



Overwhelming and unjust: A qualitative study of fathers' experiences of grief following neonatal death

Shazleen Azeez, Kate Louise Obst, Clemence Due, Melissa Oxlad & Philippa Middleton

To cite this article: Shazleen Azeez, Kate Louise Obst, Clemence Due, Melissa Oxlad & Philippa Middleton (2022) Overwhelming and unjust: A qualitative study of fathers' experiences of grief following neonatal death, *Death Studies*, 46:6, 1443-1454, DOI: [10.1080/07481187.2022.2030431](https://doi.org/10.1080/07481187.2022.2030431)

To link to this article: <https://doi.org/10.1080/07481187.2022.2030431>



Published online: 02 Feb 2022.



Submit your article to this journal [↗](#)



Article views: 982



View related articles [↗](#)



View Crossmark data [↗](#)



Citing articles: 7 View citing articles [↗](#)



Overwhelming and unjust: A qualitative study of fathers' experiences of grief following neonatal death

Shazleen Azeez^a , Kate Louise Obst^a , Clemence Due^a , Melissa Oxlad^a , and Philippa Middleton^b 

^aSchool of Psychology, University of Adelaide, Adelaide, South Australia; ^bSouth Australian Health and Medical Research Institute, Adelaide, South Australia

ABSTRACT

Limited research has examined the grief experiences of fathers following neonatal death. Using a qualitative research design, ten fathers were interviewed, and thematic analysis resulted in three overarching themes: 'A complicated grief experience: Neonatal death is highly emotional', 'Grief is multidimensional' and 'Sense of injustice'. Overall, results showed that grief was a multidimensional experience for fathers, with expressions of grief including strong feelings of anger and guilt and the manifestation of grief in physical symptoms. In addition, the findings also indicated a sense of injustice that contributed to the disenfranchisement of grief for fathers. The results of this study contribute to developing a better understanding of the grief that fathers experience following neonatal death, and can inform improvements in healthcare practices after the death of a baby in the neonatal period, including father-specific programs and adequate provision of information.

The death of a baby in the neonatal period has profound adverse impacts on parents' physical and psychological well-being (Banerjee et al., 2016; Lang et al., 2011). Neonatal death has been frequently researched in conjunction with miscarriage and still-birth, but very few studies have focused solely on neonatal death, despite potential differences in experiences and associated grief (Woodroffe, 2013). Existing research concerning neonatal death has also focused primarily on mothers (Martinez et al., 2019), finding high levels of distress and grief (Vance et al., 2002). Recent studies have acknowledged a gap in understanding regarding men's grief following pregnancy loss, and researchers have sought to rectify this (e.g., see (Jones et al., 2019; Martinez et al., 2019; Nguyen et al., 2019; Obst et al., 2020, 2021). This study aimed to contribute to this understanding by exploring Australian fathers' grief experiences after the death of their baby in the neonatal period.

Background and previous literature

Pregnancy loss and neonatal death terminology

In Australia, neonatal death – defined as the death of a baby within the first 28 days after birth (Australian

Bureau of Statistics, 2018) – occurs in approximately 2.5 of every 1000 pregnancies (Australian Institute of Health & Welfare, 2020). The term 'pregnancy loss' refers to any death in-utero, including miscarriages (occurring at less than 20 weeks' gestation) and stillbirths (a death in-utero or at birth, from at least 20 weeks' gestation or over 400 grams in weight) (Australian Bureau of Statistics, 2018).

Models of grief

Grief after the death of a loved one can be an acute and complicated response, often unique to each individual (Aho et al., 2006). However, general patterns have been identified in the grief literature. For example, Doka and Martin (2011) differentiated between intuitive and instrumental grief styles; the former characterized by expressing the grief experience, such as talking about painful feelings and crying, and the latter characterized by engaging in activities and attending to practical responsibilities. Traditionally, intuitive styles were considered more 'feminine' and instrumental styles were considered more 'masculine' in many cultures. However, Doka and Martin (2011) emphasized that these two styles are at opposing ends of a continuum rather than

discrete grieving styles. They suggest that individuals can be at any point on this continuum, as well as exhibit a blended grieving style.

