview that his baby died beyond the 28-day neonatal period.

As reflected in Table 1, participants were aged between 31 and 42 years ($M = 35$ years, $SD = 3.46$) at the time of the interview, and time since loss was between one and 12 years ago ($M = 3.90$ years, $SD = 3.87$). The age of the baby at the time of death varied, from 30 minutes to 27 days ($M = 8$ days, $SD = 8.64$). All participants were in a relationship with the mother of their baby at the time of the interview. One father had completed secondary education, and the other eight fathers completed tertiary education. All fathers were employed at the time of their baby's death and when their interview was conducted. To protect the identity of participants, only some of the demographic information collected from participants has been reported in Table 1.

Table 1.

Participant characteristics

Name*	Age	Other children	Age of baby	Time since loss
Sam	42	Three children	9 days	12 years
Paul	35	Three children	10 days	10 years
Cameron	Not provided	Two children	3 days	3 years
Nathan	38	Four children; one is a surviving twin	27 days	2 years
Bill	31	No other children	Lost twins at 3 days and 12 days	2 years
Harrison	32	Two children	3 days	2 years
Ben	33	Partner is currently pregnant	30 minutes	2 years
Adam	38	Partner currently pregnant, one child prior to loss	21 days	1 year
Max	34	One child	32 minutes	1 year

* Participant names are pseudonyms

2.2 Procedure

The University of Adelaide Human Research Ethics Committee approved this study (HREC-2018-273) on the 28th of April 2020. Survey respondents who had experienced a neonatal death and had indicated an interest in participating in a follow-up interview were contacted via email. Potential participants were invited to send a return email if they wished to participate. Men who indicated interest were then contacted to schedule their interview, to be held either over the telephone or Zoom. Due to the implications of COVID-19, face-to-face interviews were not offered.

Participants were emailed a Participant Information Sheet and Consent Form (Appendix A and B) outlining the study and providing information regarding support resources for parents who have experienced a neonatal death. One participant who showed a high level of emotional distress during the interview was reminded of their right to end the interview, however, chose to continue. Following ethics approval criteria, all participants were sent a follow-up email within a week of the interview, with contact details for additional support resources.

Interviews, conducted between May and July 2020, were recorded using a digital recording device. Interviews ranged between 45 and 97 minutes in length (M = 63 mins, SD = 17.75). The researcher and an academic supervisor conducted a pilot interview in May 2020 with the first participant to assess the suitability of the proposed interview schedule. Following the interview, no changes were required; the interview schedule was deemed appropriate for the remaining interviews. The pilot interview was therefore included in the final analysis.

Given the exploratory nature of the research, interviews took a semi-structured approach with open-ended questioning. Interview questions (Appendix C) were developed based on previous studies in the pregnancy loss literature (Jones et al., 2019; Kimble, 1991;

Smith et al., 2020) including the findings of the larger program of research (Obst et al., 2020). Post-interview field notes (Appendix D) were written by the researcher after each interview to reflect on the interview process, identify any required alterations to future interview questions and to highlight additional insights into the data collected (Braun & Clarke, 2013).

Interviews were transcribed verbatim using an orthographic method which included all verbal talk and utterances (Braun & Clarke, 2013). Each participant was allocated a pseudonym to maintain confidentiality and anonymity, and all identifying features were removed from the transcripts. Audio recordings were uploaded to a password-protected computer before being deleted from the recording device.

Following Tracy's (2010) criteria for robust qualitative research, participants were asked if they would like a copy of their transcript to provide any feedback. This consultation (termed member reflections) ensured that the data collected was representative of participants' views and that they were not misrepresented. Five participants requested a copy of their transcript, and one participant provided additional feedback. This participant highlighted the difference between neonatal death and other pregnancy loss types and emphasised the need for support services to be specialised to the type of loss experienced.

Tracy (2010) also highlights the importance of self-reflexivity in qualitative research. The researcher is a young woman with no personal experiences of pregnancy loss or neonatal death. This may have influenced participants' willingness to openly share views with the researcher, as they may have felt that she would be unable to directly relate to their grief experiences. However, multiple participants expressed a strong desire to discuss their neonatal death experiences and verbalised their appreciation for research focusing on this under-represented area of men's grief. Most participants expressed a hope that sharing their experience would contribute to better support for men in the future.

2.3 Data analysis

This study was informed by a realist epistemology, whereby meaning was not applied beyond the participants' interview data (Braun & Clarke, 2013). Thematic analysis was used to analyse the data. After the interviews were transcribed, the six steps to comprehensive thematic analysis (Braun & Clarke, 2013) were undertaken. This began with the researcher immersing herself in the data, noting potential items of interest and coding anything of relevance. The researcher then searched for themes within the coded data, highlighting potential patterns, before creating a thematic map displaying the relationships between the provisional themes and subthemes. Following the steps outlined above and the research questions for this study, an inductive approach was used to identify themes from the data, guided by the research questions. Through discussions with the supervisory team, themes were refined, named and cross-checked to increase reliability and consistency as recommended by Braun and Clarke (2013), and extracts to represent the themes were chosen.

CHAPTER THREE

Results

3.1 Overview

Thematic analysis generated four overarching themes: '*Neonatal death is a highly emotional experience', 'Sense of injustice', 'From hospital to home: continuity of care'* and '*Gendered support approaches'*. Each theme includes two to four subthemes, as shown in Figure 1.

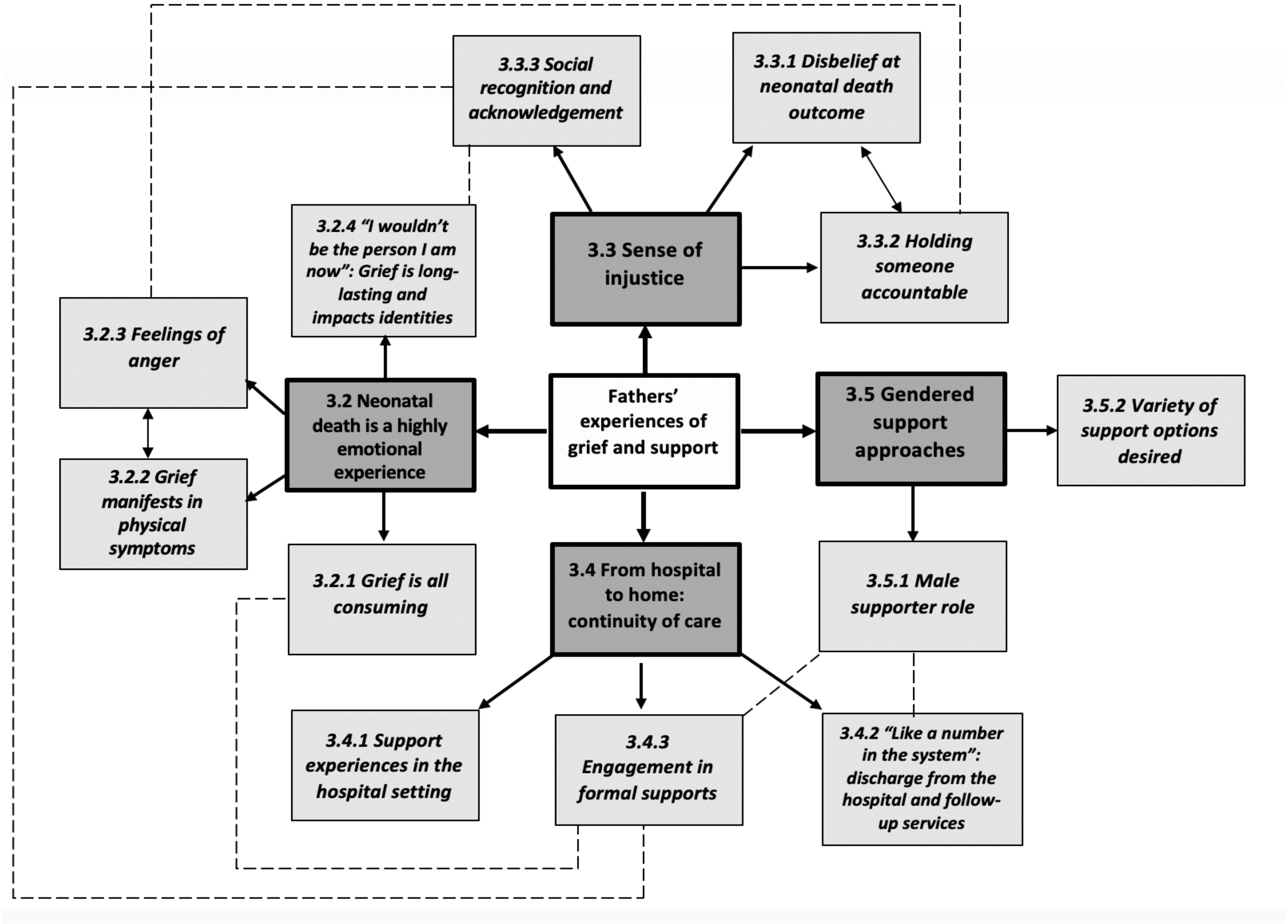

Figure 1. Thematic map representing relationships between themes and subthemes

3.2 Neonatal death is a highly emotional experience

3.2.1 Grief is all consuming

All fathers described the death of a baby in the neonatal period to be highly emotional and "*the worst time in your whole life*" (Sam, Lines 474-475). For most fathers, the death of their baby was sudden and unexpected. Fathers report being somewhat aware of the likelihood of other pregnancy losses such as miscarriage, however they had not considered the possibility of neonatal death. For some fathers, the unexpected nature of the death of their baby was amplified by being unaware of any medical complications before their baby's birth:

