Men’s experiences of grief and support following pregnancy loss and neonatal death

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Bachelor of Psychology (Honours)

Thesis submitted for the degree of

Combined Doctor of Philosophy/Master of Psychology (Health)

School of Psychology

Faculty of Health and Medical Sciences

University of Adelaide

February, 2022

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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), 29. https://doi.org/10.1186/s12884-020-03514-6

Obst, K. L., Due, C., Oxlad, M., & Middleton, P. (2020). Australian men's experiences of leave provisions and workplace support following pregnancy loss or neonatal death. *Community, Work and Family*, 1-12. https://doi.org/10.1080/13668803.2020.1823319

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. https://doi.org/10.1186/s12884-019-2677-9

Conference presentations

Obst, K., Due, C., Oxlad, M., & Middleton, P. (2021). *Men’s experiences and need for targeted support after termination of pregnancy for foetal anomaly: A qualitative study*. Oral presentation at the Helen Mayo House Conference 2021, Adelaide.

Obst, K., Due, C., Oxlad, M., & Middleton, P. (2021). *Men’s grief following pregnancy loss or neonatal death: Adopting a socio-ecological perspective as a framework to develop future support and policy*. Oral presentation at the 2021 APS College of Health Psychologists Conference. Held online due to COVID-19 pandemic.

Obst, K., 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.* Oral presentation at the ISA/ISPID 2021 Conference. Held online due to COVID-19 pandemic.

Obst, K., 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.* Oral presentation at the Australasian Marcé and Tresillian Conference 2021. Held online due to COVID-19 pandemic.

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Obst, K. (2020). *Men's grief following baby loss: Taking a socio-ecological approach to understand experiences and inform support.* Oral presentation at the Perinatal Infant Group Liaison Education and Training (PIGLET) Network. Held online due to COVID-19 pandemic.

Obst, K. L. (2020). *Men and pregnancy/neonatal loss: understanding grief and contributing factors*. Oral presentation at Men's Health Connected: Australian Men's Health Form. Held online due to COVID-19 pandemic.

Obst, K. L., Due, C., Oxlad, M., & Middleton, P. (2020). *Factors contributing to men's grief following pregnancy loss and neonatal death: further development of an emerging model in an Australian sample*. Poster presentation at 14th Annual Florey Postgraduate Research Conference. Held online due to COVID-19 pandemic. **Awarded School of Psychology and Vernon Roy East Prizes for Best Poster*

Obst, K., & Oxlad, M. (2019). *Psychosocial Care Following Pregnancy Loss*. Invited presentation to Midwifery Department, Universitas Brawijaya Indonesia. Held via online tele-conference.

Obst, K., Due, C., Oxlad, M., & Middleton, P. (2019). *Men's grief following pregnancy loss and neonatal loss: A systematic review and emerging theoretical model*. Oral presentation at The International Stillbirth Alliance's 11th Annual Conference. Madrid, Spain.

Obst, K. (2019). *Men and baby loss: Understanding grief to inform support*. Oral presentation at Stillbirth CRE 2019 Annual National Stillbirth Forum. Brisbane, Australia.

Obst, K. L. (2019). *How do men experience grief following pregnancy loss?* Poster presentation at 2019 APS College of Health Psychologists Conference. Glenelg, South Australia.

Obst, K. (2019). *Working with bereaved fathers following pregnancy loss and neonatal loss: Recent Australian research findings*. Invited workshop presentation at the Maternity Services Department, Sunshine Coast University Hospital.

Obst, K., Due, C., Oxlad, M. & Middleton, P. (2019). *Men's Grief Following Pregnancy Loss and Neonatal Loss: A Systematic Review*. Oral presentation at 23rd Annual Congress of the Perinatal Society of Australia and New Zealand Conference. Gold Coast, Australia.

Obst, K., & Due, C. (2018). *Australian men's experiences of support following pregnancy loss*. Oral presentation at 2018 International Conference on Stillbirth, SIDS and Baby Survival. Glasgow, United Kingdom.

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Obst, K. L. (2018). *How do men experience grief following pregnancy loss?* Poster presentation at 12th Annual Florey Postgraduate Conference. University of Adelaide. **Awarded School of Psychology and Vernon Roy East Prizes for Best Poster*

Media articles and outreach activities

Baby Loss Project (2021). Invited interview for a corporate training program on supporting employees after the death of a baby. Included in Module 1: "Real Life Stories" to share findings and recommendations for workplaces from research on men and grief. See: https://www.babylossproject.com/training-program/about-the-training

Obst, K., Azeez, S., Due, C., Oxlad, M. (2021). *Fathers and Grief*. Miracle Babies Foundation https://www.miraclebabies.org.au/content/fathers-and-grief/gknicg

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Obst, K. (2020). *"Grief was a journey shared by both of us": Why we need to recognize fathers' grief following stillbirth and tailor support appropriately*. Healthy Newborn Network. https://www.healthynewbornnetwork.org/blog/grief-was-a-journey-shared-by-both-of-us-why-we-need-to-recognize-fathers-grief-following-stillbirth-and-tailor-support-appropriately/

Obst, K., Due, C., & Oxlad, M. (2020). *"The father is just as upset": why we need multi-level strategies to support men when a baby dies*. BMC Series Blog. https://blogs.biomedcentral.com/bmcseriesblog/2020/01/10/the-father-is-just-as-upset-why-we-need-multi-level-strategies-to-support-men-when-a-baby-dies/

Two Shrinks Pod (2019). *Men's responses to a miscarriage or still-birth - with Kate Obst*. https://www.twoshrinkspod.com/podcasts/2019/5/9/44-mens-grief-following-a-miscarriage-or-still-birth-with-kate-obst

Australian Government Stillbirth Senate Inquiry (2018). In addition to written submission, invited by the Select Committee to present our research relating to men's experiences of pregnancy loss at the Adelaide Public Hearing. Findings included in Chapter 6 of the report and Recommendation 9. View our submission and full report: https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Stillbirth_Research_and_Education/Stillbirth/Submissions

ABSTRACT

This thesis explored men's experiences of grief and support following pregnancy loss and neonatal death. While many parents experience emotional distress and enduring grief after pregnancy loss and neonatal death, little is known about men's grief. Given potential gendered differences concerning grief styles, help-seeking and service access, this is an important gap. The research questions for this thesis were: (1) how do men experience grief following pregnancy loss and neonatal death; (2) what factors influence men's grief following pregnancy loss and neonatal death; (3) how does type of loss (i.e., miscarriage, stillbirth, termination of pregnancy for life-limiting foetal anomaly [TOPFA], or neonatal death) impact men's grief experiences; and (4) how can future services and bereavement care guidelines best support men following pregnancy loss and neonatal death?

This thesis comprised four studies and four published papers. Study 1 was a systematic review of men's grief following pregnancy loss and neonatal death. Following Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines and screening according to pre-defined eligibility criteria, 46 studies were included. Findings indicated that men's grief experiences are highly varied; however, specific challenges to grief expression include balancing a desire to both support and be supported, and being overlooked as fathers by current health/support services and systems/policies. A Socio-Ecological Model of Men's Grief was proposed as a result of this review.

Study 2 was a nationwide online survey to further explore the factors contributing to men's grief. A convenience sample of 228 men from Australia completed the survey comprising quantitative/psychometric scales and open-ended questions. Data were analysed using multiple linear regression. Findings indicated that men can experience significant grief regardless of loss type. Factors contributing to grief also differed depending on grief styles, which ranged from intuitive (emotion-focused) to instrumental (activity-focused). Study 3 explored a subset of survey data reflecting men’s experiences of returning to work following pregnancy loss and neonatal death using a combination of descriptive statistics and content analysis. Findings highlighted the importance of available workplace leave to provide recognition of men’s grief and to allow time to be with their partner, attend to practical needs, and process emotional impacts.

Study 4 involved in-depth interviews with 10 men who had experienced a TOPFA. Thematic analysis resulted in the generation of three overarching themes, each with two sub-themes. Overall, findings indicated that TOPFA is an extremely difficult experience for men, characterised by challenges in decision-making and perceived stigma toward termination. Participants described feeling overlooked by current pregnancy and TOPFA support services and indicated that they need support tailored to men to assist with their grief.

Overall, the findings indicated that understanding the factors contributing to men’s grief requires a socio-ecological conceptualisation including individual, interpersonal, community and policy/system perspectives. Following pregnancy loss and neonatal death, men can experience high levels of grief, requiring acknowledgement, validation and tailored support from healthcare professionals, family/friends, and communities/workplaces. Future support and policy strategies should consider grief styles and expansion of existing perinatal care infrastructure, drawing upon existing family-centred recommendations that are father-inclusive.

DECLARATION

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name, for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

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Finally, I acknowledge the support I have received for my research through the provision of an Australian Government Research Training Program Scholarship, and a Westpac Scholars Trust 2018 Future Leaders Scholarship.

Kate Obst (2 February 2022)

ACKNOWLEDGEMENTS

Over the last four years, I have been blessed and honoured to receive support from several incredible people, without who, this program of research would not have been possible. First and foremost, my eternal gratitude goes to my research supervisors and academic mentors. To Clemmi – my thanks goes beyond words – for taking a chance on me as an undergraduate and never looking back. You have helped me to believe in myself and grow as a person and researcher. I wouldn't have found this research, nor pursued a PhD, without you. To Mel, for your unwavering enthusiasm and expert guidance throughout this research and my clinical training. To Philippa, for your kindness, wisdom and considered feedback. It has been a privilege to work with and learn from you all. Also to Anna Chur-Hansen for supporting my endeavours, sharing in the excitement of my achievements and encouraging me to put my hand up for opportunities. To have such a dream team of successful and inspiring women behind me on this journey has meant the world.

I am indebted to the incredible people behind Australia's pregnancy loss and neonatal death support and research organisations for providing consumer feedback, sharing invaluable advice and support, and helping to disseminate research advertisements and findings. My special thanks goes particularly to Claire Foord, Gary Sillett, Dorothy Crosby, Amanda Bowles, Adrian Raftery, Fran Boyle, Dell Horey, Kylie Pussell, Sam Payne, Renée Miller and Jackie Mead. My thanks also extends to Margaret McGee for assisting with dissemination of the research promotional materials, Maureen Bell for invaluable systematic review guidance, and Suzanne Edwards for statistical support.

I was immensely fortunate in receipt of a Westpac Future Leaders Scholarship, without which I would not have had the means to travel the world, attend conferences, and learn from international leaders in the field of reproductive health and grief. I especially thank Sarah Meaney, Margaret Murphy, and Daniel Nuzum for warmly welcoming me to

Cork and generously sharing their expertise and knowledge with me. And Julia Bueno, for agreeing to meet a stranger from Twitter and being such a kind and generous support person ever since. Also to Dan Caprar, Amy Lyden, Amy Blacker, and my 2018 FLs cohort for inspiring and believing in me right from the beginning of this experience.

To my family – *all* of you! Especially to Mum and Dad, for your hard work, sacrifices, love and support to provide the foundation for my life and education. To Julie, for encouraging me to do my best. To Phil, for being my partner and biggest support person through all the ups and downs, and for growing alongside me over the last eight years. And to Phil's beautiful family, for loving and supporting me as one of your own.

To Krystal, for your incredible friendship over the years and your never-ending enthusiastic support in everything I do. To my fellow PhD and Masters buddies – especially Christianna, Ally, Jane, Danielle, Anneka, my 'lifelong colleagues and friends', and 'green corridor crew' – for sharing the rollercoaster journey of higher education with me.

Last, but absolutely not least, my heartfelt thanks goes to the men whose experiences formed this research. Hearing and writing about your stories has been an immense privilege, and I will be forever indebted to each of you for so generously sharing your time and experiences. It is my hope that this thesis, resulting publications and ongoing advocacy work does justice to your stories and contributes to improvements in care and support for men and families in future. A special mention particularly to Brett Carter and John De'Laney, who have both been incredible sources of support and guidance. Thank you for reaching out to me, sharing your beautiful babies' stories, and your ongoing work to improve families' lives. The world is a better place because of you.

Finally, to Nick; thank you, from the bottom of my heart, for being so open, raw, honest and inspiring. Your perspectives and suggestions were truly instrumental in shaping this research.

DEDICATION

For all bereaved parents, and their precious babies who are no longer earth-side. Thank you for sharing your stories of loss and love. I will forever carry these my heart.

Birthday for Babies, 2020

LIST OF ABBREVIATIONS

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
APA	American Psychiatric Association
CASP	Critical Appraisal Skills Program
COREQ	Consolidated Criteria for Reporting Qualitative Research
CSS	Crisis Support Scale
CMNI	Conformity to Masculine Norms Inventory
DSM	Diagnostic and Statistical Manual
GEI-L	Grief Experience Inventory-Loss Version
GP	General Practitioner
GPI	Grief Patterns Inventory-Revised
HREC	Human Research Ethics Committee
ICF	International Classification of Functioning
IES	Impact of Events Scale
LMIC	Low and middle income country
MDD	Major Depressive Disorder
MRNI-SF	Male Role Norms Inventory-Short Form
NBCP	National Bereavement Care Pathway
NICU	Neonatal Intensive Care Unit
NZ	New Zealand
PAAS	Paternal Antenatal Attachment Scale
PGS	Perinatal Grief Scale
PICO	Population Intervention Comparison Outcome
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PSANZ	Perinatal Society of Australia and New Zealand
PTSD	Post-Traumatic Stress Disorder
RCT	Randomised Control Trial
RIMS	Revised Impact of Miscarriage Scale
SD	Standard Deviation
SIDS	Sudden Infant Death Syndrome
Stillbirth CRE	NHMRC Centre of Research Excellence in Stillbirth
TOPFA	Termination of pregnancy for foetal anomaly

TRIG-F	Texas Revised Inventory of Grief
UK	United Kingdom
UNICEF	United Nations Children’s Fund
UN IGME	United Nations Inter-agency Group for Child Mortality Estimation
USA	United States of America
WHO	World Health Organization

OVERVIEW

Outline of thesis

This thesis explored men's experiences of grief and support after pregnancy loss and neonatal death. The program of research built upon preliminary research completed for my Honours thesis in Psychology, which was a qualitative investigation of men's experiences of support following pregnancy loss (including miscarriage and stillbirth) in South Australia (Obst, 2018). Two papers were published from my Honours thesis, one focusing on men's experiences of receiving support (Obst & Due, 2019a), and the other on service providers' experiences of providing support to men (Obst & Due, 2019b). The program of research and studies included in this thesis also aimed to expand on the small body of existing published research exploring men's experiences, providing a comprehensive understanding of how men experience grief, and identifying specific support needs and service gaps for men, after pregnancy loss and neonatal death.

This thesis is presented in publication format, with all four papers accepted for publication in peer-reviewed academic journals. Chapter 1 provides an introduction and literature review to contextualise the research topic and detail the specific research questions for the thesis. Chapter 2 outlines the justification for the research methods, including details that could not be included in the papers for publication, and the overarching guiding theoretical frameworks. Chapter 3 reports the results of a systematic review on men's grief following pregnancy loss and neonatal death, Chapters 4 and 5 present results from a nationwide online survey of men's grief and support, and Chapter 6 details qualitative interviews with men. Finally, Chapter 7 provides a synthesis of the main research findings and outlines important theoretical and practical implications, including recommendations for health systems and future research.

Outline of candidature

The current thesis was undertaken to fulfil the requirements of a combined Doctor of Philosophy/Master of Psychology (Health) degree at the University of Adelaide, South Australia. This program includes a full Masters coursework program (two years full-time equivalent) and a full research program for a Doctor of Philosophy (three years full-time equivalent). The four published papers that were produced from the program of research, along with the seven Masters subjects and three clinical placements, were completed within four years of full-time study. All subjects and practical requirements of the Masters component of the program were completed successfully, leading to eligibility for general registration as a Psychologist with the Australian Health Practitioner Regulation Agency (AHPRA). This thesis is submitted to fulfil the requirements of a Doctor of Philosophy.