The Dual-Process Model (DPM) of coping with bereavement also differentiates between two styles of coping: loss-oriented strategies and restoration-oriented strategies (Shannon & Wilkinson, 2020). Again, while within many cultures loss-oriented strategies are considered more ‘feminine’, and restoration-oriented strategies more ‘masculine’ (Shannon & Wilkinson, 2020), the DPM suggests that individuals oscillate between the two methods (Schut & Stroebe, 1999; Stroebe & Schut, 2010). This approach is consistent with existing neonatal death and grief research, whereby bereaved parents alternate between focusing on their grief and trying to adjust to a world without their baby (Currie et al., 2019).

While gender, as noted, does not define grief styles, grief is strongly influenced by factors including gender role socialization, personality and culture (Doka & Martin, 2011). In Western societies, gender roles have typically led to the outward emotional expression of grief from women and expectations for men to remain ‘strong’ (Fisher et al., 2018). 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).

In addition to grief styles and models of coping, the unanticipated and ambiguous nature of pregnancy loss and neonatal death has been associated with high levels of disenfranchised grief (Shannon & Wilkinson, 2020); defined as grief that has not been publicly acknowledged or socially supported (Lang et al., 2011). Bereaved parents are likely to face a lack of social recognition for their grief (Badenhorst et al., 2006), uncertainty in norms surrounding how to mourn their baby (Lang et al., 2011) and challenges in finding meaning in their loss (Nuzum et al., 2018). Research shows that disenfranchised grief is particularly salient for men experiencing pregnancy loss more generally (Due et al., 2017) and is also likely for those who experience neonatal death. In addition to their grief, heterosexual men often face an additional expectation that they will assume the role of ‘supporter’ to their female partner (Obst et al., 2020). This expectation is consistent with norms in Western cultures, where men are required to exhibit emotional control (Fisher et al., 2018). Therefore, bereaved fathers are likely to experience a ‘double-bind’, where they are expected to support their family whilst also

adequately coping with their grief (Cholette, 2012; Cook, 1988).

Men and grief following neonatal death

Most research on neonatal death has been conducted in the United Kingdom (UK) or the United States (US) and primarily consists of qualitative studies on the experiences of mothers or parents generally (Clyman et al., 1980; Currie et al., 2019; Redshaw & Henderson, 2018; Waugh et al., 2018), as well as studies that address both neonatal death and stillbirth (Barr, 2012). Vance et al. (2002) study of experiences and grief following neonatal death found that anxiety, depression and sleep difficulties were common among mothers and fathers. A qualitative study in the UK found that mothers experienced enduring symptoms of post-traumatic stress disorder and complex grief (Waugh et al., 2018), while a review of parental grief after the death of a baby in the neonatal intensive care unit (NICU) described the experience of neonatal death as overwhelming and traumatic for parents (Woodroffe, 2013). Also in the UK, a quantitative study found that mothers are often included in the decision to withdraw life support for a baby. However, mothers have reported an impaired ability to process information from healthcare providers, due to the overwhelming nature of grief which hindered their decision-making capacity (Redshaw & Henderson, 2018). Only one previous study (Kimble, 1991) focused exclusively on fathers’ experiences of neonatal death. This qualitative study of 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.

Several studies have focused on fathers’ experiences within the NICU more generally, including for men whose babies did not die during this time (Archibald, 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 ride of closeness and separation” (Fisher et al., 2018, p. 308), with fathers feeling overwhelmed at seeing their baby in an incubator (Stefana et al., 2018). Another 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).

Aims and research questions

Recent systematic reviews have highlighted a need for updated research on fathers' experiences of grief following neonatal death (Jones et al., 2019; Obst et al., 2020). This exploratory, descriptive study aimed to address this gap and explore fathers' bereavement experiences following neonatal death through the following research questions: (1) what are fathers' experiences of neonatal death, and (2) how do fathers experience grief following neonatal death?

Materials and methods

Participants

This study formed part of a more extensive program of research exploring Australian fathers' grief and support experiences following pregnancy loss or neonatal death (other results published elsewhere; Azeez et al., 2021; Obst et al., 2020). As part of this larger study, 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 ($N=14$). Participants for this study were ten Australian men (71% of those who expressed interest in an interview). 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 minimize distress).

At the time of the interview, participants were aged between 31 and 42 years ($M=35$ years, $SD=3.46$), and the time since the loss was between one and 12 years ago ($M=3.9$ years, $SD=3.87$). The age of the baby at the time of death varied from 30 minutes to 27 days ($M=8$ days, $SD=8.64$; see Table 1). 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 eight of the fathers completed tertiary education (one father did not provide detail on his level of education). All fathers were employed at the time of their baby's death, and when their interview was conducted.