> *"…I was also just kind of bracing myself at the same time for, you know, miscarriages are obviously common physically [before] the twelve week mark but I think, I guess what really took us by surprise was that we could lose the baby at this at that kind of gestation where it was you know, twenty-odd weeks we just didn't - that completely blindsided us."*
>
> (Max, Lines 106-111)

As neonatal death was such an unexpected outcome, fathers reported little preparation for the intensity of emotion accompanying the death of their baby. Once healthcare professionals confirmed medical complications, accompanying decisions occurred very quickly, with limited time for fathers to process the circumstances. As such, many fathers described reaching a point where they were overwhelmed and struggled to process or retain any new information. This was highlighted by Paul, who became confused when trying to comprehend his baby's medical condition:

> *"…there's a little meeting room, a little counselling room, where they explain everything, and we weren't getting it, we just weren't in the right headspace. I remember I kept getting the name of the [condition] wrong, it was Cerebral Palsy and*

> *I kept saying Cystic Fibrosis. I just didn't know what was going on. I just, I kept saying it and it was like why am I - I was so confused and it was exhausting."*
>
> (Paul, Lines 226-231)

Overall, fathers reported intense psychological distress and feeling as though *"there [was] nothing else in your life"* (Sam, Lines 474-476). In addition to this intense distress, fathers reported that grief manifested in many ways, reported in the subthemes below.

3.2.2 Grief manifests in physical symptoms

Fathers indicated that they experienced physical symptoms such as nightmares, stabbing pain, or general bodily pain as a result of their grief. Symptoms varied in both timing and intensity, with some occurring frequently for short periods and others infrequently for more extended periods. For Adam, the confronting image of his baby attached to a ventilator in the NICU turned into nightmares and adversely impacted his sleep, after the death of his baby:

> *"In probably the couple of weeks post her death, so when she was in NICU she was ventilated and she had a whole range of different ventilation solutions they were trying to use, um one of them was a high frequency ventilation where it's kind of quite rapid in small amounts of air they pushed in and I did have several nights afterwards where I'd wake up and the bed would be shaking and I would feel like I'm being ventilated and sort of wake up in that."*
>
> (Adam, Lines 95-102)

Similarly, Sam experienced physical symptoms in the form of sharp pains:

> *"…I said well you know, most of the day I feel like every five minutes I'm being stabbed in the chest you know because it became a physical, the grief became a physical pain."*
>
> (Sam, Lines 86-89)

Another father, Harrison also experienced physical pain and attributed this to the anger he felt after his baby died. Harrison reported that while the frequency of pain varied, the pain itself was long-lasting. He attributed the reduction in pain to the formal support he sought to assist his grief process. Harrison also described the re-emergence of this physical pain as a sign of upcoming grief:

> *“…I just had like really, really severe pain in my jaw for months and months and the counsellor ended up telling me that that was most likely due to anger and just the stress that that puts on your body, so working through sort of some of those problems and bringing that all to the surface and talking about it really helped. Now my jaw doesn’t hurt very much, unless I have days where [baby]’s loss really affects me again and then those days, you can tell it comes on it’s like aw my jaw hurts okay, I’m leading into a pretty bad day today.”*
>
> (Harrison, Lines 90-97)

As Harrison noted, the physical pain he experienced was attributed to anger. Experiencing anger following the death of a baby was common in fathers’ accounts, as seen in the following section.

3.2.3 Feelings of anger

Anger was a common response reported by participants. One father found that his anger was triggered by events perceived as “*trivial*”, which led to embarrassment related to expressing his anger:

> *“…even when I got angry over trivial things, where it in hindsight probably losing [baby] was the real thing that I was angry at, in the moment, when you’re getting angry at these trivial things it’s a bit embarrassing ((pauses)) when I’m sad about it I don’t mind who sees that, it’s a hard thing to lose a child, you should be able to be to*

> *be sad about it, but when it seems like you're being angry over trivial things [I feel] a bit embarrassed."*
>
> (Ben, Lines 184-189)

Anger was experienced and managed by fathers in different ways. As can be seen in the extract above, in hindsight, Ben could appreciate that his anger was a result of his grief, although this was not apparent at the time. Notably, Ben expresses that sadness is the socially expected grief expression, while anger is less acceptable. This could potentially lead to maladaptive coping strategies among men who experience grief in this way, with Cameron reporting the use of alcohol consumption and damage to property as his outlet for anger:

> *"…the first night back in [city] my friends threw a party for me that I didn't know about and I got, like, really, really out of control drunk and angry and ended up passing out, out the side of my house on a hill, face down in the dirt covered in vomit. My wife came out and checked on me and thank God if she didn't come out and get all the crap outta my mouth I probably would've died. At that point I didn't care if I lived or died […] the next couple of weeks I went out to a friend's birthday party and the same thing happened I got very out of control and angry, did a large amount of criminal damage to community facilities, just out of control. I woke up the next morning, I walked home which was like a thirty [kilometre] walk […] slept it off, woke up, went to work Monday morning and by lunchtime I had resigned."*
>
> (Cameron, Lines 262-275)

In addition to physical expressions of anger, Cameron resigned from his workplace as a result of his grief. This was in contrast to other participants who, in an attempt to cope with their grief, described initially going into *"a practical mode where things just had to get done"* (Paul, Lines 81-82), rather than experiencing anger. Similarly, Adam described using work and exercise to shift the immediate focus away from his grief because they "*allowed me to have that mental break from it.*" (Adam, Lines 109-115).

3.2.4 "I wouldn't be the person I am now": Grief is long-lasting and impacts identity

Finally, fathers described that the significant psychological distress and grief following the death of their baby was long-lasting, although it did lessen over time, with Adam describing: *"like someone just slowly turns the volume down"* (Adam, Lines 432-434). Another father, Bill, whose twin babies died, described not having control of his grief, which he felt also changed who he was as a person. Mirroring the physical manifestations reported earlier, Bill likened his ongoing grief to physiological sensations, where he was unable to predict its frequency or manage its timing:

> *"…this type of thing never leaves you. It changes you and it forces you to live with [it] but you never lose it, no it's more of a, you felt like you missed a breath, suddenly you're breathing you're inhaling you, you feel like you miss an inhale um and that's every time I think of the girls […]if I'd lost this feeling or it suddenly disappeared, I wouldn't be the person I am now and that way then the girls would've never existed."* (Bill, Lines 656-666)

Importantly, in addition to discussing the intensity of his grief, Bill also noted that he did not want his grief to "*disappear*", because then it would be as though "*the girls… never existed*", indicating the complex and dilemmatic nature of grief experiences for fathers. In terms of changes to identity, Harrison also indicated that he felt his grief impacted his identity and perspective toward the world. He referred to a distinct separation between his behaviours and priorities before and after the death of his baby:

> *"I guess the easiest way to explain it is there's like my life before [baby] and then there's my life after [baby]. There's like a really clear-cut line there between who I*

> *was before and who I am now, so it's changed pretty much everything about me from how I look at life and how I approach things and how I sort priorities.*
>
> (Harrison, Lines 34-38)

Overall, grief after neonatal death was described as an all-consuming, highly emotional experience. The grief experience was reported to be influenced by the ability to process new information, feelings of anger and physical symptoms. Fathers used both adaptive and maladaptive strategies in response to their grief, and the death of their baby often had long-lasting impacts on identity.

3.3 Sense of injustice

3.3.1 Disbelief at neonatal death outcome

Accompanying the unexpected nature of neonatal death and the subsequent feelings of anger highlighted in Section 3.2, was a sense of injustice. This primarily stemmed from what one father described as *"the basic principles of life"* (Paul, Line 124), where good people are not expected to experience traumatic events. Fathers often described their disbelief at the death of their baby, followed by reflections of it being unfair and unjust. This belief was reflected by Paul, who described being actively engaged in medical appointments and taking every possible measure to ensure his baby was healthy:

> *"...we were just onto everything you know, my wife was eating the right foods she was super careful with what she did, we're worriers, and every time we had a medical appointment we'd make sure we were on top of everything and there was nothing going wrong. So yeah I guess that was also part of the shock as well, that we'd done all the right things and we felt really cheated by the experience, felt really cheated, cheated by life [...] you know we're good people and this had happened to us [...] if you're a good person you do the right thing, you know you don't get these things, [they] don't happen to you. But they do and that really took us by shock."*

(Paul, Lines 68-74; 122-126)

In trying to make sense of why their babies died, some fathers compared their experience with those of their friends and family. Ben described a comparison to his brother who has fathered multiple surviving children, and was perceived not to be as deserving of fatherhood as Ben himself:

> *"…so it's difficult to see that, within your own family where from my perspective, honestly I feel like I deserve to be a father more than he does and I, not that I don't feel like I'm a father, but I don't have a child to raise, where, he should have three and at the moment he only has one in his custody."*
>
> (Ben, Lines 167-172)

Mirroring psychological theories of perceptions of injustice discussed in the final section of this thesis, fathers experienced a sense of disbelief at the death of their baby, often leading them to try and hold someone accountable, as seen in the following theme.