“The ones who left footprints on our hearts left stories worth telling”

- Unknown author

CHAPTER 1. INTRODUCTION AND LITERATURE REVIEW

1.1 Preamble

This program of research aimed to explore men's experiences of grief and support after pregnancy loss and neonatal death, focusing particularly on how men experience grief and understanding the factors that influence men's grief to inform future service provision and bereavement support. As an introduction to the research, this Chapter details a literature review on the theoretical development and current approaches to understanding loss and grief, including application of these views to the experience of pregnancy loss and neonatal death for bereaved parents. I also provide an overview of the clinical applications of current theory to grief support services and bereavement care guidelines after pregnancy loss and neonatal death. This overview includes a summary of previous research on bereaved parents' experiences of care, highlighting current gaps in service provision – particularly for men – that informed the specific aims and research questions underpinning the program of research.

1.2 Literature review

1.2.1 Loss and grief

1.2.1.1 *Overview and definitions*

In response to the death of a loved one, grief is a natural, yet complex experience that is unique to each person and dependent on a variety of contributing factors. Grief has been defined as the deeply personal response to loss that manifests across physical, emotional, behavioural, cognitive, spiritual and social dimensions (Buglass, 2010). Mourning is the external or active expression of grief that is influenced by social and cultural norms, and bereavement refers to the general state of having experienced a loss (Barrera et al., 2007; Buglass, 2010; Davies, 2004; Hall, 2014). Over time, explanations and models of grief and bereavement have developed and shifted in focus from prescriptive stage and phase models to process and meaning-making models, which allow for more flexibility depending on individual and circumstantial characteristics (Buglass, 2010; Hall, 2014; Wright & Hogan, 2008).

1.2.1.2 *Grief models*

Freud (1917) provided the first major conceptualisation of grief and bereavement. From a psychoanalytic perspective, he argued that the primary psychological function of grief was to gradually allow the individual to detach or 'let go' from their bond with the deceased and return to a 'normal' level of functioning (Buglass, 2010; Freud, 1917; Hall, 2014). Without successfully engaging in this separation process and readjustment to life, termed 'grief work', the individual would be at higher risk of experiencing pathological psychological outcomes (Freud, 1917; Wright & Hogan, 2008). Influenced by Freud's work, Lindemann (1944) later proposed a differentiation between 'normal' and 'pathological' grief responses, based on work among individuals bereaved by disasters. Abnormal reactions included a delayed or absent grief response, disruptions to social relationships and self-destructive behaviours. Lindemann developed a theory of grief comprising five distinct stages: (1) somatic disturbance; (2) preoccupation with the deceased; (3) guilt for the death; (4) hostility or anger; and (5) difficulty with everyday tasks (Buglass, 2010; Lindemann, 1944). Like Freud, he argued that individuals must work through these stages and ultimately learn to detach from the deceased and adjust to a new reality without them. However, despite the conceptual interest these theories generated, their validity and generalisability were questioned, as they were derived entirely out of 'rational thought' and general clinical observations among clients bereaved by disasters or those with Major Depressive Disorder (MDD), as opposed to empirical research (Shackleton, 1984; Wright & Hogan, 2008).

Despite a lack of empirical evidence for these theories, the idea of structuring grief as predictable stages or phases influenced much of the work on grief in the second half of the 20th century. Kübler-Ross (1969) proposed a 'five stages of grief' model, based on research literature and her clinical experience with terminally-ill patients and their families. Although expanded for use among many forms of bereavement, the model was initially one of anticipatory grief, when the death was expected due to long-term illness. The five stages of grief comprised denial, anger, bargaining, depression and acceptance. By implication, failure to engage in all these stages would complicate the grieving process (Hall, 2014). Similarly, Buglass (2010) highlighted how Bowlby's (1980) theory of attachment similarly proposed four overlapping phases of grief that result from the involuntary loss of attachments: shock, yearning and protest, despair and recovery. Later, Worden (1991) suggested a more active approach to grief, identifying four tasks that must be accomplished to resolve grief: (1) accept the reality of the loss; (2) work through the experience of grief; (3) adjust to an environment without the deceased; and (4) withdraw emotionally from the deceased and 'move on' with life. Buglass (2010) noted that these stage and phase models were enthusiastically and widely adopted among professionals working with bereaved individuals due to their simplistic appeal. However, these models have also been widely criticised for their weak empirical evidence base and an inability to address the multifaceted and diverse nature of grief, which includes physical, psychological, social and spiritual dimensions impacting both the bereaved and those around them (Hall, 2014). Crucially, researchers began to question the rigidity of the requirement for individuals to engage in the process of 'grief work' and sequentially move through a series of prescribed stages (Davies, 2004; Hall, 2014; Stroebe & Schut, 1999).

To address these shortcomings, Stroebe and Schut (1999) introduced the Dual Process Model of coping with bereavement. The Dual Process Model was developed based on concepts from Cognitive Stress Theory, which describes four key components related to coping with a stressful situation: (1) the cause or nature of events leading to stress; (2) the appraisal or assessment of the threat of the stressor; (3) the way one copes with the threat/s, and (4) the mental and physical health outcomes of coping (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). Stroebe and Schut argued that rather than being a linear process, grief involves an ongoing oscillation between two categories of appraising and coping with bereavement; namely, ‘loss orientation’ and ‘restoration orientation’. The former occurs when the griever engages in emotion-focused coping (i.e., emotional expression of grief), and the latter occurs when the griever engages in problem-focused coping (i.e., expression of grief through activities), becoming preoccupied with the external demands of life and associated adjustments. The authors argued that both expressing emotions and re-engaging with life are important, and coping styles may differ between and within individuals depending on a range of contextual factors, individual characteristics (i.e., personality or gender), and cultural backgrounds (Buglass, 2010; Stroebe & Schut, 1999, 2010). This model has been influential in recognising the individuality and diverse nature of grief; however, it remains open to debate due to its focus on the individual and a lack of emphasis on the role of broader factors – such as interpersonal relationships – on grief and coping (Buglass, 2010).

Another questionable aspect of previous models of grief is the requirement for bereaved individuals to ‘move on’ from, or ‘let go’ of, their relationship to the deceased. Importantly, these conceptualisations of grief work were not based on the experiences of bereaved parents whose child had died. Christ and colleagues (2003) also noted that when Freud experienced the unexpected death of his daughter, he later wrote about his experience of grief as a “hurt that is not to be healed” (Jones, 1957, p. 20); a perspective that was seemingly contradictory to his original assertions of needing to ‘let go’ of the deceased. Alongside broader continuing research on loss and grief, researchers conducting early studies exploring bereaved parents’ experiences after the death of a child led calls away from the concept of ‘moving on’ toward the importance of maintaining ongoing relationships with the deceased (e.g., Benfield et al., 1978; DeFrain, 1991; Friedman, 1974). For example, following a 10-year ethnographic study on a self-help group of bereaved parents, Klass (1993) found that rather than ‘forgetting’ their children, bereaved parents maintained ongoing (and often lifelong) connections, through means including symbolic objects (e.g., their children’s toys or items of clothing), religious devotions/rituals, and sharing memories of their children with others (Davies, 2004). Termed ‘continuing bonds’, this concept has been corroborated by a large body of studies involving interviews and surveys of bereaved parents (e.g., Barrera et al., 2007, 2009; Keesee et al., 2008; Shankar et al., 2017). This concept of continuing bonds contrasted with earlier assumptions, which conceptualised an ongoing relationship with the deceased as an ‘abnormal’ reaction to grief (Davies, 2004). Rather than the need to ‘move on’, grief researchers have since argued that bereaved individuals need to engage in sense-making to construct or locate meaning in the experience of loss (Davies, 2004; Hall, 2014). For example, bereaved parents may think of their child as being in heaven with other loved ones who have died or adopt a belief that the deceased is ‘in a better place’ (Hall, 2014).

In the context of continuing bonds, memories of the deceased have also been identified as important in shaping the grief experience over time. While initially the experience of grief commonly involves potential experiences of shock, sadness and yearning, accounts in research among bereaved individuals suggest that through engaging in processes such as storytelling or remembrance rituals that aid sense-making, grief can be transformed over time into fond memories of the deceased (Bosticco & Thompson, 2005). In line with the Dual Process Model, individuals may also begin to oscillate between initial ‘raw’ feelings of grief and fond memories (Stroebe & Schut, 2010).

Overall, these more recent models and descriptions of the grief process challenged previously dominant assumptions regarding the traditional ‘grief work’ hypothesis. Rather than following predefined stages, later models emphasised the unique nature of grief and the importance of memory-making, rituals, remembrance activities, and learning new ways to live with loss, to allow for continuing relationships with the deceased (Davies, 2004; Kochen et al., 2020).

1.2.1.3 *Current approaches to grief*

Using an integration of historical theories and various models of grief, current understandings emphasise the universal yet simultaneously individual nature of grief, which encompasses biopsychosocial (and cultural) impacts on functioning. The general consensus is that most people will learn to integrate their grief into a new reality of life with time and adequate social support (Shear et al., 2011). However, depending on factors including the context of the death and various individual, social and cultural factors, some people may develop prolonged or complicated grief, which may require more intense psychological intervention (Shear et al., 2011).

1.2.1.4 *Biopsychosocial understanding of grief*

Grief is a process that extends beyond the psychological experience alone, encompassing biological impacts and existing within a social and cultural context (McCoyd & Walter, 2015). The psychological effects of grief are perhaps most immediately apparent; common affective presentations of grief include difficulties in coping, anger, irritation, loneliness, insomnia and suicidal ideation (Stroebe et al., 2007). Cognitively, individuals may experience a sense of depersonalisation, rumination about the deceased person, or difficulties concentrating (Doka & Martin, 1998; Worden, 1991). Where grief challenges an individuals' belief system, they may also spend time re-evaluating their perspectives in an attempt to identify a sense of meaning associated with the loss (Doka, 1994; Doka & Martin, 1998).

Grief may also be expressed physically through aches, pains or general somatic distress, particularly in the short-term (Buckley et al., 2012; Carey et al., 2014; Kowalski & Bondmass, 2008; Lindemann, 1944; Stroebe et al., 2007). The strong negative emotions experienced in grief may trigger physiological stress reactions which have numerous effects on biological functioning, including reduced immune efficiency, disturbed cortisol responses and sustained neuroanatomical changes; all of which can increase individual susceptibility to illness, disease and mortality (McCoyd & Walter, 2015; Stroebe et al., 2007). When compared with matched controls, bereaved individuals frequently experience higher rates of illness and disability, somatic symptoms including headaches and chest pain, as well as increased use of medications and medical services (Stroebe et al., 2007). Significant associations have also been found between grief and a heightened risk of early mortality from numerous causes, including suicide or a ‘broken heart’, which may result from the secondary consequences of psychological distress (Carey et al., 2014; Latham & Prigerson, 2004; Molina et al., 2019; Moon et al., 2011; Stroebe et al., 2005).

Grieving can also be a highly social activity, whereby the bereaved individuals’ reactions affect and are affected by those around them (Zinner, 2000). Therefore, social norms frequently define social ‘rules’ of mourning, determining the appropriate mechanisms and expected length of grief-related activities by individuals (McCoyd & Walter, 2015). Where discrepancies exist between such rules and an individual’s expression of grief, the mourning process can be adversely impacted, and grievers may feel marginalised or ignored by others (Doka, 1999; Doka & Martin, 2002; Zinner, 2000). Grief which is unrecognised or unacknowledged – for example, in cases of early pregnancy loss, abortion, or the death of a pet, where relationships with the deceased are assumed to be ‘less significant’ than the death of an adult companion – is termed ‘disenfranchised’ (Doka, 1999; Lang et al., 2011; Spain et al., 2019). Disenfranchised grief has been associated with a substantially increased risk of the individual developing complicated or prolonged mourning responses (Doka, 1999). In contrast, where bereaved individuals have access to strong social support networks and acknowledgement of their grief from family, friends, community, peers or healthcare professionals, significant reductions in acute and long-term levels of distress and grief are usually seen (Aoun et al., 2019; Kaunonen et al., 2001; Kreicbergs et al., 2007; Robinson & Pond, 2019; Scott et al., 2020). These understandings provide a biopsychosocial perspective of grief, which recognises the interactions between psychological, biological and social factors on individuals' grief.

1.2.1.5 *Classification of grief in the Diagnostic and Statistical Manual of Mental Disorders (DSM–5)*

Grief is a normal human process that occurs in response to loss, including the death of a loved one or loss of something valued (e.g., relationship, job). Although the experience of grief can be intense and enduring for some individuals – particularly immediately following a death – grief-related distress for most people eases with time and does not require significant psychological intervention (Shear et al., 2011). However, typical symptoms of grief, including sadness/emptiness, loss of energy or interest and disruptions to sleep, share many features with MDD and may be difficult for clinicians to disentangle. Historically, the *Diagnostic and Statistical Manual of Mental Disorders* (DSM; American Psychiatric Association [APA], 1980, 1994, 2013b) has viewed grief and depression as distinct phenomena, with grief defined as a reaction to an external event (i.e., the death of a loved one) and depression defined as a mood dysfunction internal to the individual (Thieleman & Cacciatore, 2014). Typically, the defining feature of grief is a preoccupation with the loss and yearning for the lost person or object, with fluctuating emotions that often "occur in waves" and change with time (APA, 2013a, F.34). In contrast, MDD is marked by *persistent* feelings of depressed mood, markedly diminished interest or pleasure in all (or most) activities, feelings of worthlessness or excessive guilt, and cognitive impairments (APA, 2013a; Beutel et al., 1996; Brown & Stoudemire, 1983).

The diagnostic criteria for MDD in previous versions of the DSM included a bereavement exclusion, with MDD unable to be diagnosed if an individual's distress was related to experiencing a bereavement within the last year (DSM-III; APA, 1980); in the DSM–IV (APA, 1994), this timeframe was revised to the last two months (Thieleman & Cacciatore, 2013). Controversially, revisions to the most current version (DSM–5; APA, 2013b) removed the bereavement exclusion altogether, theoretically allowing MDD to be diagnosed within the first two weeks following a death. Although a footnote remains advising clinicians to use careful judgement in delineating the symptoms of depression from grief, some researchers have noted concerns that removing the exclusion may lead to a pathologising of grief, or over-prescription of antidepressant medication for grief-related distress (Iglewicz et al., 2013; Sabin & Daniels, 2017; Thieleman & Cacciatore, 2013; Zachar et al., 2017).

In a small number of cases, grief may continue in intensity and duration to the extent where it may be considered 'complicated' or 'prolonged' (Shear et al., 2011). To account for this possibility, the DSM–5 (APA, 2013b) also added a new diagnosis, Persistent Complex Bereavement-Related Disorder, in Section III of the manual, which outlines diagnoses requiring further study (Thieleman & Cacciatore, 2013). In 2020, a proposal was made to add Prolonged Grief Disorder (PGD) to the Depressive Disorders chapter of the manual (APA, 2020). To meet the criteria for a diagnosis of PGD, grief-related distress must be present for at least 12 months following the death of a loved one, cause clinically significant distress or impairment on more days than not, and clearly exceed cultural, religious or age-appropriate norms (APA, 2020). Eligible symptoms include emotional numbness, feeling that life is meaningless, intense loneliness, difficulty moving on with life, and avoidance of reminders that the person is dead (APA, 2020).