Procedure

The study followed an interpretive, exploratory qualitative methodology informed by a realist epistemology, whereby meaning was not applied beyond the participants' interview data (Braun & Clarke, 2013).

Table 1. Participant characteristics.

Name*	Age	Ethnicity	Education/Qualification	Other children	Age of baby	Time since loss
Sam	42	Australian	Undergraduate	Three children	9 days	12 years
Paul	35	Australian/European	Postgraduate	Three children	10 days	10 years
James	NP	New Zealander	TAFE/Trade	Two children	26 days	4 years
Cameron	NP	Australian	TAFE/Trade	Two children	3 days	3 years
Nathan	38	Australian	NP	Four children; one is a surviving twin	27 days	2 years
Bill	31	European	Undergraduate	No other children	Lost twins at 3 days and 12 days	2 years
Harrison	32	Australian	Undergraduate	Two children	3 days	2 years
Ben	33	Australian	High school	Partner is currently pregnant	30 minutes	2 years
Adam	38	Australian	Postgraduate	Partner currently pregnant, one child prior to loss	21 days	1 year
Max	34	Australian	Postgraduate	One child	32 minutes	1 year

*Participant names are pseudonyms.

NP: Not provided.

The University of Adelaide Human Research Ethics Committee approved this study 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. Interviews were then scheduled with men who replied to this email and were held either over the telephone or in Zoom. Due to the implications of COVID-19, face-to-face interviews were not offered. Prior to the interview, participants were provided with an information sheet that outlined details of the research, researcher contact information, feedback pathways, and bereavement/crisis support organizations. In one case, an interview participant exhibited distress during the interview. For this participant, breaks were offered, and contact numbers were provided for two of the authors of this study (one of whom is a clinical and health psychologist), for the participant to debrief. At the conclusion of the interview, this participant indicated that they did not need further support from the research team. All participants received a follow-up email a few days after their interview, to further highlight the key support organizations available to them and provide an update about their transcript.

Interviews were conducted by the first author between May and July 2020 and audio-recorded using a digital recording device. Interview length ranged between 45 and 97 minutes ($M = 61$ mins, $SD = 17.17$). The first author, together with the third author, conducted a pilot interview in May 2020 with the first participant to assess the proposed interview schedule's suitability. The pilot interview was included in the final analysis as the interview schedule was deemed appropriate for the remaining interviews.

Given the exploratory nature of the research, interviews took a semi-structured approach with open-ended questioning. Interview questions concerning experiences of neonatal death and grief outcomes were developed based on previous studies in the pregnancy loss literature (Jones et al., 2019; Kimble, 1991; Smith et al., 2020). Interviews were transcribed verbatim. To ensure anonymity, each participant was allocated a pseudonym.

Several steps were undertaken to ensure trustworthiness in the methodology, guided by Tracy's (2010) "Big Tent" criteria. Specifically, an audit trail was maintained, and participants were offered the opportunity to provide feedback on their transcript or on the theme overview to ensure this was representative of their experiences. This consultation (termed member reflections) ensured that the data collected was representative of participants' views. One

participant provided additional feedback and highlighted the need for specialized support services dependent on the type of loss (neonatal death, miscarriage, stillbirth or other).

Tracy (2010) also highlights the importance of self-reflexivity in qualitative research. The first author is a young woman with no personal experience 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 verbalized their appreciation for research focusing on this under-represented area of men's grief. Among the other authors, two have experiences of pregnancy loss, and one has an experience of neonatal death.

Data analysis

In line with descriptive, exploratory research, inductive thematic analysis was conducted. After initial transcription of the interviews, Braun and Clarke (2013) six steps to comprehensive thematic analysis were undertaken: familiarization with data, generating initial codes, searching for themes, reviewing themes, defining themes and writing up of analysis. An inductive approach, guided by the research questions, was used to identify themes from the data.

Results

Overview

Thematic analysis generated three overarching themes: 1) *A complicated grief experience: Neonatal death is highly emotional*, 2) *Grief is multidimensional* and 3) *Sense of injustice*. Each theme comprises a number of subthemes, with the relationship between the themes and subthemes demonstrated in Figure 1.