3.3.2 Holding someone accountable

As noted previously, fathers reported experiencing anger following neonatal death. In many cases, anger led to fathers looking for someone to blame or hold accountable for the death of their baby. Fathers revisited decision-making, medical care and support systems in search of an explanation. Ben described the additional struggle he experienced as a result of being unable to direct his feelings of anger when he could not find someone to hold accountable for the death of his baby:

> *"…there was a fair bit of anger on my part because there wasn't really an explanation for what happened and that it, it couldn't be directed at anyone you know I don't blame [my wife] for what happened, I don't blame any of the doctors or medical staff for what happened. We attended the hospital afterwards for a follow-up, they couldn't really give an explanation as to why it happened and it's challenging*

> *when something like that happens and [you're] sad and you're angry and there's no one and nothing to direct that anger at."*
>
> (Ben, Lines 38-44)

When fathers could not find someone to hold accountable, some turned the focus onto themselves. These fathers tried to determine if there was a chance that the outcome for their baby would have been different if they had made different decisions. For example, Nathan was aware of his twin babies' medical complications before their birth. He described experiencing guilt and regret for not being more insistent on an earlier caesarean, a decision he felt may have resulted in a different outcome for one of his twins:

> *"…because we had the complications with the pregnancy I kept on asking if we should be having an elective caesar[ean] earlier to get [the twins] out into the world and when [baby] then had the complications he had, I had and still do have a bit of guilt about not - forcing's not the right word - but not being more uh, persistent or insistent […] even though there [were] complications involved with prematurity I would prefer to be dealing with those than to be dealing with the regret. I still have guilt that I didn't do more to try and get them out earlier."*
>
> (Nathan, Lines 65-76)

Similarly, Sam described experiencing guilt when evaluating the decisions he made about having a baby and holding himself accountable. Sam described blaming himself because he influenced the timing of the pregnancy, despite this decision not directly affecting his baby's medical condition:

> *"…I certainly felt, to blame to some degree um if that makes sense because as I said my wife had wanted another child and I guess I felt like I had, had made the timing of having the third child so in some ways I felt guilty [for] you know, not understanding*

> *the need earlier or whatever it was. I felt guilty that you know, that I had set off this chain of events sort of led to having a child that had died."*
>
> (Sam, Lines 103-108)

3.3.3 Social recognition and acknowledgement

Most fathers expressed that they did not feel as though the people around them recognised their grief, further adding to a sense of injustice. Fathers described the importance of talking about the birth and death of their baby, however found that others were often not willing to engage in these discussions. Some fathers noted that although others were not trying to be hurtful, they were unaware of appropriate ways to respond to a parent who has experienced neonatal death. Harrison explained:

> *"I think a lot of people were too scared to have said anything. I had a lot of friends who would just never bring it up and just act like you know, nothing ever happened we were never pregnant, [baby] was never born, which hurts, and I think that's just because people don't know how. I mean what do you say, there's not really any words that can make it better, so I suppose that's just people trying to protect themselves as well as protect you."*
>
> (Harrison, Lines 410-415)

Paul expressed an almost identical experience, where he strongly desired acknowledgement for his baby:

> *"…like all our friends disappeared. People just didn't call anymore, even siblings, no one would bring it up. It's all we wanted to talk about, it's all we cared about, is our baby and it died, but no one would talk about it because they didn't want to upset us."*
>
> (Paul, Lines 338-341)

This lack of social recognition resulted in additional adverse consequences for some fathers, further compounding a feeling of injustice. For example, Adam took three weeks leave from work after the death of his baby, however his workplace deemed this time period 'too long' and he was subsequently made redundant. This heightened sense of injustice contributed to a change in Adam's perspective of society:

> *"I had about three weeks off, after [baby] died and then I had another week where I kind of worked from home and then when I got back to work I was told that I'd had too much time off over this and that they would be uh terminating my position as a result of that ((pauses)) so I had to find another job [...] it made you realise what you have to deal with. I mean if you just lost a child [and] someone would literally call you into a room and say I'm going to sack you because you've taken too much time off like, you sit there and go well okay, that's just not the way the world should work."* (Adam, Lines 388-392; 420-424)

Overall, the sense of injustice experienced by fathers resulted primarily from disbelief at the death of their baby and an inability to determine why their baby died. This feeling was consistently exacerbated when fathers were unable to find someone to hold accountable, or their grief was not recognised by others.

3.4 From hospital to home: continuity of care

3.4.1 Support experiences within the hospital setting

Most fathers reported positive experiences of support within the NICU and hospital. Adam described: *"I cannot speak more highly of [our paediatrician] or her team, of the counsellors that they have"* (Lines 205-206). Similarly, Nathan praised the NICU nurses that cared for his baby: *"The NICU staff, the nursing staff particularly, were brilliant"* (Line 143). Despite fathers feeling that they had limited processing capacity to retain information about their baby's medical condition, clear, sensitive communication from healthcare professionals was described:

> *"Everyone was really good right from the initial appointment after the first positive test, to the radiology, the medical imaging, the ultrasounds and right through to the hospital where we spent five or six days. Everyone was amazing and spoke clearly and um presented our options in the most professional manner they could."*
>
> (Ben, Lines 77-81)

All fathers described being provided time with their baby at the point of death. Many of these fathers highlighted that healthcare professionals encouraged bonding with their baby. This was also the case for babies who had no chance of survival and were therefore not admitted to the NICU. Some fathers were also provided with private time with their baby before their death, with one father describing effort from the NICU nurses to ensure his baby's wellbeing was not compromised:

> *"…we hadn't actually had the chance to you know put him on our lap and sit with him and so when [my wife] asked to do that, they had like six nurses come in and work together to move all the machinery and [baby] around to make sure that everything stayed connected and nothing got broken. We did sit with him for a bit and then so once they did that, we realised that okay we can get him off his little bed sit him with us whenever we want so that became a realistic thing to do. Yeah they were really um ((pauses)) what's the word um, caring I think is the easiest way to put it, they're very caring people."*
>
> (Harrison, Lines 175-184)

Many fathers reported feeling included in the NICU and the hospital. Sam described that both he and his wife *"were included and basically put at the same level"* (Line 208). However, some fathers noted that in the hospital, there was a clear focus on the mother of their baby as the patient. There were often minimal practical facilities and space to accommodate fathers, despite their baby's severe medical complications and limited chance of survival. This was reflected by Cameron, who stayed at the hospital for the three days that his baby survived:

> *"So my wife had a private room um and it had like a bench, it was almost single bed length, not quite single bed width, but yeah they provided blankets and stuff I just had to like clean them up, fold them up and just re-use them. They wouldn't replace them and that was fine. The first couple of nights I just slept in the, um well one of the nights I slept in the family room, in the NICU, for like an hour and I was like the only one in there."*
>
> (Cameron, Lines 508-514)

While Cameron was not provided with a place to sleep in the hospital, he noted that he and his family were given privacy when sensitive medical information was delivered and after their baby's death. Consistent with statements presented in Section 3.2.1 (*Grief is all consuming*), Cameron discussed how healthcare professionals moved his family to a quieter ward after his son's death:

> *"…when he died, they moved everyone into a separate room where it wasn't as busy a ward. They put a blue butterfly on the door [as a] signal [of neonatal death]. The others on the street don't know what it is, but all the midwives and nurses and stuff, doctors, all know what that means and that you've lost a child."*
>
> (Cameron, Lines 749-753)

3.4.2 "Like a number in the system": discharge from the hospital and follow-up services

While fathers mostly felt that hospital services before the death of their baby and in the NICU were sufficient, there were inconsistencies in experiences after their baby died and following discharge from the hospital. The hospital's focus on the mother of the baby extended to emotional supports provided to parents after their baby's death, with some fathers reporting that they were unable to access hospital bereavement services as they were not a patient in the hospital. With regards to provision of information and in line with recommendations from PSANZ, all fathers received information about supports available after discharge in the form of booklets or pamphlets. Overall, fathers were provided with a variety of information, targeted at the mother of the baby or at both parents. Two fathers received a pamphlet about supports specifically tailored for fathers. No other father-specific supports were reported. All fathers described this provision of information to be the only support offered by the hospital at the point of discharge:

> *"…all of the support we were given was basically, booklets and things like that and with information to the places like [organisation] and [organisation] and things like that but no direct contact majorly."*
>
> (Sam, Lines 249-251)

In addition to limited information about male-specific supports after discharge, Harrison described that he found it challenging to obtain additional support from the hospital:

> *"…I remember they definitely offered their services to us to help, but I also remember after that they were really hard to get hold of. The social worker we had was um ((pauses)) probably a very busy person but trying to get hold of her to book in meetings or just have a chat, seemed really difficult."*
>
> (Harrison, Lines 244-248)

Most fathers did not receive a follow-up telephone call from the hospital. Ben described receiving no contact, after explicitly being told he would receive a call from the assigned social worker:

> *"…the social worker that we were seeing at the hospital had said that she would give us a call a week or two weeks after we returned home and, we didn't receive a call. It's possible that we didn't receive it because we're in a bit of a dodgy reception area,*

> *[...] but there was um, no other form of contact from the social worker that we're aware of either."*
>
> (Ben, Lines 280-284)

Several fathers were offered a review meeting with a healthcare professional in the hospital. These meetings were to enable parents to discuss their baby's medical complications and their grief. However, the focus of review meetings was on the mother of the baby and as such, some fathers perceived their grief to be overlooked:

> *"...there was a review session with the hospital as well, there was a definite focus on [my wife] rather than myself as the dad. She did suffer postnatal depression with [baby] and is therefore predisposed to it so then that was probably one of the reasons for the additional focus on her, [...] that may also have been because I was a little bit closed off as well, but they would more often talk to her about what was going on and uh sort of like what feelings were happening for her rather than specifically approaching me about them."*
>
> (Nathan, Lines 144-151)

Bill likened this lack of direct follow-up support from the hospital to being treated *"like a number in the system"* (Line 364).