Although such delineations of grief may be helpful for clinicians in distinguishing between reactions to relatively common experiences of loss and death, these classifications may not be entirely suitable for specific populations of bereaved individuals who experience unexpected and traumatic losses (Thieleman & Cacciatore, 2013). While grief symptomatology is typically related to the loss of a relationship with the deceased, trauma symptomatology is associated with the circumstances surrounding the death (Nazaré et al., 2014). For example, where the death is unexpected or shocking, trauma symptoms may accompany or compound symptoms of grief. One such widely accepted form of traumatic bereavement is the death of an infant or child (Kamm & Vandenberg, 2001; Thieleman & Cacciatore, 2014). Often, this type of death is sudden or unexpected and can lead to feelings of isolation or not knowing how to cope (Kamm & Vandenberg, 2001; Rando, 1983; Vance et al., 2002). In previous research, bereaved parents have reported intense grief reactions along with high levels of 'atypical' grief, which can continue for years or decades following the death of their child (Sanders, 1980; Thieleman & Cacciatore, 2014). According to DSM classifications (APA, 2013b), such symptomatology could meet the criteria for complicated or prolonged grief disorders. However, in the context of such a devastating life event, the intensity and duration of bereaved parents' grief has been argued to represent a normal and expected response, which should not be pathologised (Thieleman & Cacciatore, 2014). Further research is required to understand and educate clinicians and mental health professionals on the unique needs of these specific populations.

1.2.1.6 *Coping with loss and grief*

Given the highly individualised nature of grief, helpful strategies for coping with grief and adjusting to loss can vary depending on individual characteristics and cultural background. However, since grief is a normal and natural response to loss, most bereaved individuals will cope well over time, with support from relatives, friends and/or regular healthcare professionals (Boelen & Smid, 2017). Socially-prescribed rituals, such as funerals or other visible memorialising activities, can also be fundamental to aiding the mourning process and providing recognition and social support to the bereaved (McCoyd & Walter, 2015; Muller & Thompson, 2003). Additional rituals to support continuing bonds, such as celebrating important anniversaries, writing letters to the deceased, or creating a place or object in memory of the deceased, may also assist in expressing grief in the months or years following the loss (Castle & Phillips, 2003; Mitima-Verloop et al., 2019). In line with a biopsychosocial conceptualisation of grief, activities to support physical health such as regular exercise, exposure to daylight and a balanced diet may also assist individuals in managing the potential physical impacts of grief (McCoyd & Walter, 2015).

However, where grief becomes complicated, or a bereaved individual feels they require additional support, counselling or psychological interventions may also be sought. In this context, common therapeutic approaches are generally guided by the ‘tasks’ of grieving (outlined in Section 1.2.1.2), including re-visiting the story of the loss, facilitating therapeutic conversations with the deceased, and reimagining or planning meaningful goals for the future (Neimeyer & Currier, 2009; Stroebe et al., 2007). In addition, therapies focusing on specific theories or models of grief, such as the Dual Process Model (Stroebe & Schut, 1999, 2010), may also assist individuals in contextualising their experiences, and normalise adaptive processes including an ongoing oscillation between loss-oriented and restoration-oriented tasks of grief over time (Neimeyer & Currier, 2009). While reviews have found mixed evidence regarding the efficacy of psychological interventions for bereaved individuals (e.g., Currier et al., 2008; Johannsen et al., 2019; Neimeyer & Currier, 2009; Wittouck et al., 2011), the general consensus is that theoretically-informed interventions targeted to high-risk populations are beneficial in the short- and long-term. One such example is Complicated Grief Therapy; underpinned by attachment theory, key components encourage engagement in a balance of loss- and restoration-orientated tasks of grieving, including repeated retelling of the loss experience combined with therapeutic prompts to promote new perspectives, and attending to current relationships and renewed life goals (Shear, 2010; Wetherell, 2012). Outside of formal psychological supports, some bereaved people are also more likely to access more informal – including peer and religious – social support systems. While research regarding the influence of religious or spiritual beliefs on grieving is mixed, beliefs that support the bereaved to engage in helpful grief rituals, or increase their access to social support, have generally been found to be efficacious (Becker et al., 2007; Wortmann & Park, 2008). Further discussion of peer support for bereaved parents is provided in Section 1.2.4.5.

1.2.1.7 *Socialisation of grief according to gender*

Although the grief process is highly dependent on a range of individual coping characteristics, researchers have identified that complex implicit and explicit social expectations also determine how individuals experience and express grief (Doka & Martin, 2002; Lister, 1991; Stroebe et al., 2001; Zinner, 2000). In general, early research concerning grief responses supported stereotypes that men are less likely to display their feelings and emotional reactions outwardly, and experience more difficulty than women in seeking or accepting help for grief and adjustment to loss (Addis & Mahalik, 2003; Doka & Martin, 1998). For example, following the loss of a spouse, infant or child, women were found to be more expressive of affective responses and more likely to actively seek out formal and informal support than men (Carroll & Shaefer, 1994; Dyregrov & Matthiesen, 1987; Stroebe et al., 2001; Versalle & McDowell, 2016). Some researchers have explained these effects using gender socialisation and social role theories, which purport that traditionally in some cultures, women are encouraged to be more emotionally expressive and dependent, whereas men are encouraged to display stoicism and independence (Chafetz, 1978; Eagly & Wood, 2016; Lister, 1991; Versalle & McDowell, 2016).

While there is limited research on men's bereavement generally, early research suggested that men typically experienced a struggle between expressing and suppressing their grief. Cook (1988) and Doka and Martin (2002) noted that men often encountered a cultural 'double bind' when experiencing loss and grief; particularly following the death of a child. The concept of a 'double bind' explained that while socially boys and men were typically taught to 'be strong' and control/suppress their emotions, simultaneously, they were also criticised for not openly expressing their grief, as this was the socially 'accepted' form of grieving (Cook, 1988; Zinner, 2000). Similarly, early research on men who experience the death of a spouse suggested they were more likely than women to demonstrate a lack of emotional expression in response to their loss, and a tendency to return to work promptly and re-partner or remarry sooner than women (Bandini & Thompson, 2014; Bennett, 2007; Silverman & Thomson, 2018). These behavioural responses to grief have been contextualised as aligning with traditional masculinity norms (discussed further in Section 2.1.7.2), which many men seek to maintain, alongside experiencing deep sadness following their loss/es (Bennett, 2007).

Early findings regarding gender and grief resulted in the establishment of a separation between 'feminine' and 'masculine' grief responses in many models of grief; the former characterised by outward displays of affective responses and active support seeking and the latter by cognitive, problem-solving approaches to grief, and coping in isolation and privacy (Doka & Martin, 1998; Martin & Doka, 2000). However, although these patterns generally reflected the experiences of many women and men in early research, later work acknowledged that a variety of highly individualised grief responses can occur for women and men, challenging the rigidity of grief classifications by gender alone (Barrera et al., 2007; Doka & Martin, 2011; Versalle & McDowell, 2016). These fewer gender differences in bereavement research were attributed to changes in social and cultural attitudes toward traditional gender roles (Doka & Martin, 2011; Silverman & Thomson, 2018). In response to these issues, Martin and Doka (2000) proposed a continuum of grief reactions, ranging from ‘instrumental’ grief, characterised by cognitive, problem-solving grief management (the more ‘masculine’ form), to ‘intuitive’ grief, characterised by emotive, help-seeking grief management (the more ‘feminine’ form). In general, they emphasised that although grief patterns may be gender-related, they are not entirely determined by gender (Doka & Martin, 2011; Martin & Doka, 2000).

Historically, intuitive expressions of grief were generally portrayed to be the more conventional form of grieving. Fuelled by early research which focused on the grief experiences of women, particularly women who experienced the death of a spouse (e.g., Ball, 1977; Parkes, 1964; Vachon, 2017), popular culture representations frequently depicted a ‘visible pain’ picture of grief involving tears, sadness and subdued behaviour (Zinner, 2000). Similarly, early models of effective or adaptive grieving, such as those discussed in Section 1.2.1.2, also emphasised the importance of actively engaging with the experience of grief and openly expressing or talking about emotions in order to ‘work through’ and integrate the loss into one’s life. As such, intuitive or feminine styles of coping with grief were perceived to be the most adaptive or useful response, suited well to traditional grief therapies and support groups (Zinner, 2000). Alternative expressions of grief, including coping in isolation and reluctance to confront emotional tasks – which align with a more instrumental or normative masculine style – were considered less adaptive and not as amenable to traditional grief therapy (Doka & Martin, 1998).

Contrary to early assumptions that an instrumental grief style is a maladaptive form of coping, later research highlighted that instrumental grievers are no more likely to develop complicated grief; instead, the strategies characteristic of instrumental patterns may provide similar benefits to outward emotional expression, just through different means (Doka &

Martin, 1998; Lister, 1991; Zinner, 2000). For example, focusing on completing tasks or enjoyable activities can reduce the burden of intense emotions, and shoulder-to-shoulder companionship through ‘doing’ can be just as effective as face-to-face talk therapy (Carverhill, 1998; Zinner, 2000). In line with the Dual Process Model (Stroebe & Schut, 1999), both loss-oriented and restoration-oriented styles of grieving can benefit individual grievers. Rather than expecting instrumental grievers to ‘fit’ traditional therapeutic support systems that have historically favoured intuitive grievers, there is a need to validate and adapt services to the strengths of the spectrum of grieving styles to promote adjustment to grief (Carverhill, 1998; Lister, 1991; Zinner, 2000).

1.2.1.8 *A note on cultural considerations*

It is important to note that the grief paradigms discussed in this thesis are generally reflective of a specific cultural perspective. Specifically, most research on grief styles and patterns to date has been conducted in high-income countries including the United States (USA), United Kingdom (UK) and Australia, on samples of women and men of predominately Caucasian background. These experiences may not reflect other cultural or ethnic groups, among whom different social roles and grieving styles may be relevant (Davies, 2004; Stroebe, 1998). For example, open grieving practices and rituals are explicitly permitted and encouraged in some societies. These include forms of self-injury as a form of coping with grief, or smiling and singing during grief where religious or cultural beliefs suggest that these behaviours would enhance the deceased’s passage to the afterlife (Lister, 1991). The primary focus of the program of research that forms this doctoral thesis concerns grief experiences of men in Australia; a high-income country that, while multicultural and shaped by migration, is nevertheless broadly considered to align with what could be termed ‘western’[1] norms, including those related to gender roles, grief behaviours, and understandings of loss and death. However, cultural and individual differences in grief reactions will be explored where appropriate.

1.2.2 Grief following pregnancy loss and neonatal death

1.2.2.1 *Rates and definitions of pregnancy loss and neonatal death*

Despite incredible advancements in medical technologies over the last few decades, pregnancy loss and neonatal death remain a significant global public health concern and a devastating reality experienced by millions of families worldwide each year (World Health Organization [WHO], 2012). Annually, approximately 2.6 million babies are stillborn and another 2.4 million babies die within the first month following a live birth (Frøen et al., 2016; WHO, 2020b). Most of these deaths occur in low- and middle-income countries in sub-Saharan Africa and South-East Asia. However, stillbirth and neonatal death is also a significant health issue in high-income countries, including Australia, the UK, USA and Canada (United Nations Inter-agency Group for Child Mortality Estimation [UN IGME], 2020). While many high-income countries have observed a slow decline in rates of infant mortality and neonatal death since the 1980s, rates of stillbirth have generally remained stagnant for over two decades, at between four and seven deaths per 1,000 live births in high-income settings (Callander et al., 2020; House of Parliament, 2016; Hoyert & Gregory, 2016; Statistics Canada, 2017).

While the majority of pregnancy losses and neonatal deaths globally occur in low- and middle-income settings, substantial disparities in rates of perinatal deaths also exist within high-income countries, including Australia, the UK, US, Denmark and the

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[1] The term ‘western’ is used in this thesis to describe a broad set of social and cultural norms, values and belief systems that have traditionally been present in industrialised countries categorised as belonging to the ‘western world’, including the USA, UK, Canada, and Australia. While I acknowledge this term cannot be wholly inclusive of all norms, values and beliefs in Australia – particularly given the variety of cultural groups represented today – this term has been used where appropriate, and for consistency.

Netherlands (Kingdon et al., 2019; Pruitt et al., 2020; Rasmussen et al., 2021; Ravelli et al., 2011; Rowland & Silver, 2011). For example, in Australia, Aboriginal and Torres Strait Islander women and women of migrant and refugee backgrounds experience double the rate of stillbirth compared to the total Australian population (Farrant & Shepherd, 2016; Rumbold et al., 2020). Although the causes of many miscarriages and stillbirths are not known, research has identified that up to one-third of stillbirths in high-income countries are preventable (Andrews et al., 2020). For instance, major modifiable risk factors include maternal overweight and obesity, maternal smoking, screening for growth restriction, maternal sleep position, the timing of birth, and culturally-appropriate preconception and antenatal care (Flenady, Koopmans, et al., 2011; Flenady, Middleton, et al., 2011). In response, the Safer Baby Bundle initiative in Australia was recently developed to educate health professionals on five key stillbirth risk factors and empower them to address these with pregnant women and their families (Andrews et al., 2020). Encouragingly, a recent study in Victoria, Australia, also found an association between the public reporting of a foetal growth restriction performance indicator and improved detection of severe cases of small for gestational age, which led to a decrease in the rate of stillbirths (Selvaratnam et al., 2020).

A wide range of terms have been adopted to distinguish between pregnancy losses that occur at different stages of gestation, from conception until a full-term birth (Murphy & Cacciatore, 2017; Wright, 2011). The WHO recommends a definition of stillbirth as a loss after 28 weeks' gestation, yet over 30 different stillbirth classification systems have been identified across the literature (Korteweg et al., 2006; Lawn et al., 2010; Vogel et al., 2014). By Australian conventions – which this program of research followed – a miscarriage is defined as a death in-utero at less than 20 weeks' gestation (Brier, 2008). Given that many miscarriages occur early in pregnancy before a woman[2] may even realise she is pregnant, the exact prevalence is difficult to determine. However, a miscarriage is estimated to occur for 15-20% of all pregnancies (Breeze, 2016; Hure et al., 2012; Rinehart & Kiselica, 2010). While the causes of most miscarriages are unknown, approximately 9% of all first trimester losses are due to ectopic pregnancy (Goksedef et al., 2011; McQueen, 2011; Murray et al., 2005). Occurring in approximately 1-2% of all pregnancies, an ectopic pregnancy refers to when the fertilised ovum implants outside of the uterus, typically in the fallopian tube (Breeze, 2016; Goksedef et al., 2011; Hajenius et al., 2007). While some ectopic pregnancies result in spontaneous miscarriage, others require surgical or medical intervention to prevent rupture of the fallopian tube (McQueen, 2011).

In Australia, stillbirth is defined as a death in-utero from at least 20 weeks' gestation or over 400 grams in weight (Australian Institute of Health and Welfare [AIHW], 2019). An antepartum stillbirth occurs when the baby dies before labour or birth, and an intrapartum stillbirth occurs when the baby dies during labour or birth (AIHW, 2019). According to the latest available data, in 2018, a total of 1,682 babies were stillborn in Australia, equating to approximately one in every 180 births (Australian Bureau of Statistics [ABS], 2019; AIHW, 2021). In Australia, national data on TOPFA is not collected due to varying state-based cut-offs regarding the gestational age at which a medical termination can be legally performed. Where an anomaly is identified after 20-24 weeks' gestation (depending on local definitions), permission to medically terminate the pregnancy must be sought from registered medical practitioners or be subject to independent review from multiple healthcare professionals or hospital ethics boards. Thus, TOPFA is frequently excluded from overall perinatal mortality rates encompassing stillbirths and neonatal deaths. In South Australia (where the research for

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[2] While the term 'woman' is used here, I recognise that not everyone who is pregnant identifies as a woman. However, given this thesis focuses on the pregnancy and loss experiences of heterosexual men in a relationship with a woman, this term has been used where appropriate, and for consistency.

this thesis was conducted), the 2017 perinatal mortality rate not including TOPFA was 5.1 per 1000 live births; including TOPFA, this rate increased to nine per 1000 live births (SA Health, 2019). Overall, it has been estimated that most Australian parents whose pregnancies are deemed life-limiting, or are affected by chromosomal anomalies (approximately 65%) will elect for a medical termination. The majority of these terminations occur before, or soon after, 20 weeks' gestation (Victorian Law Reform Commission, 2008). Finally, neonatal death refers to the death of a newborn infant within the first 28 days following a live birth (AIHW, 2021). Generally, the death of a baby which occurs within the first 24 hours following birth is referred to as 'very early neonatal', the first seven days an 'early neonatal', and the first eight to 28 days as 'late neonatal' (AIHW, 2021). In Australia, neonatal deaths occur for between two and three per 1,000 live births, due to causes including congenital anomalies, spontaneous preterm birth, intrauterine growth restriction, and infection (AIHW, 2019, 2021).