A complicated grief experience: neonatal death is highly emotional

All-consuming nature of grief

All fathers described the death of a baby in the neonatal period as highly emotional, with one father, Sam, describing it to be "the worst time in your whole life," reflecting the complex and multidimensional experiences of fathers. For most fathers, the death of their baby was sudden and unexpected. For some fathers, the unexpected nature of the death of their

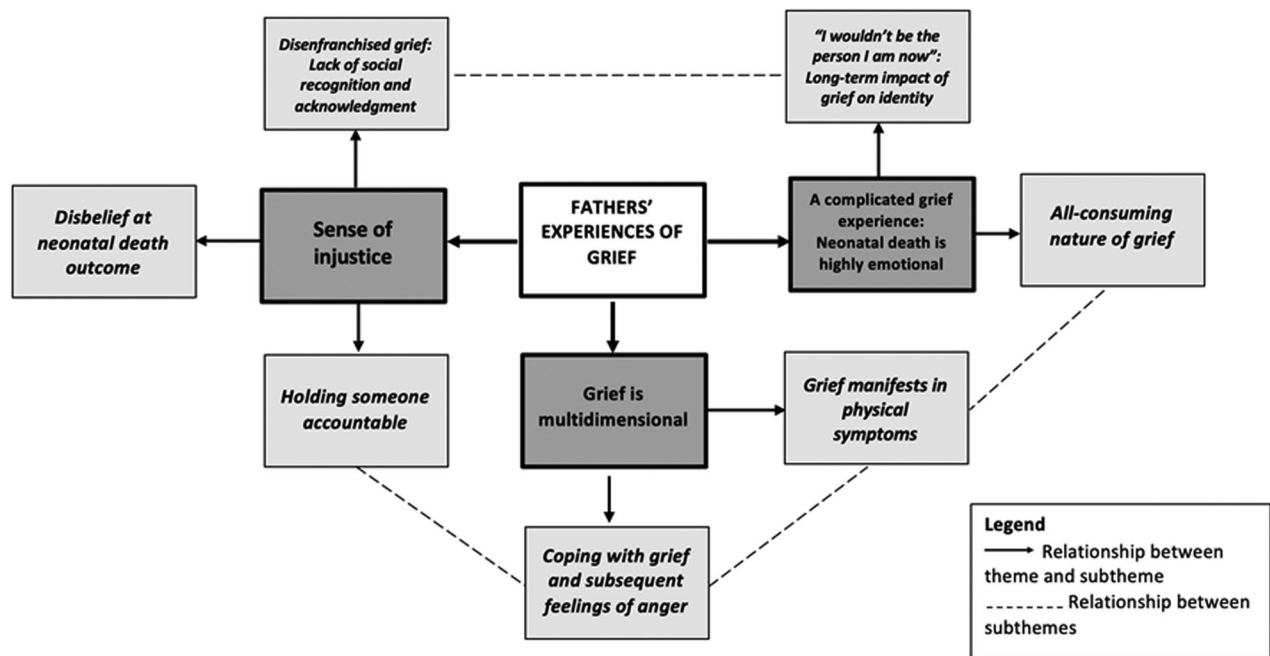


Figure 1. Relationship between themes and subthemes.

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)

As neonatal death was an unexpected outcome, fathers reported little preparation for the intensity of emotion accompanying their baby's death. Once healthcare professionals confirmed medical complications, accompanying decisions occurred rapidly, with limited time for fathers to process the circumstances. Many fathers described an acute grief reaction with impaired ability to process or retain any new information. This impairment was highlighted by Paul, who became confused when trying to comprehend his baby's medical condition:

... we weren't getting it, we just weren't in the right headspace. I remember I kept getting the name of the [medical 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.

In addition to Paul's description of confusion and exhaustion here, James described that the intensity of emotion left him feeling "numb." Overall, fathers reported heightened symptoms of psychological

distress, including feeling as though "there [was] nothing else in your life" (Sam).

"I Wouldn't be the person I am now": long-term impact of grief on identity

The impact of the overwhelming nature of grief was long-lasting for many fathers. While some fathers reported that this impact lessened over time, with Adam describing: "[it's] like someone just slowly turns the volume down," other fathers experienced permanent changes to their identity. Another father, Bill, whose twin babies died in the neonatal period, described acute symptoms of grief including repetitive and unpredictable physiological sensations:

... 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.

Importantly, although Bill's grief was painful, it served as a reminder of his twin daughters' lives, indicating the complex and dilemmatic nature of fathers' grief experiences. Harrison also indicated that he felt his grief impacted his identity and perspective toward the world. He referred to a distinct separation between his priorities and behaviors before and after his baby's death:

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.