3.4.3 Engagement with formal supports

Across the sample, engagement with formal supports was limited. Formal support, particularly individual counselling, was more likely to be used by fathers if they had previously accessed it in the past. For example, Adam actively sought support from a psychologist familiar to him:

> *"He's a person that I did see probably ten years before that. I had a lot of things happen in my career that I felt very hard to deal with, I lost a whole career because of a medical issue, so he helped me in a short period of time just, reconcile with that a*

> *little bit and provide a bit of direction. So I was quite comfortable knowing I was going to a person who I knew and trusted so that made it a bit easier"*
>
> (Adam, Lines 281-286)

In contrast, when Adam was offered to attend a support group connected to the NICU, he chose not to engage due to fear of openly expressing his emotion:

> *"So there's a men's help, uh, support group within the NICU, and they met once a week. Given what was happening with us I didn't go ((pauses)) um I think there's probably two parts to it, one I was you know, it was a lot to deal with and that was just another thing I didn't want to have to deal with, but there also is a lot of fear in that too. I'm going to have to go in there and address everything that I'm feeling about it [...] I'm better off just ((pauses)) staying focused on the task at hand and doing it that way. Looking back on it I probably should've done that, but, you know, it's optional they don't make you do it.*
>
> (Adam, Lines 261-271)

As noted in Section 3.2.2 (*Feelings of anger*), Adam used work and exercise to shift his focus away from grief. His reluctance to express his grief and desire to stay focused on practical tasks rather than attend support groups reflects an instrumental grief style. However, other fathers expressed positive experiences with support groups. These groups were open to mothers and fathers, with no support groups specific to fathers. One father described his support group as being a place to share and connect, and to receive acknowledgement for his baby:

> *"Support groups were good they were very close and quiet and people just sharing stories and pictures or, you know not sharing stories or pictures if they were just there to listen, but it was nice just to go somewhere like once a month and not have to worry about getting upset or saying the wrong thing and people just getting it."*

> (Harrison, Lines 281-295)

However, Paul found that some formal supports were not specialised enough regarding neonatal death. Combining supports with other pregnancy losses such as miscarriage made it more difficult for Paul to find an appropriate parent to relate to:

> *"…we always hated it when people would compare a miscarriage experience to a neonatal death, so whenever we kind of talked about our experience and somebody was talking about miscarriage we felt that's not even in the same realm […] we kind of [felt as] though they're not the same thing and you can't – the services need to be different because there's different needs."*
>
> (Paul, Lines 627-641)

Overall, men identified that follow-up supports from the hospital were minimal and inconsistent, leading to a lack of continuity of care. As such, men had to seek out support for themselves, with varying degrees of success. In general, fathers felt that information on male-specific supports was not adequately provided or tailored to their needs. Continuity of care, therefore, was perceived as an issue following discharge from the hospital, when fathers were experiencing intense grief and required assistance in accessing subsequent supports.

3.5 Gendered support approaches

3.5.1 Male supporter role

As highlighted in all themes described so far, many fathers focused on practical tasks and being the supporter for their female partner and family following neonatal death, which aligns with an instrumental grief style. This style of grief was considered a barrier for some fathers, who found it difficult to balance expressing their grief with being 'strong' to support others and attend to responsibilities. Adam described how this delayed his grief process and emphasised the importance and difficulty of the supporter role:

> *"…whether it's expected or not expected you have your own expectation that you have to step up you have to be there you have to you know, be the man kind of thing. Which is fine like, I kind of think that's the right thing but it doesn't make it easier to do it and I think that does delay you know, dealing with the grief a little bit as well, because you're so focused on making sure [wife's] healthy and that [older son]'s fed and he's happy and you know and the house is functioning and clean and all of the things that you would normally have to do and then you have to go back to work as well, so you just stack every waking minute of your life up to deal with that and you kind of have to but it's not easy."*
>
> (Adam, Lines 248-258)

As stated in the previous section, father-specific support groups were unavailable. Participants attributed the limited availability of male-specific support groups to a lack of engagement by other fathers:

> *"…I don't think I did any dad's support groups. Maybe they tried and there was, you know, not much interest for it. Um, but it was very rare that I'd see other dads in the support groups. It was mostly mums on their own ((pauses)) a few times people would bring their partners, but it was, it was pretty rare."*
>
> (Harrison, Lines 317-320)

Cameron also attempted to access support advertised specifically for fathers, but this was cancelled due to limited demand. Cameron suggested that this low uptake may be a result of the male supporter role:

> *"…they were really good to [wife] not so much for me. Um ((pauses)) they had like a father's group thing but the take up on that, like there was supposed to be like a coffee thing that I was going to go to but then they cancelled it because there was only two people that said yes, and they just, like I don't know - don't know if it's a cultural*

> *thing [or] like a masculinity thing that you know, we'll just grin and bear it or they've got other kids other responsibilities to work or whatever."*
>
> (Cameron, Lines 585-592)

In line with this, Bill, described a hesitancy to actively seek support as he was a *"stereotypical bloke"* who *"wouldn't be willing to ring this support group"* (Lines 763-764). In contrast, Sam, who could not find the emotional connection he was looking for when his baby died, went on to volunteer for a pregnancy loss/neonatal death support organisation in an attempt to provide fathers with an opportunity to connect with another father. Consistent with the experiences of other fathers seeking father-specific support, Sam found that the demand for men's services was low, as he did not receive a single call:

> *"…I actually ended up uh later on uh, training at [organisation] as a volunteer myself but was never I was called up once in the whole time that I volunteered there, so I don't think […] a lot of men [engage]."*
>
> (Sam, Lines 278-281)

3.5.2 Variety of support options desired

All fathers indicated that supports focusing mainly on the mother of the baby were somewhat warranted, as the mother experienced the physical process of pregnancy and birth. Despite this, most fathers advocated that they still required support and that they wanted to normalise fathers' expression of grief from fathers following neonatal death. For example, Harrison said:

> *"I'm usually pretty, pretty quiet um, and usually keep to myself but this is something that I just wanted people to understand and wanted people to know how, how much it hurt and so I was trying to be pretty open with how I felt through the whole process."*
>
> (Harrison, Lines 48-51)

Fathers also indicated that the form of support for fathers may need to differ to support for mothers. For example, Paul described how his grief was different from his wife's experience:

> *"…it affected my wife straight away and it's obviously because she had that physical connection with him um being in her and going through the birth, whereas I was just - I almost distracted myself by focusing on some of the medical and technical things that happened and I think I was affected emotionally, in a more slow and over a longer period of time, so I think it's the different kind of support."*
>
> (Paul, Lines 471-476)

Several fathers also highlighted a need for support options that allowed expression of emotion from men, as they *"need to feel the grief and anger and whatever else that [they] want to feel, otherwise it can overtake [them]"* (Ben, Lines 330-331). In general, however, the supports currently available to men were considered to be insufficient, with greater variability and availability desired. One father explained that others kept trying to push him towards support groups when that type of support did not appeal to him:

> *"…I think everyone tries to push you into these group things […] I don't know maybe they are successful, I don't know but for me it was just not something that, you know, I'm not too sure I would um, recommend how hard they push you into that and I think that, if they could offer different forms, it seems to be that that's the only way, it's like hey there's a men's group go over there. That seems to be the answer once you leave the hospital."*
>
> (Adam, Lines 459-466)

Finally, many fathers expressed a desire to relate to another father to make sense of their experience. This desire to relate to others aligned with the concept of disenfranchised grief and the limited social recognition fathers experienced regarding their grief. Harrison, who attended a formal support group, described the need for male-specific supports throughout his experience:

> *"…the support groups are really good but you know, sitting in there when you're the only dad and it's full of you know eight or nine mums it's hard [because] mum and dads have different connections. Like I didn't carry [baby] for nine months, I don't have the scars from the surgery so, there's a lot of differences between how [wife] and I were grieving at the start that, it was sort of harder to connect with the mums on that level. So I think if there was a dads group running, I think that would've helped a little bit more, at least just to start knowing that everything I was feeling was normal for the situation that I was in, because a lot of the time you doubt yourself like am I allowed to laugh at these jokes or you know am I allowed to smile today […] I don't know everything just felt different so, having someone or having a group of people to reinforce that you know, it's normal for what it is, would've been super helpful."*
> (Harrison, Lines 492-506)

Overall, many fathers highlighted the male supporter role and limited access to male-specific supports as barriers to engagement. The available support options were reported to focus primarily on the bereaved mother and fathers expressed a need for a greater variety, as some were unable to access the type of support they desired. Several fathers expressed relating to another father would have been helpful in processing their grief.