This thesis will use the term 'pregnancy loss' to refer to any death in-utero or during birth, including ectopic pregnancies, miscarriages, TOPFA and stillbirths. Experiences of loss due to planned induced abortion for non-medical reasons (e.g., in the case of unwanted pregnancy) were excluded. Although research suggests that parents may experience grief following planned abortion, the manifestation of potential grief and other repercussions (e.g., social) may be different to grief following a spontaneous or unexpected pregnancy loss (Broen et al., 2004; Coyle & Rue, 2015; Olsson et al., 2014). Men who experienced TOPFA were included in this research, as studies have suggested that parents who experience TOPFA report experiences of grief and symptoms of post-traumatic stress, anxiety and depression similar to parents who experience spontaneous miscarriage or stillbirth (Korenromp et al., 2005; Nazaré et al., 2014).

In reference to TOPFA, the term ‘life-limiting foetal anomaly’ was used in this thesis. While other terms are used throughout the literature, including fatal/lethal abnormality, lethal malformations, and foetal anomaly, these terms have been subject to conceptual challenges, and there are no clear or universal standards regarding the terms used or perceived to be acceptable to most bereaved parents (Health Service Executive, 2016; Wilkinson et al., 2012). Therefore, the term ‘life-limiting’ was chosen for use in this research, in line with international standards and guidelines for best practice bereavement care (Health Service Executive, 2016) and the decision to exclude terminations of pregnancy for foetal anomalies that were not life-limiting. Finally, perinatal death is a composite term used inconsistently throughout the literature to refer to miscarriage and stillbirth, stillbirth and neonatal death, or all types of pregnancy loss and neonatal death collectively. This thesis only used the term ‘perinatal death’ where prior publications had used it and it was not possible to ascertain the specific type of loss; otherwise, it specified types of loss to which any collective terms refer to. For brevity, this thesis referred to the included loss types outlined above collectively as ‘pregnancy loss and neonatal death’; where pregnancy loss included ectopic pregnancy, miscarriage, TOPFA and stillbirth.

1.2.2.2 *Use of the term ‘baby’*

As will be discussed in Section 1.2.2.3 below, parents often experience deep and enduring grief following the death of a baby during pregnancy, regardless of gestational age. It is now recognised in best practice bereavement care guidelines worldwide that acknowledging the impact of the loss is essential to validating parents’ experiences and supporting them in their grief (Boyle et al., 2020; Health Service Executive, 2016; National Bereavement Care Pathway [NBCP], 2020c; Sands Australia, 2018). The use of sensitive and affirming language is an essential part of providing this validation. Accordingly, several recommendations have been made to guide the conversations that healthcare professionals and the wider community have with bereaved families (Jonas-Simpson & McMahon, 2005; Nuzum et al., 2017; Xafis et al., 2016).

Throughout the literature on bereaved families' experiences of pregnancy loss, many parents have reported a desire to have their loss recognised as the loss of a baby, as this affirms their experience of grieving for a child (Jonas-Simpson & McMahon, 2005; Nuzum et al., 2017; Peters et al., 2015). Historically, biomedical language was frequently used in medical settings, with terms including 'the dead foetus', 'products of conception' and 'reproductive wastage', particularly in the context of early miscarriage. It is now recognised that the use of biomedical terms to refer to parents' babies can carry harmful meanings which have the potential to intensify parents' suffering and grief (Flenady et al., 2014; Health Service Executive, 2016; Janvier et al., 2014; Jonas-Simpson & McMahon, 2005).

However, it is also important to acknowledge that parents' perceptions and preferences regarding pregnancy are mixed; for example, not all parents will consider early miscarriage equivalent to a later-term pregnancy loss. Similarly, in instances such as unplanned or adolescent pregnancy, or difficult circumstances such as family violence, feelings of relief have also been reported following miscarriage or access to abortion (Brady et al., 2008; Broen et al., 2004; Madden, 1994; Purcell et al., 2014). As outlined in Section 1.2.2.1 above, stage of gestation is also used to categorise loss types to determine legal status and guide decision-making surrounding abortion and medical terminations. Whilst not seeking to undermine the experiences or preferences of some parents, nor legal questions surrounding cases including abortion, the term 'baby' was chosen for use throughout this thesis when referring to experiences of pregnancy loss (regardless of gestational age), given the focus on grief and bereavement.

1.2.2.3 *Parents' grief following pregnancy loss and neonatal death*

Research has long recognised that parents' grief following the death of a child is one of the most overwhelming and stressful forms of grief, and that general models and theories of grief do not necessarily reflect the unique experiences or needs of bereaved parents (Davies, 2004; Dyregrov & Matthiesen, 1987; Rando, 1983; Youngblut et al., 2017). Studies suggest that in general, bereaved parents experience higher incidences of physical illness, increased mortality, depressive symptoms and feelings of anger or hostility compared to parents who have not experienced the death of a child (Barrera et al., 2007; Kreicbergs et al., 2004; Li et al., 2003; Rando, 1983). The grief experience is often compounded by reports of guilt for a perceived failure to protect the child or disrupted family and social relationships (Kamm & Vandenberg, 2001). Parents whose children die suddenly, or die due to violence, may also experience complications, including severe grief or symptoms of Post-Traumatic Stress Disorder (PTSD; Barrera et al., 2007; Murphy et al., 2003). In line with Stroebe and Schut's (1999) Dual Process Model, many bereaved parents report an oscillation between being consumed by their grief and having to attend to daily tasks. Some also report an active avoidance of grief through distractions such as returning to work or distancing themselves from objects and situations associated with their deceased child (Stevenson et al., 2017).

However, when considering the death of an unborn or newborn baby, parents' grief is further complicated. Pregnancy loss and neonatal death have been identified as complex and ambiguous forms of loss (Avelin et al., 2013; Cacciatore et al., 2008; Lang et al., 2011; Shannon & Wilkinson, 2020). Firstly, with complex loss, bereaved parents have noted that in addition to losing a baby, they also experience a sense of reproductive failure (in the case of pregnancy loss), loss of hope and anticipation for the future of raising a child, and a lack of memories with the baby to assist the mourning process (Hutti, 2005). Secondly, ambiguity refers to the simultaneous physical absence *and* continuing psychological presence of the baby, leaving parents to question their identity as parents, with and without the presence of other surviving siblings (Cacciatore, 2013; Cacciatore et al., 2008; Collins et al., 2014; Lang et al., 2011; McCreight, 2008; Séjourné et al., 2010; Shannon & Wilkinson, 2020).

Complex social factors also impact the experience of pregnancy loss and neonatal death, compounding an existing sense of complexity and ambiguity (Murphy, 2019). Both pregnancy loss and neonatal death meet the criteria for being defined as disenfranchised grief; that is, the grief experienced when a loss is, or cannot, be openly acknowledged, mourned or recognised (Doka, 1999; Doka & Martin, 2002). Disenfranchised grief is particularly salient following a pregnancy loss, given a frequent lack of social recognition for the unborn baby as a living individual, and often an absence of prescribed norms and rituals surrounding how to mourn the death of an unborn or stillborn baby (Brier, 2008; Collins et al., 2014; Lang et al., 2011; Mulvihill & Walsh, 2014). In previous research on miscarriage and stillbirth experiences particularly, some parents have reported that family and friends tend to downplay the significance of their loss; others also avoid talking about it due to discomfort in not knowing what to say, or not wanting to make the situation worse (Cacciatore et al., 2008; Fernández-Sola et al., 2020; Lang et al., 2011; Rinehart & Kiselica, 2010). As discussed further in Section 1.2.2.4 below, a baby’s gestational age can impact the amount and type of social recognition that parents receive for their loss, with earlier losses typically associated with less societal recognition and, therefore, higher levels of disenfranchisement.

Different types of pregnancy loss or neonatal death, then, can also carry unique challenges and considerations that can impact parents’ experiences of grief. Particularly following stillbirth (Brierley-Jones et al., 2015; Pollock, Pearson, et al., 2020; Pollock, Ziaian, et al., 2020) and TOPFA (France et al., 2013; Hanschmidt et al., 2018) for example, many bereaved parents have reported experiencing perceived stigma from others regarding their loss, due to social silence and awkwardness around discussing stillbirth, as well as ongoing contentions surrounding abortion which is frequently accompanied by moral and ethical concerns regarding decision-making. Stillbirth stigma has been identified as a critical barrier to reducing high stillbirth rates and supporting bereaved parents, through means including a lack of awareness surrounding risk/protective factors and reduced frequency of help-seeking (Heazell, 2016; Horton & Samarasekera, 2016; Pollock, Ziaian, et al., 2020). Feelings of shame, blame, guilt and discrimination can also compound or worsen grief in parents and lead to a higher risk of developing complicated grief reactions (Nazaré et al., 2014; Pollock, Ziaian, et al., 2020). Although probably unintentional, an absence of open acknowledgement and understanding among healthcare professionals and bereaved parents' families and communities can compound bereaved parents' grief due to isolation and lack of support.

1.2.2.4 *Factors related to grief following pregnancy loss and neonatal death*

In line with biopsychosocial understandings of grief, studies have explored a wide variety of factors that may contribute to parents' grief responses following pregnancy loss and neonatal death. These include individual personality traits and pre-loss coping resources/resilience, the nature of the relationship with the unborn/newborn baby, history of mental health concerns, infertility or prior loss(es), the relationship between parents, experiences of healthcare, and availability of social supports (Avelin et al., 2013; Barr, 2004; Brier, 2008; Huffman et al., 2015; Hutti et al., 2015; Lin & Lasker, 1996). Many of these studies have explored factors associated with grief either in small clusters or in isolation, rather than comprehensively in a single model. In general, studies have found that individuals/couples with a history of anxiety, depression or infertility, lower levels of marital satisfaction (Huffman et al., 2015; Tseng et al., 2017), conflicting grief styles, high levels of anticipation or identification with the unborn baby (Avelin et al., 2013; Beutel et al., 1996;

Brier, 2008; Huffman et al., 2015), and low levels of social or healthcare professional support (Brier, 2008; Erlandsson et al., 2011; Tseng et al., 2017) have more intense and/or prolonged grief reactions. Overall, however, factors identified are general in nature and have been considered “potential moderators” for grief following pregnancy loss and neonatal death (Brier, 2008, p. 457). Chapter 3 outlines more details concerning the literature on factors contributing to grief for men.

Despite the medical (and legal) differences between losses according to different periods of gestation (discussed previously in Section 1.2.2.1), there is currently mixed evidence to suggest that the psychological experience of loss or intensity of grief is determined by gestational or newborn age (Brier, 2008; McCreight, 2008; Nazaré et al., 2014; Obst & Due, 2019a; Riggs et al., 2018). Early research on pregnancy loss suggested that losses in earlier stages of gestation were generally considered to be ‘less traumatic’ than losses that occurred later in pregnancy (Lovell, 1983; Murphy, 2019). In general, quantitative studies measuring parents’ grief responses using self-reported psychometric grief inventories have found lower average grief scores among parents who have experienced early miscarriages compared to parents who experienced later-gestation stillbirths or neonatal death (Cuisinier et al., 1993; Goldbach et al., 1991; Hutti et al., 2013; Lasker & Toedter, 2000; Mcgreal et al., 1997; Theut et al., 1990). However, with the widespread availability of early pregnancy detection tests and detailed prenatal screening procedures, it has been identified that parents’ attachment to their unborn babies can begin early in – or even before – conception; particularly in cases where there has been a history of infertility or difficulty conceiving (Brandon et al., 2009; Condon, 1985; Doan & Zimerman, 2003).

In qualitative studies exploring parents’ experiences of miscarriage, those who develop deep bonds with their unborn babies and ascribe high meaning to their pregnancy frequently describe lasting feelings of grief, particularly when they receive a lack of recognition for their grief due to a poor healthcare experience and/or low levels of social support (Bellhouse et al., 2018; Brier, 2008; DeFrain et al., 1996; Due et al., 2018; Hiefner, 2020; Miller et al., 2019; Obst & Due, 2019a). Consequently, the early idea positing 'hierarchies of grief' – whereby a miscarriage is assumed to have less impact than stillbirth, and stillbirth less impact than neonatal death – has been challenged, particularly in qualitative studies on pregnancy loss, whereby parents' grief has been found to depend more on levels of attachment to their babies than gestational age alone (Brierley-Jones et al., 2015; Letherby, 1993; Lovell, 1983; Meaney et al., 2017; Murphy, 2019; Rinehart & Kiselica, 2010).

1.2.3 Men and pregnancy loss and neonatal death

1.2.3.1 *Men's involvement in pregnancy and childbirth*

Prior to the mid-to-late 20th century, pregnancy and childbirth were considered to be exclusively a 'women's issue' in 'western' societies (Due et al., 2017; Maken et al., 2018), with men historically being actively discouraged from being involved in pregnancy or attending the birth of their baby (King, 2012). However, in recent decades and particularly in high-income countries, fathers have become increasingly engaged throughout pregnancy, childbirth and early parenting. In many countries, including Australia, New Zealand (NZ), the USA, the UK, Sweden and Canada, it is now common practice for fathers to participate in antenatal screening, labour and parenting groups (Draper, 2002, 2003; Eggermont et al., 2017; Leavitt, 2003; Plantin et al., 2011; Redshaw & Henderson, 2013). While in many cultures fathers have shared parenting over time, shifts in fathering identities and practices, particularly in 'western' cultures, have been associated with the Women's Liberation Movement, which saw increasing numbers of mothers engaging in paid employment; in turn, encouraging increased parenting involvement and caring responsibilities from fathers (Dempsey & Hewitt, 2012). Along with changing socio-cultural norms relating to more shared or equal parenting, the emergence of 'multiple masculinities' (discussed further in

Section 2.1.7.2) and rapid development of health technologies including ultrasound imaging, have contributed to fathers engaging in relationships with their unborn babies earlier in the pregnancy (Locock & Alexander, 2006; Rosich-Medina & Shetty, 2007; Vreeswijk et al., 2014).

Beyond supporting women's flexibility and engagement in workplace roles, a growing body of recent research has also demonstrated that fathers' involvement throughout pregnancy and infant care is associated with improved short- and long-term health and psychosocial outcomes for mothers and babies (Fisher et al., 2018; WHO, 2013). For example, greater engagement of fathers in pregnancy and newborn care has been associated with increased maternal antenatal visits and attendance at antenatal classes, higher rates of exclusive breastfeeding, greater infant weight gain, reduced levels of infant stress and stronger father-infant attachment, which results in improved social and cognitive child development (Fisher et al., 2018; Kothari et al., 2019; Plantin et al., 2011; Redshaw & Henderson, 2013; Tokhi et al., 2018; Yargawa & Leonardi-Bee, 2015). In recognition of these findings, key global health bodies, including the WHO (2015), have recommended investing in the development and evaluation of interventions to increase men's involvement during pregnancy, childbirth and post-birth, to facilitate and support the health and safety of women and newborns.

It is important to note that while interventions to increase men's involvement in pregnancy and childbirth have been recommended by international bodies, including the WHO, men's involvement needs always to prioritise respect for the birthing women's wishes and uphold the safety and needs of the mother and infant (WHO, 2015). Guided by international standards for Respectful Maternity Care (Miller et al., 2016; O'Keefe, 2016; White Ribbon Alliance, 2014; WHO, 2018), there may be cases where men's involvement is not possible, preferable or safe (e.g., for cultural/religious reasons, or in cases including family and domestic violence). Individual needs and preferences of women and their families must always be respected. Chapter 2 provides further discussion on father-inclusive practice guidelines.