In addition to the complex and long-lasting nature of grief, fathers reported various manifestations of their grief, as reported in the theme below.

Grief is multi-dimensional

Grief can manifest in physical symptoms

Several fathers indicated that acute levels of grief were accompanied by physical symptoms such as sleep disturbances, nightmares, stabbing pain, or general bodily pain. Mirroring the physical manifestations of grief reported by Bill earlier, the onset of physical symptoms was often unpredictable for fathers. Symptoms varied in 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 which adversely impacted his sleep after his baby's death:

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.

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

...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.

Another father, Harrison, also experienced physical pain which he attributed to the anger he felt after his baby died. Harrison reported that while the frequency of pain varied, the pain itself was long-lasting. Harrison also described the reemergence of this physical pain as a sign of his 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 [...] 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.

Here, Harrison describes how physical pain became for him a symbol of his baby's death, reemerging on days where his baby's death is particularly difficult to cope with. Overall, the pervasive, multidimensional experiences described by participants highlights the multiple ways in which they were affected by, and grieved for, their baby's death.

Coping with grief and subsequent feelings of anger

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

...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)

Notably, Ben indicated here that sadness is the socially-expected grief expression, while anger is less acceptable. This could potentially result in maladaptive coping strategies among men who experience grief in this way. For example, Cameron reported using 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 out of 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.

In contrast, other fathers focused on practical tasks and supporting their female partner and family following neonatal death. Many fathers indicated that they found it challenging to balance expressing their grief with a desire to support others and attend to responsibilities. Adam described how this delayed his grief process and emphasized 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.

Similarly, Paul described initially going into "a practical mode where things just had to get done," as a way of coping with his grief and not acting on feelings of anger.

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

Sense of injustice

Disbelief at neonatal death outcome

Accompanying the unexpected nature of neonatal death and subsequent feelings of anger was a sense of injustice. For some fathers, this sense primarily stemmed from what one father described as "the basic principles of life" (Paul), where 'good' people do not expect to experience traumatic events. For example, Paul 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 [...] 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.

In trying to make sense of why their babies died, some fathers compared their experiences 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.

In general, then, fathers experienced a sense of disbelief at their baby's death, often leading to a need to direct blame toward someone, as seen in the following subtheme.

Holding someone accountable

As noted previously, fathers reported experiencing anger following neonatal death, which, in many cases, 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:

... 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 [...] 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.

When fathers could not find someone to hold accountable, some turned the focus onto themselves. 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 cesarean, a decision he felt may have resulted in a different outcome for one of his twins:

... 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.

Similarly, Sam described blaming himself because he influenced the timing of 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.

Disenfranchised grief: lack of social recognition and acknowledgement

Most fathers expressed that they did not feel that the people around them recognized their grief, further adding to a sense of injustice. Fathers described the importance of talking about their baby's birth and death. However, they found that others were often

unwilling to engage in these discussions. Some fathers noted that due to a societal stigma surrounding infant death, others may be 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.

Paul expressed a similar experience, where he strongly desired acknowledgement for his baby, but did not receive this:

... 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.

This lack of social recognition resulted in additional adverse consequences for some fathers, further compounding their grief and feeling of injustice. For example, Adam took three weeks' leave from work after the death of his baby, however his workplace deemed this 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 [...] it made you realize 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.

Overall, fathers' sense of injustice resulted primarily from disbelief at their baby's death and an inability to determine why their baby died. This feeling was consistently exacerbated when fathers could not find someone to hold accountable or others did not recognize their grief.

Discussion

Consistent with previous neonatal death literature (Kimble, 1991; Waugh et al., 2018; Youngblut et al.,