CHAPTER FOUR

Discussion

4.1 Overview

Four overarching themes were identified in this study. Overall, fathers experienced substantial and overwhelming grief, which, for some, resulted in anger, a strong sense of injustice and in some cases, manifested in physical symptoms. The intensity of grief was found to be influenced by social recognition of their baby's death, normative expectations of men as supporters, and the positive or negative impacts of available supports. Fathers reported a clear focus on mothers in the hospital setting, with limited follow-up services. These experiences are consistent with fathers' support experiences reflected in the wider pregnancy loss literature (Cacciatore et al., 2013; Obst et al., 2020). Barriers to engagement in formal supports included gender role socialisation and masculine norms within society, and limited availability of supports. The primary facilitator for accessing support was adequate facilitation of ongoing supports by healthcare professionals.

4.2 Fathers' experiences of grief after neonatal death

The grief experiences reflected in this thesis highlight the overwhelming nature of neonatal death, consistent with previous neonatal death literature (Kimble, 1991; Waugh et al., 2018, Youngblut et al., 2017). Fathers in this study had little to no preparation for the possibility of neonatal death, and several fathers described feeling "*blindsided*" (Max, Line 111), an experience that aligns with the reactions of fathers in stillbirth research (Jones et al., 2019).

Consistent with Doka and Martin's (2011) theory of grief styles, existing on a continuum from instrumental to intuitive, fathers in this sample described behaviours that reflected both instrumental and intuitive styles in their response to the death of their babies. Importantly, fathers that engaged in restoration-oriented strategies of the DPM (Stroebe &

Schut, 2010) that align with a more instrumental grief style, highlighted that the intensity of their grief was not diminished, but that the grief impacted them differently. For example, some fathers described the intensity of grief as being “*delayed*” (Paul, Line 470). Several fathers also reflected a more intuitive style of grief, where they focused on loss-oriented strategies of the DPM, such as seeking emotional connections with others and opportunities to express their grief (Doka & Martin, 2011; Stroebe & Schut, 2010). These fathers reported being unsuccessful in finding male-specific formal support options that suited their needs.

Regardless of grief style, fathers reported an increase in emotional intensity when the birth and death of their baby, and their position as a grieving father, was not acknowledged. This finding is consistent with Doka and Martin’s theory of disenfranchised grief (2011), experienced by fathers in this sample within the hospital setting, from their friends and family, in the workplace and from formal support approaches that focused on the mother of their baby. This experience echoes several studies in the pregnancy loss literature (Cacciatore et al., 2013; McCreight, 2004; Obst & Due, 2019). The individualised nature of grief after neonatal death highlights the importance of specialised support options to assist fathers in processing their grief and validating their experience.

In this study, some fathers’ grief was exacerbated by a sense of injustice. After the shock of neonatal death, and subsequent diminished processing capacity, some fathers struggled to make sense of their experience, with overwhelming feelings of being undeserving of their circumstance and a search for someone to hold accountable for their loss. Perceptions that ‘good things happen to good people’ and these are ‘the basic principles of life’ were reflected by fathers. This finding is consistent with just-world belief theory, where the breakdown of these expectations can lead to denial and feelings of anger (Lench & Chang, 2007).

In addition to feelings of anger, a sense of injustice also brought feelings of guilt for fathers. For some, these feelings manifested in physical symptoms. Feelings of guilt, anger and physical symptoms after neonatal death is consistent with Kimble’s study (1991), as well as the wider pregnancy loss literature (Barr, 2012; Jones et al., 2019). In contrast, responses for mothers reported in other research were more likely to be anxiety, depression and post-traumatic stress disorder (Waugh et al., 2018). These differences in the responses of mothers and fathers have also been highlighted in pregnancy loss literature (Badenhorst et al., 2006; Vance et al., 2002), emphasising the need for father-specific research to ensure the effectiveness of support options after neonatal death.

4.3 Fathers’ experiences of support after neonatal death

In the broader pregnancy loss literature, positive experiences with healthcare providers and formal supports have been suggested to assist parents in processing their grief (Cacciatore et al., 2013). Fathers have highlighted differences in experiences depending on the type of pregnancy loss. Neonatal death presents unique challenges in comparison to other pregnancy losses due to the emotional toll of having a baby admitted to the NICU, additional considerations regarding the baby’s medical care and the potential decisions regarding withdrawal of life support (Fry & Henner, 2016). This difference may be overlooked by guidelines such as those of PSANZ, that encompass both stillbirth and neonatal death. Despite this, all fathers in this study reported positive experiences within the hospital setting including being provided with privacy, clear explanations of medical complications and sensitive delivery of information. However, while most fathers reported feeling included by hospital and NICU staff, limited facilities and space for fathers to stay in hospital with their baby was also reported. This issue is consistent with literature that examines fathers’ experiences in the NICU (Serlachius et al., 2018).

Inconsistencies in support were most commonly reported in relation to follow-up services and the provision of information upon hospital discharge. In accordance with the PSANZ guidelines, fathers were provided with written information on support options, however few of these supports were specific to fathers. The need for a greater focus on grief experiences and male-specific support options was emphasised by the fathers in this study, as well as fathers who have experienced pregnancy loss (Obst & Due, 2019). Restoration-oriented tasks helped fathers across the sample 'distract' themselves from their grief and regain a sense 'normalcy'; however, this 'masculine' grief style is also associated with unease when engaging with supports that require open expression of grief.

Support groups and individual counselling have been the primary forms of formal support available to fathers in studies on pregnancy loss (Aho et al., 2009; Obst & Due 2019; Shannon & Wilkinson, 2020) as well as the fathers of this study. While no research specific to support groups for fathers after neonatal death were found, reduced feelings of isolation and validation of grief have been previously observed in bereavement support groups for parents whose child has died (Umphrey & Cacciatore, 2011). The need for increased follow-up support and facilitation of referral to services that are tailored to grief styles was highlighted in this study by fathers who desired greater emotional and practical support but did not engage in any of the existing support options available to them. The few fathers who attended a support group, also reported adequate facilitation of services by the hospital, emphasising the opportunity within the hospital to establish support options after neonatal death. Adequate facilitation of referral to services by the hospital is paramount in ensuring continuity of care for fathers and the engagement in appropriate supports once fathers have returned to their homes.

Mixed experiences with family and friends were reported. While some were supportive and helpful, negative comments from others were hurtful and detrimental to coping with grief, increasing feelings of anger and the sense of injustice. Support from other bereaved parents is essential when parents face limited social recognition and disenfranchised grief (Doka & Martin, 2011). The differences in support needs between types of pregnancy losses were also highlighted, with a requirement for specialised support services due to the varying implications of miscarriage, stillbirth and neonatal death.

4.4 Barriers and facilitators to accessing supports

This study identified two main barriers to support engagement. Firstly, the male supporter role that exists in Western cultures (Addis & Mahalik, 2003; Bonnette & Broom, 2012) was consistently reported by the fathers in this study. The male supporter role became a more explicit barrier to engagement in support when this role was imposed by healthcare professionals, friends and family, and when supports were focused on the mother of the baby. Fathers in this study experienced minimisation of their grief and lack of validation from healthcare providers, consistent with pregnancy loss research (Jones et al., 2019; Obst & Due, 2019). However, some fathers acknowledged that the male supporter role brought them relief by providing a distraction from the intensity of their grief.

Secondly, most fathers reflected that the supports available to them were limited in variety and availability. Despite support groups and counselling encouraging the expression of grief, some fathers reported that the emotional connection they were seeking was still unavailable due to the minimal supports that facilitated connection between bereaved fathers. While the fathers who participated in this study did not wish to detract from the grief experience of the mother, fathers advocated that the support they required was different and that the gap between the availability of supports for mothers versus fathers is substantial. Some fathers, particularly those with an instrumental grief style, struggled to find support options that were suited to their grief style. This finding emphasised the highly individualised nature of grief after neonatal death, and that support cannot take a one-size-fits-all approach.

Facilitators to support included adequate provision and facilitation of services by healthcare providers. All fathers in this study reported positive experiences within the NICU, with many also reflecting positive support experiences with their in-hospital social worker or counsellor, who provided them with written information of available community support services after discharge. This positive relationship is potentially the key to ensuring continuity of care from the hospital to home. With this existing relationship, the in-hospital social worker or counsellor is well-positioned to suggest formal support options after hospital discharge and encourage engagement in those supports, limiting the additional emotional toll fathers face when accessing an unfamiliar support option. Successful facilitation of supports is dependent on the normalisation of male grief, where healthcare providers and the wider society understand more 'masculine' styles of grief responses. In normalising male grief and providing tailored support options, the ability for mothers and fathers to fall anywhere on the continuum between intuitive and instrumental must be acknowledged (Doka & Martin, 2011).