Despite emerging evidence of men’s greater involvement in pregnancy and childbirth in many settings, until recently, there has been limited research into men’s experiences of conception, pregnancy and childbirth (Locock & Alexander, 2006; Lohan, 2014; Marsiglio et al., 2013). However, a growing body of qualitative research documenting men’s experiences has identified that although many desire to be, and often are, actively involved throughout pregnancy and birth, men frequently report feeling under-prepared and unsupported by the healthcare system (Fenwick et al., 2012; Poh et al., 2014; Steen et al., 2012; Widarsson et al., 2012).

It is important to note that woman-centred maternity and perinatal care is essential to upholding the health, safety and wellbeing of a birthing woman and her infant. Whilst men do not experience the physical process of pregnancy (and thus do not warrant medical attention), some level of support is required to acknowledge their role as partner and co-parent in heterosexual couples. In previous studies, language used by fathers to describe their experiences of being present at their baby’s birth has included feeling as though they were “invisible” (Poh et al., 2014, p. 550), a “bystander” (Locock & Alexander, 2006, p. 1352; Poh et al., 2014, p. 550; Steen et al., 2012, p. 430), “sidelined” (Fenwick et al., 2012, p. 6), and “merely a passenger” (Daniels et al., 2020, p. 5). Feelings of exclusion have also been reported by Swedish fathers, despite a decades-long history of inclusive policies to support men’s involvement in birth/parenting in Sweden (Wells, 2016). Research has concluded that these experiences largely result from a combination of cultural role expectations for men, which often prescribe a peripheral role; and healthcare systems that do not formally admit men/partners as patients having a necessary focus on women during birthing, where men may be subsequently overlooked even after labour ends and the mother is stable (Fenwick et al., 2012; Steen et al., 2012). When fathers have been acknowledged in pregnancy-related healthcare settings, it has frequently been exclusively as the ‘support person’, with little space to express their own emotions, feelings and need for support (Daniels et al., 2020).

Positive pregnancy and birth experiences have been reported by men who engaged in reciprocal calm, patient and clear communications with healthcare professionals regarding their role throughout the birthing process, and where they were encouraged by individuals and systems to be actively involved throughout pregnancy (Daniels et al., 2020; Premberg et al., 2011). A national survey of 4,616 pregnant women in the UK found the highest levels of paternal engagement among partners of white women who have been pregnant and given birth once before, planned pregnancies, and those living in higher socio-economic areas (Redshaw & Henderson, 2013). The authors hypothesised that these findings may be due to sample characteristics; white, middle-class men may have more opportunity to take workplace leave than those in lower socio-economic groups and experience a cultural norm or expectation to be actively involved in pregnancy and childbirth. In the same study, greater levels of paternal engagement were also positively associated with early contact with healthcare professionals when their partner’s pregnancy was 12 weeks’ gestation or less, as well as attending a higher number of antenatal checks, scans and antenatal classes, and taking paternity leave (Redshaw & Henderson, 2013). However, two studies exploring healthcare professionals’ perspectives of working with men in pregnancy and childbirth suggest that although the inclusion of fathers has increased, there is a need for support that is father-inclusive and tailored to parents’ needs (Rominov et al., 2017; Wells et al., 2017).

1.2.3.2 *A note on men’s engagement in low and middle-*income countries

While this thesis will not focus on the experiences of men in low and middle-income countries (LMIC), it is important to note the substantial challenges faced for engaging men in pregnancy and birth in these settings, given that these populations experience the highest burden of pregnancy loss and neonatal death worldwide. In some LMICs, the inclusion of men remains relatively new due to continuing complexities resulting from a range of cultural, policy and structural/systemic factors (Firouzan et al., 2019; Nesane et al., 2016; Sapkota et al., 2012). While estimates of men who accompany their wives/partners to antenatal checks are mixed (as low as 6% in Uganda or up to 65% in Myanmar), attendance at birth is generally much lower, and there remain some countries where men are explicitly excluded from birthing wards (Kariuki & Seruwagi, 2016; Wai et al., 2015).

However, it is also important to note that in many LMICs, limited resources, lack of support and mistreatment during birth remain significant issues not only for men, but for birthing women (Mgawadere & Shuaibu, 2021). The 'Three Delays Model', for example, has been used to identify that maternal and neonatal mortality are "overwhelmingly due to delays in: (1) decisions to seek appropriate medical help for an obstetric emergency; (2) reaching an appropriate obstetric facility; and (3) receiving adequate care when a facility is reached" (Barnes-Josiah et al., 1998, p. 981; Kaselitz et al., 2021; Upadhyay et al., 2013; Waiswa et al., 2010). Many women continue to experience significant barriers to accessing care, and/or receive poor quality maternity care, including a lack of information and education regarding pregnancy/birth, absence of informed consent prior to procedures, and verbal or physical abuse (Gage et al., 2019; Mahase, 2019). Challenges to involving men in maternity services in LMICs must also be considered alongside the broader context of ongoing and substantial challenges in prioritising safe and accessible pregnancy care to birthing women.

In a recent qualitative study, healthcare professionals from Uganda (including midwives, nurses and traditional birth attendants) noted substantial challenges to involving men, including a lack of training and guidelines regarding making services men-friendly, inadequate resources, infrastructure and space to accommodate men, and inconsistencies between policy and implementation of men's involvement in interventions (Gopal et al., 2020). In another qualitative study exploring fathers' perspectives in Uganda, men reported seeing themselves as responsible for supporting their partner throughout pregnancy and childbirth, and desired active involvement in the delivery, labour and interactions with decision-makers regarding healthcare (Kaye et al., 2014). However, they frequently reported receiving little information or education from healthcare professionals on their role, having to wait outside during antenatal appointments, and for hours during labour with little information on their partners' condition. These circumstances resulted in feelings of alienation and substantial concern for their partner's wellbeing, particularly when there were birth complications (Kaye et al., 2014).

While men in some studies have expressed a desire to be involved during pregnancy and in childbirth, lack of involvement in some LMICs has also been identified to be a direct result of requests from women to maintain their privacy (Firouzan et al., 2019), or a lack of desire among men to be involved (Maluka & Peneza, 2018; Vermeulen et al., 2016). In many cultures, grandmothers and mothers-in-law are also seen as the owners of traditional pregnancy/birth knowledge and main supporters to birthing women rather than male partners (Gupta et al., 2015; Masvie, 2006; Negin et al., 2016). A recent qualitative study of men's experiences in Sierra Leone (McLean, 2020) also noted caution in assuming 'western' definitions of men's participation should be applied in all cultural settings. In a fieldwork study conducted in Sierra Leone, men described their involvement as largely centring on providing material support for a healthy and safe birth (e.g., transportation to healthcare facilities, provision of medicines and supplies); to them, this represented a culturally-acceptable and socially meaningful form of support (McLean, 2020).

Overall, there is a pressing need for future research focused in LMICs to better understand the barriers and facilitators to engagement in pregnancy and childbirth for men, and to identify locally-accessible and culturally-appropriate ways to engage men at a level that supports the health and wellbeing of childbearing women and their infants. However, exploring the experiences of men in these contexts (and indeed other high-income countries) is beyond the scope of the current thesis.

1.2.3.3 *Defining 'men'*

No restrictions on gender identity or sexuality (beyond identifying as a 'man') were placed on participation in the studies for this thesis. However, only two participants identified as bisexual, with the remaining all identifying as heterosexual. Thus, most of the research within this thesis details the experience of heterosexual men in a relationship with a woman partner. Therefore, the term 'men' is used to refer to heterosexual men experiencing the death of a baby, and the term 'partner' refers to women, unless otherwise stated. Much of the existing literature to date has also focused on heterosexual men who have experienced pregnancy loss or neonatal death with a woman partner. The experiences of gay and/or transgender fathers, who may experience unique and additional challenges concerning pregnancy and pregnancy loss, has seldom been included or explored, representing a key gap in the literature for further exploration (Ellis et al., 2016; Hoffkling et al., 2017; Riggs et al., 2015, 2020; Ziv & Freund-Eschar, 2015).

1.2.3.4 *Men's grief after pregnancy loss and neonatal death*

To date, most of the available literature concerning grief following pregnancy loss and neonatal death has also focused largely on women's experiences, given that women have more immediate healthcare and support needs for physical and emotional recovery (Kong et al., 2010; Rinehart & Kiselica, 2010). Moreover, although a large body of research literature claims to have examined the psychological impacts of pregnancy loss on 'bereaved parents', studies on men specifically remain somewhat scarce, with most studies investigating the experiences of men compared to their partners (Badenhorst et al., 2006; Due et al., 2017;

Rinehart & Kiselica, 2010). For example, a systematic review of North American paediatric palliative care research samples by Macdonald and colleagues (2010) found that at most, ‘bereaved parent’ samples in 45 included studies consisted of 75% mothers and only 25% fathers. Three of the included studies contained 100% mothers, and gender imbalance as a sample limitation was only addressed by four included studies. In more recent studies similar gender imbalances have also been reflected, with difficulties explicitly reported regarding recruiting men to research studies examining bereaved parents’ experiences (Hunter et al., 2017; Kelley & Trinidad, 2012; King et al., 2019; Murphy, 2019; Pollock, Pearson et al., 2020; Wilson et al., 2015). Given the profound effect that gender can have on shaping experiences of grief and parenting in general, this unequal representation of mothers and fathers may underestimate men’s grief experiences, with studies identifying the need for strategies to engage men for equal representation of their lived experiences (Hunter et al., 2017; Macdonald et al., 2010; Murphy, 2019; Pollock, Pearson et al., 2020).

Most studies comparing couples’ distress and grief following pregnancy loss have found that women’s emotional responses have generally been more intense and enduring than men’s (Beutel et al., 1996; Dyregrov & Matthiesen, 1987; Goldbach et al., 1991; Kong et al., 2010; Murphy et al., 2014; Rinehart & Kiselica, 2010; Stinson et al., 1992). However, some studies have found similar grief and mental health responses between men and women (Hunter et al., 2017; Puddifoot & Johnson, 1999; Puddifoot & Johnson, 1997), and one study found higher grief responses in men (Conway & Russell, 2000). Importantly, some researchers have argued that existing research may fail to capture the complexities of men’s grief reactions following pregnancy loss and neonatal death since men may downplay or suppress their outward grief reactions or express grief differently (Avelin et al., 2013; Bonnette & Broom, 2012). For example, men have reported that they are less likely to openly cry or talk about their grief, instead relying on avoidant-oriented coping strategies and distracting themselves with other activities such as returning to work (Armstrong, 2001; Beutel et al., 1996; Johnson & Baker, 2004).

Such responses to grief, characteristic of an instrumental rather than intuitive grieving style, may be under-represented by common measures of grief employed by quantitative studies. For example, the Perinatal Grief Scale (PGS) is a standardised measure of parents' grief following the experience of a perinatal loss, which includes miscarriage, ectopic pregnancy, stillbirth and neonatal death (Toedter et al., 1988). The original PGS consisted of 84 items developed based on previous grief measures and research on specific grief constructs associated with pregnancy loss. A short form of the PGS, consisting of 33 items, was also later developed (Potvin et al., 1989). Validation of the original PGS occurred using a sample of 138 heterosexual women, recruited through obstetric practices and clinics in the Pennsylvania area of the USA, and 56 of their male spouses or partners. The short form was validated using the sample of 138 women only. A total of 63 women had experienced a spontaneous abortion (i.e., miscarriage), 18 ectopic pregnancy, 39 foetal death (i.e., stillbirth), and 18 neonatal death. The mean gestational age of the loss was 16.5 weeks, and for two-thirds of the sample, it was their first pregnancy loss. A three-factor solution best explained the resulting model: Active Grief (sadness, missing the baby), Difficulty Coping (with normal activities and other people), and Despair (withdrawal and depression). With internal consistencies ranging from 0.87 and 0.95, and multiple regression and correlational analyses that reflect support for construct validity, the PGS has since been widely adopted and translated for use in cross-cultural pregnancy loss research (e.g., Maniatelli et al., 2018; Toedter et al., 2001; Yan et al., 2010). However, given that much of the PGS's development and ongoing validation research has been based on samples primarily of heterosexual women, this measure may not accurately represent the experiences of all groups who may be involved in the experience of pregnancy loss or neonatal death; particularly men (Barr, 2006; Conway & Russell, 2000; Franche & Bulow, 1999; Huffman et al., 2015).

A small number of studies have also suggested that some bereaved parents may turn to substance use to help suppress their grief (Due et al., 2017; Jones et al., 2019). For example, Vance et al. (2002) reported that 7 to 12.3% of bereaved fathers in their study engaged in ‘heavy’ alcohol usage – defined as the consumption of five or more standard drinks per day – compared to 4.7 to 5.8% of non-bereaved fathers and 1% of bereaved and non-bereaved mothers. In addition, following the stillbirth of their baby, 26.5% of participants in Turton et al.’s (2006) study on bereaved fathers retrospectively reported using increased alcohol consumption as a coping strategy, while 18.4% of participants reported using prescribed drugs. These types of avoidant-orientated strategies have been associated with a higher risk of long-term negative psychological outcomes (Livingston et al., 2021). However, findings from these studies are preliminary and can therefore only offer a conservative estimate of the impact of loss on fathers’ grief-related behaviours (Due et al., 2017; Johnson & Baker, 2004; Turton et al., 2006; Vance et al., 2002).

In relation to pregnancy loss and neonatal death, research indicates that many men will also take on the role of a ‘supporter’ for their partner (Armstrong, 2001; McCreight, 2004; Miller et al., 2019; Miron & Chapman, 1994; Murphy, 1998; Obst & Due, 2019; Puddifoot & Johnson, 1997). For example, some research has found that men make a conscious attempt to downplay their own grief response and avoid communicating their struggles with their partner out of a fear that they might intensify their partner’s grief (Bonnette & Broom, 2012; Samuelsson et al., 2001). The supporter role has been explained in the context of normative gender expectations present in many cultures, which require men to ‘be strong’ and ‘protect’ their partners (Bonnette & Broom, 2012; McCreight, 2004). Men may respond to pregnancy loss and neonatal death by addressing the practicalities of the loss, such as informing family and friends, arranging a funeral, organising the housework, or caring for other children, all to maintain ‘control’ over the situation while their partner is recovering (Armstrong, 2001; McCreight, 2004; Murphy, 1998; Wagner et al., 2018). Given this social expectation to ‘be strong’, men have also frequently reported receiving a lack of recognition as grieving fathers from family, friends and community, which can potentially compound their grief response (Chavez et al., 2019; McCreight, 2004; Miller et al., 2019; Obst & Due, 2019a; Wagner et al., 2018). In this case, men may experience an added level of disenfranchisement compared to women (Obst & Due, 2019a).

1.2.4 Bereavement support following pregnancy loss and neonatal death

1.2.4.1 *Overview and history of bereavement support for families following pregnancy loss and neonatal death*

During the 1950s in ‘western’ industrialised countries including the USA, UK, Canada, Sweden and Australia, childbirth transitioned from a largely at-home event to an institutionalised hospital practice (Davidson, 2020). With this shift, responding to pregnancy loss and neonatal death became a core part of medical staff and health professionals’ responsibilities. However, the emotional impacts of pregnancy loss and neonatal death on bereaved parents were poorly understood and seldom acknowledged in the hospital environment (Davidson, 2020; Lovell, 1983). Influenced by early views that good grief work involved ‘moving on’ from a relationship to the deceased, mothers were discouraged from seeing or holding their stillborn or critically-ill babies after birth, particularly where their baby had a medical anomaly (Davidson, 2020). Similarly, while all live births were afforded a birth certificate, stillbirths and miscarriages were not formally recorded. These actions aimed to protect parents from further psychological distress or prolonged grief and allow them to ‘move on’ and have another baby (Lovell, 1983).