2017), this study highlights the overwhelming nature of neonatal death but does so specifically for fathers who have not typically been previously considered in research. Fathers in this study had little to no preparation for the possibility of neonatal death; an experience that aligns with fathers' reactions in stillbirth research (Jones et al., 2019). After the shock of neonatal death, some fathers struggled to make sense of their experience, with overwhelming feelings of being undeserving of their circumstances and a search for someone to hold accountable for their loss. Challenges to core beliefs that "good things happen to good people," and that parents should not outlive their children, were reflected by fathers. This finding is consistent with stillbirth research that reflects the spiritual and theological challenges faced by bereaved parents (Nuzum et al., 2017) and the just-world belief theory, where the breakdown of the expectation that good people will not experience traumatic events can lead to denial and feelings of anger (Lench & Chang, 2007). In addition to feelings of anger, a sense of injustice also raised feelings of guilt for fathers as they examined their own decision-making in a search for someone to hold accountable. For some, these feelings of anger and guilt manifested in physical symptoms. Feelings of guilt, anger and physical symptoms after neonatal death are consistent with Kimble's (1991) study and the wider pregnancy loss literature (Barr, 2012; Jones et al., 2019), in addition adding to knowledge concerning the experience of fathers specifically. In contrast, responses for mothers reported in other studies were more likely to reflect symptoms of anxiety, depression and post-traumatic stress disorder (Waugh et al., 2018). These differences in mothers' and fathers' responses have also been highlighted in pregnancy loss literature (Badenhorst et al., 2006; Vance et al., 2002), emphasizing the need for more father-specific research to inform effective support options and healthcare practices after neonatal death.

Consistent with Doka and Martin (2011) theory of grief, fathers in this sample described behaviors that reflected both instrumental and intuitive styles in response to the death of their babies. Importantly, fathers who engaged in restoration-oriented strategies of the DPM (Stroebe & Schut, 2010) highlighted that while the intensity of their grief was not diminished, the grief impacted them differently. Several fathers also described loss-oriented strategies, including seeking an emotional connection with others and opportunities to openly express their grief (Doka & Martin, 2011; Stroebe & Schut, 2010). Regardless of grief style, fathers reported an increase in emotional intensity

when their baby's birth and death, and their position as a grieving father, was not acknowledged. This finding is consistent with disenfranchised grief (Doka & Martin, 2011). Disenfranchised grief has been reported in the pregnancy loss literature (Lang et al., 2011; Obst et al., 2020); however, the relevance of this form of grief after neonatal death has been less frequently reported. After neonatal death, the individualized nature of grief further suggests the importance of targeted and flexible support options to assist fathers in processing their grief and validating their experiences.

Implications

Overall, the findings point to a range of key considerations that could lead to changes in practice when working with fathers whose babies die in the neonatal period. In relation to grief, this includes supports that acknowledge the impact gender norms may have on grief for some men, particularly concerning expressions of grief exhibited as anger or guilt rather than as anxiety or depression. Supportive programs which are father-specific and target these emotions could be particularly beneficial. It is also important to note that many fathers experienced a strong sense of injustice. To assist in this area, ensuring the provision of adequate information to fathers where possible would be particularly helpful. Overall, the study points to the critical importance of grief support that target men specifically, and that, in some cases, are run separately from other types of death/loss support programs.

Limitations and future research

Participants were recruited as part of a larger research program through pregnancy loss support organizations and actively indicated their interest to participate via email. All fathers of this study resided in Australia and fell into a similar age bracket. These factors may indicate a selection bias toward men with particular grief experiences. Similarly, all participants were heterosexual, married to their baby's mother, and reported that their bond with their wife strengthened after their baby's death. Difficulties in marital relationships after pregnancy loss or neonatal death have been highlighted in previous research (Franché, 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 who may face further disenfranchisement of grief (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 optimizing the effectiveness of support services (Peel, 2010; Wojnar, 2007).

As this research was conducted within the Australian context, it focuses on the experience of bereaved parents in particular sets of cultural norms and values. A disproportionate amount of existing research on pregnancy loss and neonatal death is situated within Western contexts, with fathers' experiences in culturally diverse settings often overlooked (Roberts et al., 2017; Shakespeare et al., 2019). Future research in a variety of cultural contexts will assist in developing an understanding of fathers' grief that may benefit across cultures.

Conclusion

This study is an important addition to the scant literature concerning the experiences of fathers whose babies have died in the neonatal period. The study points to novel findings that are specific to, or more pronounced in, fathers, including challenges regarding expression and validation of their grief, anger, guilt and physical symptoms. These symptoms were described as being both direct expressions of and stemming from, fathers' acute and complicated grief. This study contributes to the growing call for evidence-based research to inform the development of male-specific support services for fathers in the perinatal period. In particular, the study highlights some potential unique considerations in the case of neonatal death that needs to be considered in the development of such guidelines, including managing feelings of anger and guilt, and assistance to cope with feelings of injustice.