4.5 Implications

4.5.1 Practical implications

This study has highlighted the need for variety and availability of male-specific supports for fathers that reflect a range of grief styles after neonatal death. There is a need for greater recognition and facilities for fathers in the hospital setting, and for hospital follow-up supports to facilitate the transition to other formal support services. Facilitation efforts should consider grief styles, the male supporter role and fathers' readiness to access services to maximise the potential effectiveness of supports. Reconnecting with previously engaged or existing formal supports should be encouraged. Follow-up should take place outside of the hospital setting as the hospital may serve as a reminder of traumatic aspects of neonatal death.

4.5.2 Theoretical implications

The findings of this study provide support for theories regarding complex grief following neonatal death (Kimble, 1991; Smith et al., 2020). Disenfranchised grief has been reported in the pregnancy loss literature (Lang et al., 2011; Obst et al., 2020), but its presence after neonatal death has been less frequently reported. When a neonatal death occurs, the baby often only has the opportunity to meet its parents and may not enter the wider community. Given the finding that fathers' grief was frequently misunderstood by others, this study suggests that fathers do experience disenfranchised grief following neonatal death.

Theories on male-specific challenges in relation to grief are also supported, such as the double-bind that is experienced by fathers as a result of the male supporter role and what is considered "appropriate" expressions of grief in Western contexts for men (Bonnette & Broom, 2012; Cook, 1988). Fathers in this study appeared to reflect both intuitive and instrumental grief styles, emphasising that while gender influences grief responses, there is not a clear divide according to gender. Instead, the grief experiences reported by fathers in this study supported Doka and Martin's (2011) continuum theory, with both instrumental and intuitive styles being described in terms of prioritisation of practical tasks, seeking emotional connection and seeking validation for grief.

4.6 Strengths

This is the first Australian study to examine fathers' experiences of grief and support following neonatal death. Only one study specific to fathers and neonatal death was identified in the literature review, with no such papers existing in the Australian context. Future research can build on this contribution, allowing for a deeper understanding of men's grief and the development of a more extensive evidence-base. A comprehensive evidence-base is vital in informing highly needed specialised support services for fathers after neonatal death.

The qualitative design of this study, with semi-structured interviews and open-ended questioning, allowed for the in-depth exploration of fathers’ experiences. An inductive method of analysis after initial coding of the transcripts allowed for the emergence of themes directly from the data and the discovery of unanticipated findings (Braun & Clarke, 2013). Moreover, this study focused directly on fathers’ perspectives through the voices of men themselves, giving this historically under-researched population a platform to address a significant gap in the bereavement support space. Time since neonatal death varied in the sample from one year to 12 years, allowing the researcher to review the lasting nature of grief after neonatal death. Data saturation was achieved upon completion of the eighth interview, with one additional interview undertaken and included in the sample. Data analysis was cross-checked by the academic supervisory team, and all themes and subthemes were agreed upon regarding appropriateness and fit to the data.

4.7 Limitations and future research

Participants were recruited as part of a larger research program through pregnancy loss support organisations. All participants were very motivated; they contacted the researcher of the pregnancy loss study in the first instance, further indicated their interest via return emails to the researcher and willingly shared their experiences for this study. All fathers of this study reside in Australia and fell into a similar age bracket. These factors may indicate a selection bias towards men with particular grief and support experiences. Although variation in the length of time since neonatal death has been reported as a strength of this study, a small number of participants experienced a neonatal death over a decade ago, so their recollections of experiences may differ to the recollections they had closer to the time of death.

All participants were heterosexual, married to the mother of their baby and reported that the bond they share with their wife has become stronger after their baby’s death.

Difficulties in marital relationships after pregnancy loss or neonatal death have been highlighted in previous research (Franche, 2001; Wallerstedt & Higgins, 1996), so the findings of this study may overlook the experiences of fathers who suffered a marital breakdown after neonatal death. Future research is also required to understand the experiences of lesbian, gay, bisexual, transgender, queer, intersex, asexual, and other gender or sexuality diverse (LGBTQIA+) parents. LGBTQIA+ parents may face further disenfranchisement of grief due to the broad heteronormative values imposed on them and the potential avoidance of formal peer supports due to fear of prejudice (Shannon & Wilkinson, 2020). Expansion on recent pregnancy loss studies that have identified unique challenges in relation to grief and support for LGBTQIA+ parents is crucial in optimising the effectiveness of supports (Peel, 2010; Wojnar, 2007).

As this research was conducted within the Australian context, it focuses on the experience of bereaved parents in a particular set of cultural norms and values. A disproportionate amount of existing research on both pregnancy loss and neonatal death is situated within Western contexts, with the experiences of fathers in culturally diverse settings often overlooked. The barriers and facilitators reported across the literature may not apply and supports may differ in other cultural settings. Future research in a variety of contexts will assist in developing an understanding of supports that may benefit across cultures. To build on the findings of this thesis, further research may focus on trialling a variety of male-specific services to determine support options that may be effective in supporting fathers with their grief after the death of a baby.

4.8 Conclusions

This study is an important addition to the minimal literature about the experiences of fathers whose baby has died in the neonatal period. The results indicated that fathers face challenges regarding the validation of their grief, supporting their family and accessing limited support options. This study provides a stepping stone for the significant evidence-base required to inform specialised support services. Targeted support strategies and facilitation of referral to formal support options are essential to the improvement of psychological outcomes for fathers who experience neonatal death.

References

Addis, M. E., & Mahalik, J. R. (2003). Men, masculinity and the context of help-seeking. *American Psychologist, 58*(1), 5-14.

Aho, A. L., Tarkka, M. T., Astedt-Kurki, P., & Kaunonen, M. (2009). Fathers' experience of social support after the death of a child. *American Journal of Men's Health, 3*(2), 93-103.

Aho, A. L., Tarkka, M. T., Astedt-Kurki, P., & Kaunonen, M. (2006). Fathers' grief after the death of a child. *Issues in Mental Health Nursing, 27*(6), 647-663.

Aho, A. L., Tarkka, M. T., Astedt-Kurki, P., Sorvari, L., Kaunonen, M. (2011). Evaluating a bereavement follow-up intervention for grieving fathers and their experiences of support after the death of a child- A pilot study. *Death Studies, 35*(10), 879-904.

Archibald, S-J. (2019). What about fathers? A review of a fathers' peer support group on a Neonatal Intensive Care Unit. *Journal of Neonatal Nursing, 25*(6), 272-276.

Australian Bureau of Statistics. (2018). Causes of death, Australia, 2018. (3303.0). Canberra: Commonwealth of Australia.

Australian Institute of Health and Welfare. (2020). Stillbirths and neonatal deaths in Australia 2017. Canberra: Commonwealth of Australia.

Badenhorst, W., Riches, S., Turton, P., & Hughes, P. (2006). The psychological effects of stillbirth and neonatal death on fathers: Systematic review. *Journal of Psychosomatic Obstetrics and Gynecology, 27*(4), 245-256.

Banerjee, J., Kaur, C., Ramaiah, S., Roy, R., & Aladangady, N. (2016). Factors influencing the uptake of neonatal bereavement support services – Findings from two tertiary neonatal centres in the UK. *BMC Palliative Care, 15*(1), 1-7.

Barr, P. (2012). Negative self-conscious emotion and grief: An actor-partner analysis in couples bereaved by stillbirth or neonatal death. *Psychology and Psychotherapy: Theory, Research and Practice, 85*(3), 310-326.

Bonnette, S., & Broom, A. (2012). On grief, fathering and the male role in men's accounts of stillbirth. *Journal of Sociology, 48*(3), 248-265.

Boyle, F., Dell, H., Middleton, P., & Flenady, V. (2019). Clinical practice guideline for care around stillbirth and neonatal death: Section 3, Respectful and supportive perinatal bereavement care. Perinatal Society of Australia and New Zealand.

Braun, V., & Clarke, V. (2013). *Successful Qualitative Research: A Practical Guide for Beginners.* London: Sage Publications.

Cacciatore, J., Erlandsson, K., & Radestad, I. (2013). Fatherhood and suffering: A qualitative exploration of Swedish men's experiences of care after the death of a baby. *International Journal of Nursing Studies, 50*(5), 664-670.

Cholette, M. (2012). Through the eyes of a father: A perinatal loss. *International Journal of Childbirth Education, 27*(2), 33-38.

Clyman, R. I., Green, C., Rowe, J., Mikkelsen, C., Ataide, L. (1980). Issues concerning parents after the death of their newborn. *Critical Care Medicine, 8*(4), 215-218.

Cook, J. A. (1988). Dad's double binds: Rethinking fathers' bereavement from a men's studies perspective. *Journal of Contemporary Ethnography, 17*(3), 285-308.

Currie, E. R., Christian, B. J., Hinds, P. S., Perna, S. J., Robinson, C., Day, S., Bakitas, M., Meneses, K. (2019). Life after loss: Parent bereavement and coping experiences after infant death in the neonatal intensive care unit. *Death Studies, 43*(5), 333-342.

Doka, K. J., & Martin, T. L. (2011). Grieving styles: Gender and grief. *Grief Matters: The Australian Journal of Grief and Bereavement, 14*(2), 42-45.

Due, C., Chiarolli, S., & Riggs, D. W. (2017). The impact of pregnancy loss on men's health and wellbeing: A systematic review. *BMC Pregnancy and Childbirth, 17*(1), 1-13.