However, in the 1960s and early 1970s, the first empirical studies on bereaved parents' (mostly mothers) and healthcare professionals' experiences of pregnancy loss and neonatal death were published in academic journals (e.g., Bruce, 1962; Johnson, 1972; Kennell et al., 1970). Accompanied by Bowlby's (1961, 1979, 1980) work on attachment theory and developing knowledge in the field of grief more generally, these accounts highlighted the strong affectional bonding and profound grief experienced by mothers, regardless of the gestational age, any medical anomalies their baby may have had, and whether or not they were able to see or hold their babies (Kennell et al., 1970). Crucially, this work challenged the common practices of placing bereaved mothers in shared maternity wards with mothers who had live babies and parents from seeing and holding their stillborn or critically-ill infants. Instead, authors advocated for clear communication with parents and opportunities to make memories with their babies to foster the development of continuing bonds (Kennell et al., 1970; Klaus & Kennell, 1976). Into the 1980s and 1990s, a growing body of qualitative studies continued to raise awareness of stillbirth and neonatal death as family tragedies which were not well acknowledged (Borg & Lasker, 1981; Klaus & Kennell, 1976; Leon, 1992; Letherby, 1993; Lovell, 1983; Reinharz, 1988; Zeanah, 1989). Quantitative research explored bereaved parents' patterns of grief and satisfaction with healthcare (Goldbach et al., 1991; Lasker & Toedter, 1991; Lin & Lasker, 1996; Potvin et al., 1989; Smith & Borgers, 1995; Stinson et al., 1992; Theut et al., 1990). Backed by health professionals' increasing awareness of the emotional impact of pregnancy loss and neonatal death and a desire to better support women and their families, hospital practices in high-income countries began to improve dramatically, and the first perinatal bereavement protocols emerged in the mid-1990s in countries including the UK, Canada, USA and Australia (Davidson, 2020). The remainder of this section will outline the key components of current bereavement care guidelines internationally and recent research on bereaved parents' experiences of bereavement care and support.

1.2.4.2 *Current clinical practice guidelines for bereavement care following pregnancy loss and neonatal death*

Given increasing recognition of the psychological and emotional impacts of pregnancy loss and neonatal death, research relating to best practice bereavement care and support services for bereaved parents increased substantially into the 21st century. Following recent publication of several systematic reviews to synthesise this bereavement research (Ellis et al., 2016; Flenady et al., 2014; Gold, 2007; Hodgson et al., 2016; Peters et al., 2016; Peters et al., 2015; Shakespeare et al., 2020), national clinical practice and bereavement care guidelines have been continually revised and updated in countries including Australia and NZ (Boyle et al., 2020; Sands Australia, 2018), the UK (NBCP, 2020b, 2020c, 2020a, 2020e) and Ireland (Health Service Executive, 2016). Organisation-based guidelines also exist in Canada (e.g., Hendson & Davies, 2018; Ontario Health, 2020) and the USA (e.g., American College of Obstetricians and Gynecologists, 2020; National SIDS & Infant Death Program Support Center, 2002). At the global level, the joint WHO, United Nations Children's Fund (UNICEF) and United Nations Population Fund *Managing Complications in Pregnancy and Childbirth* (2017) guidelines also contain a number of recommendations regarding care for parents and families following neonatal death, stillbirth and 'pre-viable death' (i.e., miscarriage).

Research has consistently identified that experiences of care received in the hospital substantially affects parents' psychological wellbeing in the weeks, months and even years following their loss (Downe et al., 2013; Ellis et al., 2016; Flenady et al., 2014). Health professionals providing care to bereaved parents can also be deeply emotionally impacted by the loss (Ellis et al., 2016; Jones & Smythe, 2015; Nuzum et al., 2014; Wallbank &

Robertson, 2008). The guidelines outlined above focus predominately on support services offered in the hospital environment. In Australia, the joint NHMRC Centre of Research Excellence in Stillbirth (Stillbirth CRE) and Perinatal Society of Australia and New Zealand (PSANZ) guidelines (lasted updated in 2019) include recommendations collectively for bereavement care following stillbirth and neonatal death (Boyle et al., 2020), and in 2021, an accompanying parent version to communicate the guideline to patients and the public, titled 'Guiding Conversations', was also released (Boyle et al., 2021). Sands Australia, a national pregnancy loss and neonatal death support organisation, also published a separate document outlining principles of bereavement care following miscarriage, stillbirth and neonatal death (Sands Australia, 2018). Ireland's national guidelines for pregnancy loss and perinatal death include recommendations collectively for miscarriage, TOPFA, stillbirth and neonatal death (Health Service Executive, 2016), and, updated in 2020, the UK's National Bereavement Care Pathway (NBCP) includes five separate guideline documents detailing specific recommendations for care following miscarriage, ectopic and molar pregnancies (NBCP, 2020a), TOPFA (NBCP, 2020e), stillbirth (NBCP, 2020c), neonatal death (NBCP, 2020b) and Sudden Unexpected Death in Infancy (SUDI; NBCP, 2020d).

Each of the guidelines contain a combination of overarching goals, standards or principles, along with more specific and detailed recommendations for bereavement care from diagnosis of a death or life-limiting anomaly, through to providing follow-up support services to parents following the birth or death of their baby. Commonalities exist across these guidelines regarding the core goals, standards or principles. These include:

- Good communication through the use of sensitive language and timely, clear and honest discussions between parents and health professionals;
- Shared decision-making to provide parents with the best available evidence and adequate time to consider their options;

- Continuity of care to increase familiarity between parents and health professionals and reduce the burden on parents in having to repeat their story;
- Recognition of parenthood through actions and opportunities that acknowledge the baby as their child (e.g., memory-making); and,
- Parent-led family involvement, including considerations for caring for partners, support people and other family members who may be involved.

With the exception of the UK's separate guidelines according to loss type, many of the recommendations outlined in national guidelines are general and applicable to multiple types of loss. For example, in line with research highlighting the importance of continuing bonds (Klass, 1993; Shankar et al., 2017), memory-making has been consistently identified as an important way to recognise parenthood and honour the life of the baby (Flenady et al., 2014; Gold, 2007; Koopmans et al., 2013; Samuelsson et al., 2001; Thornton et al., 2020). Recommendations for memory-making activities include taking photographs of the baby, creating mementoes like hand and footprints, guiding parents to bathe, dress and/or hold their baby, inviting family members, including siblings and grandparents, to meet the baby, and assisting parents to arrange a commemorative service or funeral for the baby.

However, there are practical differences between loss types regarding the medical procedures involved and the extent of memory-making activities that can occur according to the size and development of the baby. For example, while it is recommended that parents are offered the opportunity to meet, hold and parent a stillborn or critically-ill newborn baby, and will generally spend a substantial amount of time in the hospital for the labour and birth, these same activities may not be possible in the case of an early-gestation miscarriage. Given these differences, it is noteworthy that no national guidelines exist in Australia specifically for care following miscarriage. Regardless of gestational age, however, guidelines do emphasise the importance of acknowledging the life of the baby in accordance with parents' wishes and offering referrals to grief/bereavement counselling or community support services where a structured program of bereavement care or perinatal palliative care cannot be provided (Health Service Executive, 2016; NBCP, 2020a; Sands Australia, 2018).

1.2.4.3 *Representation of fathers/partners in bereavement care guidelines*

It is also important to note that although many of the recommendations in bereavement care guidelines are relevant to both parents, and all specifically state there is a need to include fathers/partners in care and support activities, there are limited recommendations specific to men's grief and how to best support men. The PSANZ/Stillbirth CRE guidelines, for example, acknowledge that fathers can form close bonds and attachments to their baby and state:

> "Studies of fathers' reactions to perinatal death highlight what is often a strong need to protect their partner. It is important to assist partners to find ways to do this and to express their own needs" (Boyle et al., 2020, p. 7).

The NBCP guidelines from the UK provide the most comprehensive representation of men, including multiple quotes from bereaved fathers' perspectives of bereavement care in the hospital across the five documents. A short paragraph is also included in all five documents specific to fathers'/partners' needs:

> "In addition to the mother, it is important to ensure that fathers and partners are offered support. Fathers and partners may wish to support the mother and may also want reassurance for themselves. Some fathers and partners may be reluctant to voice their fears in the mother's presence as they are concerned about distressing her. Staff should offer fathers and partners an opportunity to speak with staff on their own." (NBCP, 2020a, p. 37).

Overall, while fathers are not excluded from current bereavement care guidelines in Australia or the UK, specific information and practical recommendations regarding their potentially unique grief and individual support needs are not comprehensive.

1.2.4.4 *Parents' experiences of bereavement care following pregnancy loss and neonatal death*

Despite the emergence of perinatal bereavement care guidelines internationally, research among bereaved parents has identified inconsistencies in care received from the hospital and healthcare staff, both for the same loss types and between different loss types. While many parents in recent research and evaluations of bereavement care in high-income countries have reported receiving good care and support from empathetic and engaged healthcare professionals (Coffey, 2016; Donaldson, 2019), others have experienced less support, resulting in a lack of acknowledgement for their babies, their grief, and position as bereaved parents (Hodgson et al., 2016; Kelley & Trinidad, 2012; Pitt et al., 2016; Smith et al., 2020; Watson et al., 2019).

1.2.4.4.1 *Care following miscarriage*

Following miscarriage, the provision of bereavement care can be particularly challenging. While dedicated early pregnancy loss clinics are available to provide specialised care for early-gestation losses in some countries, parents frequently experience miscarriage in their own homes or the emergency department, rather than being admitted to an obstetric or labour ward (Bellhouse et al., 2018; Due et al., 2018; Edwards et al., 2018; Emond et al., 2019; Meaney et al., 2017; Séjourné et al., 2010). Many miscarriages occur spontaneously and without medical intervention, though some may require a surgical procedure. However, even where medical assistance is provided, parents' stay in a hospital is usually much shorter compared to a later-term stillbirth, leaving limited time for healthcare staff to provide comprehensive bereavement care services (Baird et al., 2018; Edwards et al., 2018; Emond et al., 2019; Warner et al., 2012). Qualitative research involving ED nurses has identified that while nurses are aware of the emotional impacts of miscarriage, they perceived system constraints of busy ED environments, as well as a lack of training and guidelines available for bereavement care, as key barriers to providing optimal emotional support to parents during miscarriage (Emond et al., 2019).

Qualitative studies involving women and men from countries including Australia (Baird et al., 2018; Bellhouse et al., 2019; Edwards et al., 2018; Miller et al., 2019; Rowlands & Lee, 2010), France (Séjourné et al., 2010) the USA (Warner et al., 2012), Ireland (Cullen et al., 2018; Meaney et al., 2017) and Canada (Emond et al., 2019; MacWilliams et al., 2016) have consistently identified a lack of confidentiality/privacy in ED waiting and consultation rooms, inadequate information on medical management, and under-acknowledgement of parents' grief as key issues with providing adequate hospital support during a miscarriage. After discharge from the hospital, parents have also reported a lack of follow-up and/or referral to community support services to assist with managing their emotional needs and mental health (Baird et al., 2018; Bellhouse et al., 2019; Rowlands & Lee, 2010; Warner et al., 2012). While negative experiences largely centre on the treatment of miscarriage as a purely medical event and common pregnancy-related complication (Baird et al., 2018; Edwards et al., 2018; MacWilliams et al., 2016; Miller et al., 2019; Rowlands & Lee, 2010), more positive experiences have been reported by parents who had access to a specialised early pregnancy clinic, or when healthcare professionals provided adequate information regarding medical procedures and empathetic care with explicit acknowledgement of parents' grief and emotional needs (Due et al., 2018; Emond et al., 2019; Meaney et al., 2017). Given that hospital contact may be limited, parents experiencing miscarriage may benefit from receiving follow-up telephone calls or appointments with the hospital or their General Practitioner (GP) who could provide referrals to community-based pregnancy loss support services, including telephone support lines or specialised perinatal grief counsellors or psychologists (Bellhouse et al., 2019; Emond et al., 2019; Miller et al., 2019).

1.2.4.4.2 *Care following TOPFA*

Despite the frequency of prenatal testing and diagnoses, international research on parents' experiences of TOPFA has also indicated mixed experiences with healthcare and decision-making support. While research from the USA, Australia and Europe has evaluated and/or recommended structured perinatal palliative care programs for families who choose to continue a pregnancy with foetal anomalies (Breeze et al., 2007; Cortezzo et al., 2020; Flaig et al., 2019; Guimarães et al., 2019; Tosello et al., 2017; Weeks et al., 2020; Wool, 2011), many parents have reported feeling inadequately supported. Specific concerns reported by parents in recent studies have included a lack of relevant information to inform decision-making regarding termination, inconsistent levels of emotional support during the termination, birth and in follow-up, and perceived negative attitudes from healthcare professionals regarding the decision to terminate (Hodgson et al., 2016; Pitt et al., 2016). Conversely, more positive experiences have been reported when parents have their decision to terminate the pregnancy validated, guidance from a maternal-foetal health specialist regarding their baby's condition/s and decision-making, and emotional support from mental health professionals to provide grief counselling and assistance in managing anxieties into future pregnancies (Asplin et al., 2014; Dekkers et al., 2019; Hodgson et al., 2016). Mental health and emotional support are important given the risk of trauma responses and complicated grief in this population of parents (Kersting et al., 2005; Korenromp et al., 2007; Nazaré et al., 2014).

1.2.4.4.3 *Care following stillbirth*

For later-term stillbirths, a birthing process (either vaginal or caesarean section) is required to deliver the baby. Induction of labour may be involved, and similarly to any birth process, the birth can be either short in duration or last multiple days (Kelley & Trinidad, 2012; King et al., 2019). Since the introduction of bereavement care guidelines for stillbirth, bereaved parents' accounts of healthcare and support in the hospital have substantially improved, with many parents participating in recent studies generally reporting high levels of satisfaction with hospital care (Basile & Thorsteinsson, 2015; Bond et al., 2018). In particular, positive experiences have been reported regarding being provided opportunities to collect mementoes of their baby (e.g., photography services and hand/foot prints); being offered an informed choice on whether to meet their stillborn baby; treating the baby like a live-born infant; empathy and sensitivity from healthcare staff; private bereavement rooms away from busy labour wards; the use of butterfly stickers on parents' room doors to indicate their loss to hospital staff; access to counselling and chaplaincy services; and the provision of informational support on grief (Bond et al., 2018; Coffey, 2016; Lisy et al., 2016; Peters et al., 2016).

However, gaps in bereavement care following stillbirth have also continued to be reported by some parents. For example, an Australian survey of 189 mothers and fathers in 2015 found that PSANZ guidelines (Flenady et al., 2009) were only implemented just over 55% of the time, with key concerns noted particularly in regards to birth options, memory-making (i.e., spending time with the baby) and information regarding autopsies (Basile & Thorsteinsson, 2015). In more recent studies, parents have also reported inconsistencies relating to the provision of follow-up care from the hospital, lack of referral to community supports, as well as insensitive comments and/or care throughout the hospital experience from some healthcare staff (Bond et al., 2018; King et al., 2019; O'Connell et al., 2016; Siassakos et al., 2018). Recent research among bereaved parents from Spain has also highlighted substantial challenges to quality bereavement care following stillbirth due to a lack of widely-available hospital guidelines and training in bereavement care among healthcare professionals (Cassidy, 2018; Fernández-Sola et al., 2020; Martínez-Serrano et al., 2019). Similar concerns have also been reported in many LMICs, where training and guidelines are currently not widely available (Shakespeare et al., 2019).