Acknowledgments

We dedicate this research to Lucas, Caleb, Charlotte, Thomas, Tristan, Odin, Fianna, Saoirse, Charlie, James and Lucy, whose fathers' stories are told here. We sincerely thank these fathers for their honest and raw accounts of their experiences and for openly sharing their stories.

Disclosure statement

The authors declare that they have no conflict of interest.

Funding

The author(s) reported there is no funding associated with the work featured in this article.

ORCID

Shazleen Azeez  <http://orcid.org/0000-0001-5369-5086>
 Kate Louise Obst  <http://orcid.org/0000-0001-6976-9035>
 Clemence Due  <http://orcid.org/0000-0001-6485-6076>
 Melissa Oxlad  <http://orcid.org/0000-0001-9067-6706>
 Philippa Middleton  <http://orcid.org/0000-0002-8573-338X>

References

- 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. <https://doi.org/10.1080/01612840600643008>
- 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. <https://doi.org/10.1016/j.jnn.2019.05.003>
- Australian Bureau of Statistics. (2018). *Causes of death, Australia, 2018*. Commonwealth of Australia.
- Australian Institute of Health and Welfare. (2020). *Stillbirths and neonatal deaths in Australia 2017*. Commonwealth of Australia.
- Azeez, S., Obst, K. L., Oxlad, M., Due, C., & Middleton, P. (2021). Australian fathers' experiences of support following neonatal death: A need for better access to diverse support options. *Journal of Perinatology*, 41(12), 2722–2729. <https://doi.org/10.1038/s41372-021-01210-7>
- 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 Gynaecology*, 27(4), 245–256. <https://doi.org/10.1080/01674820600870327>
- 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. <https://doi.org/10.1186/s12904-016-0126-3>
- Barr, P. (2012). Negative self-conscious emotion and grief: An actor-partner analysis in couples bereaved by stillbirth or neonatal death. *Psychology and Psychotherapy*, 85(3), 310–326. <https://doi.org/10.1111/j.2044-8341.2011.02034.x>
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage Publications.
- 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. <https://doi.org/10.1097/00003246-198004000-00004>
- 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. <https://doi.org/10.1177/089124188017003003>
- 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. <https://doi.org/10.1080/07481187.2018.1474285>
- 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. <https://doi.org/10.1186/s12884-017-1560-9>
- Fisher, D., Khashu, M., Adama, E. A., Feeley, N., Garfield, C. F., Ireland, J., Koliouli, F., Lindberg, B., Nørgaard, B., Provenzi, L., Thomson-Salo, F., & van Teijlingen, E. (2018). Fathers in neonatal units: Improving infant health by supporting the baby-father bond and mother-father coparenting. *Journal of Neonatal Nursing*, 24(6), 306–312. <https://doi.org/10.1016/j.jnn.2018.08.007>
- Franché, R.-L. (2001). Psychologic and obstetric predictors of couples' grief during pregnancy after miscarriage or perinatal death. *Obstetrics and Gynecology*, 97(4), 597–602. [https://doi.org/10.1016/S0029-7844\(00\)01199-6](https://doi.org/10.1016/S0029-7844(00)01199-6)
- 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. <https://doi.org/10.1097/ANC.0000000000000665>
- 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), e026344–11. <https://doi.org/10.1136/bmjopen-2018-026344>
- Jones, K., Robb, M., Murphy, S., & Davies, A. (2019). New understandings of fathers' experiences of grief and loss following stillbirth and neonatal death: A scoping review. *Midwifery*, 79, 102531–102515. <https://doi.org/10.1016/j.midw.2019.102531>
- Kimble, D. L. (1991). Neonatal death: A descriptive study of fathers' experiences. *Neonatal Network*, 9(8), 45–49.
- Lang, A., Fleischer, 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*, 63(2), 183–196. <https://doi.org/10.2190/OM.63.2.e>
- 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. <https://doi.org/10.1080/00223890701468477>
- 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*, 0(0), 1–14. <https://doi.org/10.1177/0030222819825916>
- Nguyen, V., Temple-Smith, M., & Bilardi, J. (2019). Men's lived experiences of perinatal loss: A review of the literature. *The Australian & New Zealand Journal of Obstetrics*