Due, C., Obst, K. L., Riggs, D. W., & Collins, C. (2018). Australian heterosexual women's experiences of healthcare provision following a pregnancy loss. *Women and Birth, 31*(4), 331-338.

Fisher, D., Khashu, M., Adama, E. A., Feeley, N., Garfield. C. F., Ireland, J., Koliouli, F., Lindberg, B., Norgaard, B., Provenzi, L., Thomson-Salo, F., van Teijilingen, E. (2018). Fathers in neonatal units: Improving infant health by supporting the baby-father bond and mother-father co-parenting. *Journal of Neonatal Nursing, 24*(6), 306-312.

Flenady, V., Boyle, F., Koopmans, L., Wilson, T., Stone, W., & Cacciatore, J. (2014). Meeting the needs of parents after a stillbirth or neonatal death. *BJOG: An International Journal of Obstetrics & Gynaecology, 121*(s4), 137-140.

Franche, R-L. (2001). Psychologic and obstetric predictors of couples' grief during pregnancy after miscarriage or neonatal death. *Obstetrics & Gynacology, 97*(4), 597-602.

Fry, J. T., & Henner, N. (2016). Neonatal death in the emergency department: When end-of-life care is needed at the beginning of life. *Clinical Pediatric Emergency Medicine, 17*(2), 147-155.

Harvey, S., Snowdon, C., & Elbourne, D. (2008). Effectiveness of bereavement interventions in neonatal intensive care: A review of the evidence. *Seminars in Fetal and Neonatal Medicine, 13*(5), 341-356.

Health Service Executive. (2019). National standards for bereavement care following pregnancy loss and perinatal death. Ireland.

Hearn, G., Clarkson, G., & Day, M. (2020). The role of the NICU in father involvement, beliefs, and confidence: A follow-up qualitative study. *Advances in Neonatal Care, 20*(1), 80-89.

Henderson, L., & Davies, D. (2020). Supporting and communicating with families experiencing a perinatal loss. Canadian Paediatric Society: Canada.

Ireland, S., Ray, R. A., Larkins S., & Woodward, L. (2019). Perspectives of time: A qualitative study of the experiences of parents of critically ill newborns in the neonatal nursery in North Queensland interviewed several years after the admission. *BMJ Open, 9*(5), 1-11.

Jones, K., Robb, M., Murphy, S., & Davies, A. (2019). New understandings of fathers' experiences of grief and loss following stillbirth and neonatal death: A scoping review. *Midwifery, 79*, 1-15.

Kendall, A., Guo, W. (2008). Evidence-based neonatal bereavement care. *Newborn and Infant Nursing Reviews, 8*(3), 131-135.

Kimble, D. L. (1991). Neonatal death: A descriptive study of fathers' experiences. *Neonatal Network, 9*(8). 45-49.

Lang, A., Fleiszer, A. R., Duhamel, F., Sword, W., Gilbert, K. R., & Corsini-Munt, S. (2011). Perinatal loss and parental grief: the challenge of ambiguity and disenfranchised grief. *Omega (Westport), 63*(2), 183-196.

Lasker, J. N., & Toedter, L. J. (2000). Predicting outcomes after pregnancy loss: Results from studies using the Perinatal Grief Scale. *Illness, Crisis & Loss, 8*(4), 350-372.

Lench, H. C., & Chang, E. S. (2007). Belief in an unjust world: When beliefs in a just world fail. *Journal of Personality Assessment, 89*(2), 126-135.

Martinez, A. M., Castiglione, S., Dupuis, F., Legault, A., Proulx, M. C., & Carnevale, F. (2019). Having therapeutic conversations with fathers grieving the death of a child. *Omega – Journal of Death and Dying*, 0(0), 1-14.

McCreight, B. S. (2004). A grief ignored: Narratives of pregnancy loss from a male perspective. *Sociology of Health and Illness, 26*(3), 326-350.

Michon, B., Balkou, S., Hivon, R., & Cyr, C. (2003). Death of a child: Parent perception of grief intensity – End of life and bereavement care. *Paediatrics and Child Health, 8*(6), 363-366.

National Bereavement Care Pathway. (2020). Neonatal death: Full guidance document. England: United Kingdom.

Nguyen, V., Temple-Smith, M., & Bilardi, J. (2019). Men's lived experiences of perinatal loss: A review of the literature. *Australian and New Zealand Journal of Obstetrics and Gynaecology, 59*(6), 757-766.

Obst, K. L., & Due, C. (2019). Australian men's experiences of support following pregnancy loss: A qualitative study. *Midwifery, 70*, 1-6.

Obst, K. L., Due, C., Oxlad, M., & Middleton, P. (2020). Men's grief following pregnancy loss and neonatal loss: A systematic review and emerging theoretical model. *BMC Pregnancy Childbirth, 20*(1), 1-17.

Peel, E. (2010). Pregnancy loss in lesbian and bisexual women: an online survey of experiences. *Human Reproduction, 25*(3), 721-727.

Redshaw, M., & Henderson, J. (2013). Fathers' engagement in pregnancy and childbirth: Evidence from a national survey. *BMC Pregnancy and Childbirth, 13*(1), 1-15.

Schut, H., Stroebe, M. (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies, 23*(3), 197-224.

Serlachius, A., Hames, J., Juth, V., Garton, D., Rowley, S., & Petrie, K. J. (2018). Parental experiences of family-centered care from admission to discharge in the neonatal intensive care unit. *Journal of Paediatrics and Child Health, 54*(11), 1227-1233.

Shannon, E., & Wilkinson, B. (2020). The ambiguity of perinatal loss: A dual-process approach to grief counselling. *Journal of Mental Health Counselling, 42*(2), 140-154.

Smith, L. K., Dickens, J., Bender Atik, R., Bevan, C., Fisher, J., & Hinton, L. (2020). Parents' experiences of care following the loss of a baby at the margins between miscarriage, stillbirth and neonatal death: a UK qualitative study. *BJOG: An International Journal of Obstetrics and Gynaecology.*

Stefana, A., Padovani, E. M., Biban, P., & Lavelli, M. (2018). Fathers' experiences with their preterm babies admitted to neonatal intensive care unit: A multi-method study. *Journal of Advanced Nursing, 74*(5), 1090-1098.

Stroebe, M., & Schut, H. (2010). The dual process model of coping with bereavement: A decade on. *Omega – Journal of Death and Dying, 61*(4), 273-289.

Thomson-Salo, F., Kuschel, C. A., Kamlin, O. F., & Cuzzilla, R. (2017). A fathers' group in NICU: Recognising and responding to paternal stress, utilising peer support. *Journal of Neonatal Nursing, 23*(6), 294-298.

Tracy, S. J. (2010). Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qualitative Inquiry, 16*(10), 837-851.

Umphrey, L. R., & Cacciatore, J. (2011). Coping with the ultimate deprivation: Narrative themes in a parental bereavement support group. *Omega – Journal of Death and Dying, 63*(2), 141-160.

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

Vance, J. C., Hodgen, F. M., Thearle, M. J., Najman, J. M., Foster, W. J., & Embelton, G. (1991). Early parental responses to sudden infant death, stillbirth or neonatal death. *Medical Journal of Australia, 155*(5), 292-297.

Vance, J. C., Najman, J. M., Boyle, F. M., Embelton, G., Foster, W. J., & Thearle, M. J. (1994). Alcohol and drug usage in parents soon after stillbirth, neonatal death or SIDS. *Journal of Paediatrics and Child Health, 30*(3), 269-272.

Vance, J. C., Najman, J. M., Thearle, M. J., Embelton, G., Foster, W. J., & Boyle F. M. (1995). Psychological changes in parents eight months after the loss of an infant from stillbirth, neonatal death or sudden infant death syndrome – A longitudinal study. *Pediatrics, 96*(5), 933-938.

Wallerstedt, C., & Higgins, P. (1996). Facilitating perinatal grieving between the mother and the father. *Principles and Practice, 25*(5), 389-394.

Waugh, A., Kiemle, G., & Slade, P. (2018). Understanding mothers' experiences of positive changes after neonatal death. *European Journal of Psychotraumatology, 9*(1), 1-11.

Wojnar, D. (2007). Miscarriage experiences of lesbian couples. *Journal of Midwifery & Women's Health, 52*(5), 479-485.

Woodroffe, I. (2013). Supporting bereaved families through neonatal death and beyond. *Seminars in Fetal and Neonatal Medicine, 18*(2), 99-104.

Youngblut, J. M., Brooten, D., Glaze, J., Promise, T., & Yoo, C. (2017). Parent grief 1-13 months after death in neonatal and pediatric intensive care units. *Journal of Loss and Trauma, 22*(1), 77-96.

Appendix A

Participant Information Sheet

PARTICIPANT INFORMATION SHEET

PROJECT TITLE: Australian men's grief following the experience of pregnancy loss and neonatal loss
HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2018-273
PRINCIPAL INVESTIGATOR: XX
STUDENT RESEARCHERS: XX and XX
STUDENT DEGREES: PhD/Master of Psychology (Health) and Honours (Psychology)

Dear Participant,

Thank you for your interest in contributing to this important area of research. You are invited to participate in the research project described below.