It is important to note that issues about providing medical information concerning causes of stillbirth, and autopsies of the baby to help determine causes, are important areas of research and have significant impacts on caring for parents following stillbirth (Horey et al., 2013). Research has found that bereaved parents place high importance on understanding the cause of stillbirth, particularly given that potential answers may alleviate feelings of self-blame or guilt that can complicate grief and lead to reduced fears about, or better preparation for, future pregnancies (Henderson & Redshaw, 2017; Meaney et al., 2015). However, the processes of communicating relevant medical information and autopsy consent procedures to parents – particularly at a time of such high distress – are difficult and not all parents have received comprehensive and timely information (Holste et al., 2011; Horey et al., 2012). As such, research findings from parents’ experiences of decision making surrounding autopsy have been included into many bereavement care guidelines to assist healthcare professionals in best supporting parents through this process. General themes identified from research include: ensuring that all parents are offered the option of an autopsy; providing clear explanations of autopsy processes, including options for less invasive examinations where this is preferred by parents; providing additional written information to support discussions about decision-making; assuring parents that their baby will be treated with utmost respect and care at all times; addressing concerns surrounding where the baby will be and whether parents can see them; providing an initial plain language report of the examination as soon as possible; and informing parents of clear timelines and expectations for communicating full investigation results (Flenady et al., 2020).

Overall, synthesising responses from expert stakeholders in stillbirth from 26 countries worldwide, the recently published RESPECT Study for global consensus on bereavement care following stillbirth emphasised the need for further research championing the voices of women and families in exploring strategies for widespread implementation of the highest quality bereavement care across countries worldwide (Shakespeare et al., 2020).

1.2.4.4.4 *Care following neonatal death*

While some neonatal deaths will occur shortly after birth, most babies who die in the neonatal period will be transferred to a Neonatal Intensive Care Unit (NICU) for medical management of life-limiting conditions. NICUs are usually staffed by multi-disciplinary healthcare professionals and, similarly to TOPFA, structured perinatal palliative care programs have been recommended in many countries to assist parents in preparing for their baby's death and managing grief after their baby's death (Carter, 2018; Cortezzo et al., 2015; Kenner et al., 2015; Sumner et al., 2006). Recent quantitative and qualitative studies exploring parents' experiences in the NICU have generally indicated high overall levels of satisfaction with healthcare and support (Baughcum et al., 2020; Redshaw & Henderson, 2018). In particular, parents have reported appreciation for guidance from staff regarding memory-making activities and creating keepsakes; being kept well-informed of treatment options and decisions regarding their baby's care; being provided private space to spend time with their babies; opportunities for visitation from family members (particularly the baby's siblings); and consistency in the team of healthcare professionals providing care and information (Baughcum et al., 2017; Branchett & Stretton, 2012; Levick et al., 2017; Thornton et al., 2020). However, as with other loss types, parents have also highlighted many areas for improvement relating to bereavement care. These include a need to simplify complicated medical information regarding their baby's condition; reducing the numbers of healthcare staff involved in delivering care; the need for individualised follow-up support in the weeks/months following the death of their baby from familiar healthcare professionals; opportunities for partners to stay with women postnatally; and consideration for the whole-family unit throughout the NICU stay (Baughcum et al., 2017; Branchett & Stretton, 2012; Redshaw & Henderson, 2018; Thornton et al., 2020).

1.2.4.4.5 *Care at the margins of loss types*

Bereavement care can be particularly problematic when losses occur “at the margins” of the gestational cut-offs between loss types (Smith et al., 2020, p. 869). As discussed in Section 1.2.2.1, the gestational cut-off for defining the difference between a miscarriage and stillbirth are arbitrary, varying between countries from 20 weeks’ gestation in Australia and the USA, through to 28 weeks’ gestation as recommended by the WHO (UN IGME, 2020; WHO, 2020). However, for bereaved parents, there may be no tangible differences in experiences between a late-term miscarriage (for example, occurring close to 20 weeks’ gestation) and a stillbirth (occurring at or after 20 weeks’ gestation; Jonas-Simpson & McMahon, 2005; Obst & Due, 2019a; Smith et al., 2020).

Based in the UK, where the gestational cut-off between miscarriage and stillbirth is 24 weeks, women and their partners in Smith et al.’s (2020) study reported feeling ill-prepared for the process of labour, birth and meeting their baby after being told they were ‘having a miscarriage’ between 21 and 23 weeks’ gestation. Additionally, they felt this terminology under-valued their lived experience and made it difficult to discuss the loss of their baby with family and friends. While these couples were provided with opportunities for memory-making, the lack of an official birth certificate (usually only provided following stillbirth in high-income countries) to recognise their baby’s life worsened their grief. In Australia, states and territories have recently endorsed recognition of life certificates being provided to families following a miscarriage prior to 20 weeks’ gestation (Mills, 2020; Sands Australia, 2020). These findings have also been echoed in research exploring the experiences of parents after a combination of loss types (i.e., pregnancy loss or perinatal death), with bereavement care and support following late-term miscarriages frequently receiving a lower level of recognition and care in comparison to stillbirth (Due et al., 2018; Obst & Due, 2019a, 2019b).

1.2.4.5 *Peer support following pregnancy loss and neonatal death*

Peer support involves the giving and receiving of emotional, social and practical/tangible support between individuals and can take many forms depending on context, including informal or formal support (Bartone et al., 2019; Taylor et al., 2016). Research suggests that formal peer support provided by a trained patient or carer – and defined in a health context as "the provision of support from someone who has experienced the same health problem and has similar characteristics as the proposed recipient" – is valuable and beneficial to bereaved individuals (Bartone et al., 2019; Boyle et al., 2015, p. 2; Dennis, 2003). Formal peer support services are actively promoted in UK and Australian health policies (e.g., Byrne et al., 2021; National Health Service, 2017) and are considered particularly important when more informal or social support from family and friends is unavailable. Given the high potential for disenfranchised grief and perceived stigma following pregnancy loss and neonatal death (Lang et al., 2011; Mulvihill & Walsh, 2014; Pollock et al., 2020), peer support from other bereaved parents with shared experience can be essential in providing emotional validation and reducing feelings of social isolation (Andalibi & Garcia, 2021).

In response to bereaved parents' historically unmet need for peer and social support, a growing number of community peer support organisations have been established in multiple countries, including the USA, UK, Italy, Spain, Canada, Sweden, and Kenya. In Australia, national peer support organisations for pregnancy loss and neonatal death include Red Nose/Sands Australia, Bears of Hope, the Pink Elephants Support Network, and Miracle Babies. State-based organisations, such as SIDS and Kids SA, also provide local support in specific States and Territories of Australia. Services provided by each of these organisations align with the ‘five basic processes’ of support organisations outlined by Boyle et al. (2015): (1) providing support; (2) sharing information; (3) creating a sense of belonging; (4) communication of experiential knowledge; and (5) teaching coping strategies. Specifically, services across the organisations cover both formal and informal supports, including telephone peer support provided by trained parent volunteers, face-to-face peer support groups, online chats, informational webinars/video series, and online written grief/coping information. While rigorous evaluations of peer support services remain limited, research among bereaved parents and peer supporters in the area of pregnancy loss and neonatal death have indicated multiple benefits, particularly in relation to providing validation and enhancing sense-making, through means of sharing of mutual experiences and storytelling (Boyle et al., 2015; Layne, 2006; McCreight, 2007; Umphrey & Cacciatore, 2011).

1.2.4.6 *Men’s experiences of bereavement care and support following pregnancy loss and neonatal death*

As with the research on men’s experiences of grief following pregnancy loss and neonatal death, most of the literature on bereavement care experiences has focused predominately on women’s experiences, or has combined men’s experiences with those of women. For example, two recent studies evaluating bereaved parents’ experiences of care in Australian hospitals following pregnancy loss included only six men in a sample of 189 parents (Basile & Thorsteinsson, 2015), and women-only in a sample of 36 ‘bereaved parents’ (Bond et al., 2018). The small body of (largely qualitative) research pertaining specifically to men’s experiences of support following pregnancy loss and neonatal death has identified that a generalised and continuing lack of social recognition for men’s emotional needs may lead men to perceive that limited options for support exist (Bonnette & Broom, 2012; McCreight, 2004; Miller et al., 2019; Obst & Due, 2019a). In addition, the commonly held perception of a need to ‘support’ or ‘protect’ their partners through pregnancy loss and neonatal death (McCreight, 2004; Miron & Chapman, 1994; Nguyen et al., 2019; Obst & Due, 2019a) has been contextualised as a self-fulfilling prophecy regarding support, in that when men hide their grief to take on a supporter role for their women partners, their need for support is also hidden from healthcare professionals and service providers (Bonnette & Broom, 2012).

In relation to formal support received from the hospital, studies on men's experiences have frequently identified that men often feel marginalised by healthcare professionals, given that their woman partner's physical and emotional needs were more immediately obvious compared to theirs following the loss (Bonnette & Broom, 2012; McCreight, 2004; Miller et al., 2019; Murphy & Hunt, 1997; Obst & Due, 2019a; Pabón et al., 2019; Puddifoot & Johnson, 1997). In considering their roles in the hospital and/or being involved in memory-making, some fathers have reported feeling like a "bystander" (Horstman et al., 2020, p. 543) or as though they "barely existed" (Obst & Due, 2019a, p. 3). Similar to the experiences of men in LMICs discussed in Section 1.2.3.2, Colombian men in Pabón et al.'s (2019) qualitative study also reported having to wait outside of labour wards throughout the birth process with little to no information provided to them on their partner's condition. While some men in studies from high-income countries felt they received adequate explanations and information regarding the loss and how to care for their partner, others reported leaving the hospital with poor explanations or too little information (McCreight, 2004; Miller et al., 2019; Obst & Due, 2019a). Importantly, aspects of good care for men have centred around receiving person-centred psychosocial care and genuine validation for their grief and position as a father (Cacciatore et al., 2013; Obst & Due, 2019a). Generally, however, men have reported little to no access to hospital follow-up, referrals to counselling or psychological support (Cacciatore et al., 2013; Chavez et al., 2019; Miller et al., 2019; Obst & Due, 2019a; Wagner et al., 2018).

Regarding informal supports, men have also reported feeling overlooked by family, friends, work colleagues and the wider community (Miller et al., 2019; Nguyen et al., 2019). Although community-based services including peer support groups have increased in availability over recent years in some countries, studies note that these are attended largely by women or men in the context of couples (e.g., attending together); men have reported feeling uncomfortable sharing their feelings in such settings and rarely attend alone (McCreight, 2004; Obst & Due, 2019a). Rather, these men have typically expressed a desire to have another trusted man/other trusted men to confide in, or access to anonymous forms of online support or written information on how to manage their grief (Miller et al., 2019; Obst & Due, 2019a). Although social networks have been available for some men (Armstrong, 2001; Obst & Due, 2019a), other men in the same and different studies, have reported that friends, family, or work colleagues have been unable to fulfil their need for social/peer support in grief (McCreight, 2004; Miller et al., 2019; Obst & Due, 2019a; Puddifoot & Johnson, 1997; Samuelsson et al., 2001).

In two small qualitative studies involving interviews with pregnancy loss grief/bereavement service providers, participants highlighted multiple challenges in supporting men following pregnancy loss and neonatal death (McCreight, 2004; Obst & Due, 2019b). Key barriers to supporting men reported by service providers in these studies included: the woman-centred nature of maternity and pregnancy loss support services; gendered expectations on how men should behave in the face of loss and grief; limited time in the hospital for building rapport with men and families after a loss; lack of formal assessment and follow-up of men post-discharge; lack of appeal among men for traditional grief services including counselling or support groups; and a need for educational sessions and training among hospital staff on the needs of bereaved parents, particularly men. To my knowledge, only one formal training program currently exists worldwide (in Canada) on educating and empowering health professionals to support men/fathers in mourning (de Montigny et al., 2020; also see the Movember Project). Further exploration of the barriers and facilitators to men's engagement in pregnancy loss grief and bereavement services is needed.

1.3 Aims for this research

1.3.1 Overview

As Stevenson and colleagues (2017) noted, best practice "bereavement services should (a) be based on an empirically validated understanding of parents' actual experiences, and (b) integrate current psychological theories of grief" (pp. 649-650). Given that we currently have neither a complete understanding of bereaved men's experiences of pregnancy loss and neonatal death, nor complete psychological theories that adequately describe their grief, this program of research aimed to address this gap by developing a more comprehensive understanding of men's grief following pregnancy loss and neonatal death, to inform the future of service provision for men.

1.3.2 Research questions

The research forming this thesis and the included papers were guided by the following research questions:

1. How do men experience grief following pregnancy loss and neonatal death?
2. What factors influence men's grief following pregnancy loss and neonatal death?
3. How does type of loss (i.e., miscarriage, stillbirth, TOPFA or neonatal death) impact men's grief experiences?
4. How can future services and bereavement care guidelines best support men following pregnancy loss and neonatal death?

CHAPTER 2. OVERVIEW OF THESIS AND RESEARCH METHODOLOGY

2.1 Overview of research program

This thesis reports the results of four studies concerning men's experiences of pregnancy loss and neonatal death, each employing different research methodologies and/or analyses to gain a more comprehensive understanding of the topic (see Section 2.1.1). Study 1 was a systematic review of the literature on men's experiences of grief, and factors contributing to grief, following pregnancy loss and neonatal death; Study 2 was a nationwide online survey to further explore factors contributing to men's grief in an Australian sample; Study 3 analysed a subset of data from the nationwide survey relating to men's experiences of returning to work after a pregnancy loss or neonatal death; and Study 4 was a qualitative interview study exploring men's experiences of TOPFA in Australia. This Chapter outlines the overall approach and rationale for this program of research, including guiding theoretical frameworks, followed by a description of each of the studies that form the remaining Chapters for the thesis.

2.1.1 Mixed methods research: description and rationale

Mixed methods research involves collecting and analysing quantitative and qualitative data within a single study or program of research (Johnson et al., 2007). Using a combination of approaches, mixed methodology allows for an integration of research findings that can explore relatively unknown phenomena, and explain emerging relationships between variables, for corroboration and to gain an in-depth understanding of the area of interest (Creswell & Hirose, 2019; Johnson et al., 2007).

The overarching aims of this research – to explore men's experiences of grief and factors contributing to grief in the context of pregnancy loss and neonatal death – were considered amenable to qualitative and quantitative methods of inquiry. Given a lack of previous research focusing on men's experiences of pregnancy loss and neonatal death, it was determined that attempting to categorise and explain emerging relationships from the available research (quantitative), and taking an exploratory, open-ended perspective (qualitative), would be beneficial. Therefore, except for Study 4, which was entirely qualitative, Studies 1, 2 and 3 used a combination of qualitative and quantitative approaches, measures and/or analyses to explore the research questions. Overall, a mixed methods approach was chosen to allow for initial exploration of a relatively unknown phenomenon, followed by an elaboration of the results as the studies progressed.

2.1.2 Research design

The research employed a sequential design comprising four studies, using a combination of exploratory and explanatory lenses. Data were collected and analysed in four sequential phases, using three methodologies that resulted in four studies:

1. Study 1 collected and summarised qualitative and quantitative data concurrently as part of a systematic review exploring men's grief and factors contributing to grief (exploratory approach);
2. Study 2 collected quantitative and qualitative data concurrently as part of a nationwide online survey examining factors related to grief (explanatory and exploratory approaches);
3. Study 3 analysed a subset of data from the nationwide survey relating to men's experiences of returning to work after a pregnancy loss or neonatal death, using a combination of descriptive statistics and qualitative content analysis (exploratory approaches); and,
4. Study 4 collected qualitative data from a subset of participants who responded to the online survey to gain a deeper understanding of the experiences of men who had experienced TOPFA (exploratory approach).

Before the details of each study are outlined later in this Chapter, I describe the core philosophical assumptions underlying the research below.

2.1.3 Ontology and epistemology

What we observe is not nature itself but nature exposed to our method of questioning.

- W. Heisenberg (1985)

In mixed methods research, it is important to acknowledge the core assumptions and beliefs that researchers inherently bring to the research design, process, procedures and analysis (Cain et al., 2019; Creswell, 2009). Frameworks for research methodologies can be described in terms of ontology and epistemology. Ontological positions refer to the relationship between reality and human practices or understandings, whereas epistemological positions determine what “counts as valid, trustworthy and ‘true’ knowledge” (Braun & Clarke, 2013, p. 29).