- & *Gynaecology*, 59(6), 757–766. <https://doi.org/10.1111/ajo.13041>
- Nuzum, D., Meaney, S., & O'Donoghue, K. (2017). The spiritual and theological challenges of stillbirth for bereaved parents. *Journal of Religion and Health*, 56(3), 1081–1095. <https://doi.org/10.1007/s10943-017-0365-5>
- Nuzum, D., Meaney, S., & O'Donoghue, K. (2018). The impact of stillbirth on bereaved parents: A qualitative study. *PLoS One*, 13(1), e0191635–13. <https://doi.org/10.1371/journal.pone.0191635>
- Obst, K. L., Due, C., Oxlad, M., & Middleton, P. (2020). Men's grief following pregnancy loss and neonatal loss: A systematic review and emerging theoretical model. *BMC Pregnancy and Childbirth*, 20(1), 11–17. <https://doi.org/10.1186/s12884-019-2677-9>
- Obst, K. L., Oxlad, M., Due, C., & Middleton, P. (2021). Factors contributing to men's grief following pregnancy loss and neonatal death: Further development of an emerging model in an Australian sample. *BMC Pregnancy and Childbirth*, 21(1), 1–29. <https://doi.org/10.1186/s12884-020-03514-6>
- Peel, E. (2010). Pregnancy loss in lesbian and bisexual women: An online survey of experiences. *Human Reproduction*, 25(3), 721–727. <https://doi.org/10.1093/humrep/dep441>
- Redshaw, M., & Henderson, J. (2018). Mothers' experience of maternity and neonatal care when babies die: A quantitative study. *PLOS One*, 13(12), e0208134–15. <https://doi.org/10.1371/journal.pone.0208134>
- Roberts, L., Montgomery, S., Ganesh, G., Kaur, H. P., & Singh, R. (2017). Addressing stillbirth in India must include men. *Issues in Mental Health Nursing*, 38(7), 590–599. <https://doi.org/10.1080/01612840.2017.1294220>
- Schut, H., & Stroebe, M. (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies*, 23(3), 197–224. <https://doi.org/10.1080/074811899201046>
- Shakespeare, C., Merriel, A., Bakhbakhi, D., Banaszova, R., Barnard, K., Lynch, M., Storey, C., Blencowe, H., Boyle, F., Flenady, V., Gold, K., Horey, D., Mills, T., & Siassakos, D. (2019). Parents' and healthcare professionals' experiences of care after stillbirth in low- and middle-income countries: A systematic review and meta-summary. *BJOG*, 126(1), 12–21. <https://doi.org/10.1111/1471-0528.15430>
- Shannon, E., & Wilkinson, B. (2020). The ambiguity of perinatal loss: A dual-process approach to grief counselling. *Journal of Mental Health Counseling*, 42(2), 140–154. <https://doi.org/10.17744/mehc.42.2.04>
- 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*, 127(7), 868–874. <https://doi.org/10.1111/1471-0528.16113>
- 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. <https://doi.org/10.1111/jan.13527>
- Stroebe, M., & Schut, H. (2010). The dual process model of coping with bereavement: A decade on. *Omega*, 61(4), 273–289. <https://doi.org/10.2190/OM.61.4.b>
- Tracy, S. J. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative Inquiry*, 16(10), 837–851. <https://doi.org/10.1177/1077800410383121>
- 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. <https://doi.org/10.1046/j.1440-1754.2002.00008.x>
- 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), 1528124–1528111. <https://doi.org/10.1080/20008198.2018.1528124>
- Wojnar, D. (2007). Miscarriage experiences of lesbian couples. *Journal of Midwifery & Women's Health*, 52(5), 479–485. <https://doi.org/10.1016/j.jmwh.2007.03.015>
- Woodroffe, I. (2013). Supporting bereaved families through neonatal death and beyond. *Seminars in Fetal & Neonatal Medicine*, 18(2), 99–104. <https://doi.org/10.1016/j.siny.2012.10.010>
- 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 & Trauma*, 22(1), 77–96. <https://doi.org/10.1080/15325024.2016.1187049>

Appendix A

Interview Questions

- We are interested in exploring men's experiences of neonatal death, can you tell me a bit about your experiences?
- Can you tell me about your relationship with your baby during pregnancy?
- Can you tell me about how your baby's death has impacted you?
- How did you cope with the loss?
- How do you generally approach stressful situations in your life?
- 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?
- 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?

- Did you seek any support from a professional such as a counselor, psychologist or support organisation?
- Were you satisfied with the support you received?
- What support did you receive from family, friends or work colleagues?
- What was it like returning to work?
- Has your grief changed over time? If so, how has it changed?
- 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?