What is the project about?

This project is seeking to improve our understandings of men's grief following the experience of a pregnancy loss or neonatal loss (the death of a baby within 28 days after birth) in Australia. Although a number of perinatal bereavement care guidelines exist, these are based largely on the experiences of women. Currently, our understandings of men's grief and subsequent support needs following pregnancy loss and neonatal loss are lacking. The findings of this study may be used to develop a comprehensive theory of men's grief, to inform Australian perinatal bereavement care guidelines, so fathers can be better supported in the future.

Who is undertaking the project?

This project is being conducted by XX and XX, under the supervision of XX, XX, and XX. It will form the basis for XX degree of Honours (Psychology), and contribute to XX degree of XX at the University of Adelaide. XX is supported by an Australian Government Research Training Program Scholarship, and a XX.

Why am I being invited to participate?

You are being invited to participate if you are an adult male (over 18 years) living in Australia, who has experienced the loss of a baby in Australia within the last 20 years due to ectopic pregnancy, miscarriage (defined in Australia as a loss in-utero at less than 20 weeks' gestation), stillbirth (a loss in-utero after 20 weeks' gestation), the loss of a live born infant within the first 28 days of life, or a termination of pregnancy for nonviable foetal anomaly.

What am I being invited to do?

You are being invited to participate in an interview regarding your experiences of grief following pregnancy loss and/or neonatal loss. Interviews can take place at over the telephone or over Zoom, at a time that is convenient to you. The interview will be audio recorded, so that a transcription can be made of the interview. All personally identifying information will be removed from the transcript.

How much time will my involvement in the project take?
It is anticipated that an interview will take approximately one hour of your time.

Are there any risks associated with participating in this project?
Due to the sensitive nature of the topic being discussed, you may experience some emotional distress during the interview. However, every effort will be made to minimise this possibility, and you will be provided with a comprehensive list of supports that you may wish to access following the interview. These include telephone helplines, online forums, and local organisations relevant to pregnancy loss. You can view these supports at the end of this information sheet. You can also choose not to answer questions, or to end the interview at any time.

What are the potential benefits of the research project?
This research may help to inform support organisations and healthcare professionals about how to best provide support to men and their families following pregnancy loss and neonatal loss. Although you will not receive any financial compensation from your involvement in the study, your participation in an interview may help to benefit the experiences of men following a pregnancy/neonatal loss in the future.

Can I withdraw from the project?
Participation in this project is completely voluntary. If you agree to participate, you can withdraw from the study at any time until the start of the data analysis phase.

What will happen to my information?
Your name and any identifying information will remain confidential and will be removed from any publications or reports that arise from the data. Confidential interview transcripts will be made from the audio recordings, however only the named researchers above will have access to the interview transcripts, for the purposes of analysis. Your data will be stored securely on a password-protected computer at the University of Adelaide for a period of five years.

The project will be written up in the form of a journal article, which will be submitted for publication to peer-reviewed journals. Results of the study may also be presented at national and international conferences, and the overall findings may be used to contribute to the improvement of future perinatal bereavement care guidelines in Australia. A short report of the study will also be made available to national support organisations and participants who express interest.

Your information will only be used as described in this participant information sheet and it will only be disclosed according to the consent provided, except as required by law.

Who do I contact if I have questions about the project?
Should you wish to ask any further questions about the project, please contact XX (phone: XX or email: XX) or XX (phone: XX or email: XX).

What if I have a complaint or any concerns?
The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2018-273). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research (2007). If you have questions or problems associated with the practical aspects of your participation in the project or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:
Phone: +61 8 8313 6028

Email: hrec@adelaide.edu.au
Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000
Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I want to participate, what do I do?
Please contact XX (email: XX) to organise a time and place for an interview.

Yours sincerely,
XX
XX
XX
XX
XX

Support Resources

- **SANDS (Stillborn and Neonatal Death Support) Support Lines**
  National support line available 24/7: 1300 072 637
  Dedicated men's support line: available by appointment via link below
  https://www.sands.org.au/mens-support-services
  Online support options:
  https://www.sands.org.au/online-support

- **Bears of Hope Grief Support**
  Support line: 1300 11 HOPE
  Email: support@bearsofhope.org.au

- **Red Nose Grief and Loss Support**
  Available 24/7: 1300 308 307

- **Pregnancy Birth & Baby Helpline**
  Free call 7 days a week: 1800 882 436

- **Mensline Australia**
  Available 24/7: 1300 78 99 78

- **Lifeline**
  Available 24/7: 13 11 14

- **Beyond Blue**
  Available 24/7: 1300 224 636

Appendix B

Consent Form

Human Research Ethics Committee (HREC)

THE UNIVERSITY of ADELAIDE

CONSENT FORM

1. I have read the attached Information Sheet and agree to take part in the following research project:

Title:	**Australian men's grief following the experience of pregnancy loss and neonatal loss**
Ethics Approval Number:	**H-2018-273**

2. I have had the project, so far as it affects me, and the potential risks and burdens fully explained to my satisfaction by the research worker. I have had the opportunity to ask any questions I may have about the project and my participation. My consent is given freely.

3. Although I understand the purpose of the research project, it has also been explained that my involvement may not be of any benefit to me.

4. I agree to participate in the activities outlined in the participant information sheet.

5. I agree to be audio recorded:
   ☐ Yes ☐ No

6. I understand that I am free to withdraw from the project at any time, up until the data analysis phase.

7. I have been informed that the information gained in the project may be published in a journal article, thesis, news article, conference presentations or report.

8. I have been informed that in the published materials I will not be identified and my personal results will not be divulged.

9. My information will only be used for the purpose of this research project and it will only be disclosed according to the consent provided, except where disclosure is required by law.

10. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

Name: ______________________ Signature: ________________________ Date: ____________________________

Researcher/Witness to complete:

I have described the nature of the research to ____

(print name of participant)

and in my opinion she/he understood the explanation.

Signature: ___________________ Position: _________________________ Date: ____________________________

Appendix C

Interview schedule

We are interested in exploring men's experiences of neonatal death, can you tell me a bit about your experiences? (Have you experienced the death of more than one baby? Did you name your baby? How long ago did your baby die? How old was the baby when he/she died? What were the circumstances surrounding the death of your baby?)

Can you tell me about your relationship with your baby during pregnancy? (How often did you interact with your baby? Did you view ultrasound images of your baby?)

Can you tell me about how your baby's death has impacted you? (What were some of the emotions you felt? Did you feel comfortable displaying your emotions to others? What were some thoughts that ran through your mind? Did you experience any physical responses?)

How did you cope with the loss? (What activities helped you in your coping? Did you use any personal strategies that you found helpful?)

How do you generally approach stressful situations in your life? (What helps you get through tough times? Was coping with the death of your baby different to the way you have coped with difficult situations in the past?)

Did your baby's death impact your relationship with your partner?

Can you tell me about your experiences during the time that your baby was in the neonatal intensive care unit? (What was the environment like for you? How often were you there? Did you feel included in the NICU? Did you feel included in the hospital in general? What was your experience with healthcare professionals? What information did healthcare professionals provide to explain your baby's medical difficulties? How were the options for your baby's care explained to you?)

Can you tell me about the supports you received, if any, at the time of your baby's death?

What support, if any, did you receive from the hospital staff? (Which hospital staff were most supportive? In what ways did they support you? Did you receive a follow-up call after the death of your baby? Were you offered information on men's grief or supports that may be available to you?)

Did you seek any support from a professional such as a counsellor, psychologist or support organisation? (Did you go to these professionals or organisations with your partner or alone? Are you receiving any support now?)

Were you satisfied with the support you received? (Can you describe any particularly positive experiences of support? Can you tell me about any particularly negative experiences of support?)

What support did you receive from family, friends or work colleagues? (Was it easy for you to reach out to them? Were they open to discussing the death of your baby? Did you feel as though your grief was recognised and understood by those around you?)

What was it like returning to work? (Where were you employed at the time of your baby's death? Did you inform the workplace of your baby's death? Were you offered/did you take any leave from work? Can you tell me about what type of leave you were offered (or what leave you took)? Was there anything your workplace did or could have done to support you?)

Has your grief changed over time? If so, how has it changed? (Was there anything you felt made your grief experience more difficult? Or easier?)

Was there anything that you felt prevented you from seeking support?

What types of support do you think would have been useful to you at the time of your baby's death, and now, ongoing?

Do you feel that there are any significant differences between the support needs for men and for women?

What advice would you give other men experiencing the death of their baby?

Did you feel as though the questions asked today were inclusive of all aspects of your grief experience?

Is there anything else you would like to tell me (or ask me)?

If applicable:

- How did your other children cope/react to the death of your baby?
- How were your subsequent pregnancies?

Ongoing prompts:

- Can you give me an example of…?
- What do you mean by …?
- Can you tell me more about …?

Would you like to be sent a copy of your interview transcript/ emerging results to provide feedback?

Appendix D

Post-Interview Summary Sheet

Participant:

Date:

Duration of interview:

Notes on location/environment

Participant presentation, reactions

Researcher reflection on interaction

Difficulties in interview

Changes to interview schedule during interview

Emerging themes

Analysis points

Questions/changes for subsequent interviews

Other notes