This program of research adopted a realist ontological position, whereby it was assumed that we can access an existing reality through the process of research. Therefore, participants’ accounts were taken to directly reflect their lived experiences, with no critical or additional meaning applied beyond this. In the context of limited previous research on men’s experiences of pregnancy loss and neonatal death, this approach was chosen to give voice to participants’ perspectives and provide the opportunity to maintain ownership over their stories, as a true reflection of their experiences. However, the research approach was also underpinned by a post-positivist epistemological position, which acknowledges that while a search for the ‘truth’ is achievable, researchers are influenced by their contexts and perspectives, which in turn influences the research. As such, any facts collected are not neutral reflections of the truth but theoretically influenced by the researchers’ assumptions and biases and the theoretical frameworks guiding the research (Braun & Clarke, 2013; Clark, 1998; Guba & Lincoln, 2005).

2.1.4 Self-reflexivity

In line with the post-positivist epistemological position which recognises the researchers' potential to influence the research design, data collection and interpretation of results, an ongoing process of self-reflexivity (Braun & Clarke, 2013; Cain et al., 2019; Tracy, 2010; Walker et al., 2013) was engaged throughout this program of research.

I identify as a white, cisgender, heterosexual woman. I acknowledge the immense privilege in my position to have access to higher education, both as part of a majority ethnic and cultural group and residing in a country that recognises the fundamental right for women to access education and work. I am fortunate to have been born into circumstances that have allowed me to pursue undergraduate and postgraduate study and have access to the means and platform to develop, complete, and share this research with a broad audience.

As a woman without children or experiences of pregnancy, I do not claim to be an expert on men's experience of pregnancy loss or neonatal death, nor the grief that follows this experience. While I have experienced my own forms of grief, I acknowledge the unique and specific grief of losing a baby, which I do not personally know. As neither a man nor a bereaved parent, I positioned myself in this program of research as an 'outsider', seeking permission from the research participants to act as a collector and summariser of their stories, from which we can learn important (and I believe, crucial) lessons about what it means to identify as a man grieving the death of a baby in Australia, particularly in the context of pregnancy loss and neonatal death.

Previous research suggests there are benefits to being either an 'insider' and/or an 'outsider' in research (Bonner & Tolhurst, 2002; Breen, 2007). An 'insider researcher' shares a direct identity or experience with the group and/or phenomenon of interest; while an 'outsider researcher' does not. It has been identified that insiders may hold a deeper understanding that may not be accessible to an outsider, and in qualitative research, may be perceived as more ‘legitimate’ or trustworthy to participants. For example, Dwyer and Buckle (2009) reflected that upon conducting interviews with bereaved fathers, some participants directly questioned whether the researchers had experienced the death of a child themselves and if they could truly understand the grief the fathers had experienced. However, in responding with openness and honestly about not having direct experience, they noted that ultimately such questions did not impede the interview process, and participants expressed positive feedback about the interview overall (Dwyer & Buckle, 2009). Alternatively, arguments have also been made in favour of ‘outsider researchers’ regarding their ability to maintain an appropriate level of objectivity in the research process. For example, an insider may be at risk of making assumptions regarding similarity, or cloud interpretation of the results with their personal experience, rather than focusing solely on the participants’ reports (Breen, 2007; Hewitt-Taylor, 2002). Therefore, each position (or combinations of both) equally carries potential benefits and/or biases. Rather than one position being more advantageous than the other, it is recommended that researchers maintain reflective practice throughout the research process to consider their potential impact on the research and the impact of the research on them (Grove, 2017).

My desire to undertake this program of research was inspired by my previous experience as an undergraduate psychology student. In 2015 I was involved in a summer research project that explored women’s experiences of support after miscarriage and stillbirth (a qualitative study, see: Due et al., 2018). In 2017, my Honours research explored men’s experiences of support following miscarriage and stillbirth in South Australia (two qualitative studies (see: Obst & Due, 2019a, 2019b). I found myself deeply moved by the stories of women and men that formed these projects; the utter devastation, their ongoing grief, and the lack of support and societal acknowledgement for the babies they so much loved and looked forward to meeting.

As a woman of childbearing age, I grappled with feelings of shock and anger that our society did not share these stories more often. My lack of knowledge into the real possibility of experiencing a reproductive loss in my lifetime felt like a betrayal, and my naïve assumption that children come easily into this world was shattered. Of course, there was no wonder that the one in four families who experience these losses report feeling blindsided and isolated. After beginning to share my work and feelings with those around me, I became increasingly aware of the hidden stories of loss and grief in my own social circle: countless family members, friends and peers had all been touched in some way – whether by loss, or complications or trauma in birth – and I was saddened that many had not received the support and acknowledgement they deserved. I noticed, too, that the men around me were less comfortable in discussing their experiences. There seemed to be a perception that challenges in pregnancy (and indeed, the whole experience of pregnancy in general) happened to their partners and not to them; seldom were they asked about how they felt. When I asked men (in my life and my research) how they were feeling, they expressed a combination of surprise and gratitude. Importantly, many shared with me that it was the first time anyone had asked them to tell their side of the story. Holding these accounts, I felt deeply compelled to expand my knowledge and share whatever I could more widely. If my efforts changed one person's experience for the better, I felt the pursuit was a worthwhile one.

The wider team of supervisors for this program of research are women experienced in research and psychological practice relating to reproductive health, psychology, public health, and loss and grief. Two have children, and two have personal experiences with pregnancy loss and/or neonatal death. As a team, we therefore approached this research with similar and varied lenses: as women, with and without children, and with insider and outsider experiences of pregnancy loss and neonatal death.

2.1.5 Reference group consultation

Acknowledging the positions of the wider research team, I strived to also gain additional insights from individuals with lived experience and/or expertise in pregnancy loss and neonatal death to help inform and shape the design, processes and outcomes of this research. In the early stages of conceptualising this program of research, I formed and consulted with a research reference group, comprising mothers and fathers who had experienced pregnancy loss and/or neonatal death, grief counsellors, psychologists, and individuals involved in local and national awareness and support organisations for pregnancy loss and neonatal death. These included Claire Foord from Still Aware, Dorothy Crosby from SIDS and Kids SA, Gary Sillett from Pillars of Strength, Amanda Bowles and Adrian Raftery from Bears of Hope, bereaved parent representatives from Sands Australia, and Dell Horey and Fran Boyle from the Stillbirth CRE.

These members provided valuable feedback at many stages of the research process, particularly regarding strategies to maximise men's participation in the research, and ensure that measures used/questions asked were valid and appropriate. Members also provided detailed feedback during the development of the nationwide survey for Study 2 (discussed further in Section 2.3). Additional general feedback on the wider program of research from reference group members included:

- Reducing the length of, and amount of jargon in, participant information sheets (e.g., avoiding long and technical definitions of loss types);
- Making the purpose and potential benefits of the research clear in information sheets and study flyers to improve participants' motivation to contribute to the research; and,
- Advice concerning creating a webpage to serve as a home for the research so that people could easily access information and summaries of findings. The development of a

> webpage was also seen as facilitating a sense of trust that the research was ‘serious’ and being conducted by qualified researchers.

In response to this feedback, particular emphasis was given to the potential benefits of the study to participants (or more broadly, men who may in the future experience a pregnancy loss or neonatal death) in the study flyer and participant information sheets (see Appendices 1 and 2). In addition, members provided feedback about using simple and easy to understand language. In response to the reference groups’ suggestion, I also developed a research webpage that was hosted by the University of Adelaide website. This research webpage was continually updated throughout the program of research, with summaries of study results and links to publications, media pieces and outreach activities (see Appendix 3 for a copy of the current research webpage). I acknowledge the invaluable contributions of this group in shaping the research, including the language used, questions asked, research design and dissemination approaches used to access participants. Without their feedback, this research would not have achieved the same reach, nor depth of understanding.

2.1.6 Ethical considerations

Ethical approval for this program of research which included human participation (specifically, Studies 2, 3 and 4) was granted by the University of Adelaide Human Research Ethics Committee (approval code HREC-2018-273). Given the sensitivity of the research topic, several factors were considered throughout the research process to ensure informed consent was gained and participants’ safety and wellbeing was upheld. Informational pages for Studies 2, 3 and 4 included full details of the purpose of the study, eligibility criteria, confidentiality of data, contact information for the research team, and the procedure for complaints or concerns. Participation in the studies was entirely voluntary and participants were free to withdraw at any time. In Study 4, participants could choose not to answer particular interview questions if they wished. In acknowledging the potential for the subject matter to cause emotional distress, contact details for 24/7 telephone support lines (Lifeline and MensLine Australia) were also provided as part of informational resources and in follow-up correspondence with interview participants. An included feature of the online survey platform for Studies 2 and 3 also allowed participants to take a break from responding if needed, and return to where they left off later. A similar approach was offered in interviews, should participants become distressed and require a break. Details of available 24/7 telephone support lines were also provided to all interview participants before and after the interview, and an opportunity to debrief was offered after each interview. In the event that a participant seemed particularly distressed during or after the interview, a distress protocol outlined that this would be discussed with the research supervisors (one of whom is a registered clinical/health psychologist) who would schedule a follow-up phone call with the participant to offer additional support, as well as referral to a GP in the first instance. Overall, however, no participants experienced distress that required follow-up or withdrawal from the study and no other ethical concerns were raised throughout the research.

2.1.7 Guiding theoretical frameworks

As this thesis was completed as part of a combined PhD/Master of Psychology (Health) degree, it drew upon perspectives from health psychology as a foundational framework. Broadly, health psychology considers how biological, psychological and social/cultural factors contribute to health and illness over the lifespan (Dorrian et al., 2017; Lehman et al., 2017). With a focus on using evidence-based psychological science, the core activities of health psychologists include health promotion, illness prevention, and the improvement of healthcare systems aiming to provide multi-disciplinary and holistic healthcare and support (Dorrian et al., 2017; Suls & Rothman, 2004; Wahass, 2005). Given the research focus on men’s experiences of grief and support, theoretical frameworks relevant to the psychology of men, models of support, and recent recommendations regarding father-inclusive practice were also incorporated. These frameworks impacted the research approach, including design, questioning methods, data analysis and organisation of conclusions and recommendations. Each of these guiding models/frameworks is outlined below.

2.1.7.1 *The Biopsychosocial Model*

The foundational conceptual framework for health psychology is the Biopsychosocial Model. In his landmark paper, Engel (1977) critiqued the dominant Biomedical Model for its reductionist approach to health (which typically focuses on a single primary biological cause) and for failing to consider the multitude of psychosocial and cultural factors contributing to illness and disease across the lifespan. He argued that a broader perspective within medicine and healthcare was required to fully understand the inherently human (and thus varied and subjective) nature of health and illness (Engel, 1977, 1997). His alternative, the Biopsychosocial Model, recognised the contributing factors to health and illness across biological, psychological and social/environmental domains. Using diabetes (considered a ‘somatic’ disease) and schizophrenia (considered a ‘mental’ disease) as comparative examples, Engel noted that the presence of a biological ‘abnormality’ alone is insufficient in determining the onset, severity, cause, treatment trajectory, and degree of impact on individuals. Instead, fully understanding the determinants of health and best course of treatment/care requires consideration of the individual, their social context, and the role of the healthcare system (Engel, 1997).

Since 1977, there has been a wealth of research to demonstrate the various biopsychosocial factors that interact and contribute to the human experience of health and illness (Fava & Sonino, 2017; Jull, 2017; Nakao et al., 2020; Wade & Halligan, 2017). For example, reviews and longitudinal studies have identified that while factors including psychological wellbeing, resilience, social support, safe housing and access to healthcare have a protective role for health outcomes, vulnerability to illness and poor health outcomes are heightened after exposure to periods of chronic environmental or psychological stress, presence of affective disorders (e.g., anxiety and depression), and poor health behaviours (e.g., lack of physical activity or poor diet; Gunasekara et al., 2013; Maatouk et al., 2012; Shore et al., 2018; Tammelin, 2005; Tyack et al., 2016).

The Biopsychosocial Model has also been an influential perspective in many areas of health globally. It has been used to structure guidelines including the *International Classification of Functioning (ICF), Disability and Health* (World Health Organization International Classification of Functioning (WHO ICF; 2002), inform clinical interventions (particularly for mental health and chronic conditions; (e.g., Gatchel et al., 2007; Kamper et al., 2015; van Erp et al., 2019), and provide a foundation for best practice in person-centred care (Tramonti et al., 2021; Wade & Halligan, 2017). However, its integration into healthcare systems has been limited in many settings, with the Biomedical Model remaining the dominant approach, particularly in tertiary care environments (Johnson, 2013).

While grief is not considered to be a disease or illness, it has been argued that the biopsychosocial impacts of grief on the individual, and the biopsychosocial factors contributing to grief (as outlined in Chapter 1), merit medical awareness and attention to develop evidence-based approaches to support bereaved individuals in adjusting to their loss (Engel, 1961; Stroebe, 2015; Stroebe et al., 2017). Applying a biopsychosocial perspective to this program of research aligned with current understandings of grief as outlined previously, and provided an opportunity to gain a holistic insight into the range of contributors to, and implications of, the human experience of grief. In line with this perspective, Study 1 (Chapter 3) focused on a comprehensive exploration of the factors contributing to men’s experiences of grief after pregnancy loss and neonatal death, and Studies 2, 3 and 4 considered the multidimensional impacts that may affect grief and support needs for men following pregnancy loss and neonatal death.

While the Biopsychosocial Model has been widely adopted in many primary and public health settings globally, it is important to note that it is not without its criticisms. In their (2019) book reviewing 40 years of research concerning the Biopsychosocial Model, Bolton and Gillett describe two types of major criticisms made of the model since its proposal; that it (1) lacks specificity, and (2) lacks scientific validity for classification as a 'model'. Some authors have argued that despite its broad appeal, the model suffers from 'vagueness' regarding the three overarching domains and does little to specifically and practically guide health professionals on how to approach holistic care of an individual (Benning, 2015; Ghaemi, 2009). In addition, a lack of detail into exactly how various biopsychosocial factors interact to influence health and illness creates difficulty surrounding the model's explanatory and predictive ability; which some have argued render it untestable in a scientific context (McLaren, 1998). In attempt to rectify this concern, recent studies have begun to explore causal relationships among biopsychosocial variables for health and illness concerns (e.g., see: Karunamuni et al., 2021). In addressing critiques more broadly, Bolton and Gillett (2019) reviewed decades of research documenting evidence for psychosocial causes of ill-health and how these may be addressed in practice, particularly through the adoption of multi-disciplinary allied health teams. While debates certainly remain, the Biopsychosocial Model serves as a useful conceptualisation of the various biological, psychological, and social/cultural factors that can contribute to health and illness, including in relation to grief.

2.1.7.2 *Masculinity theory and health*

In line with a biopsychosocial approach, gender has long been recognised as an important socio-cultural factor contributing to health and longevity outcomes (Courtenay, 2000b). Within this framework, 'masculinity' refers to a socially-constructed script or set of norms that guides the behaviours, social roles, and relations of people who identify as being a man within a given society (Thompson et al., 1992). Across the fields of sociology, gender studies and social psychology, an expansive literature exists on masculinity theory and its multiple and diverse impacts on a range of human behaviours and health outcomes. A full description of this literature is beyond the scope of this thesis. However, masculinity theory as it relates to health was an important consideration in this research, given the focus on men's experiences of grief and support. This aspect of masculinity is discussed further below.

This thesis drew upon a feminist and constructionist approach to masculinity theory, which recognises gender as a dynamic social structure and construct, rather than a fixed binary of male/female categorisation based on biological sex. In addition, ideals regarding what is considered to be masculine/feminine arise from complex cultural influences, and are continually negotiated through dynamic interpersonal relationships and individual agency (Connell, 1995; Courtenay, 2000b). Connell (1987, 1995) defined hegemonic masculinity as the socially dominant ideals of masculinity at a given place or time. Connell and Messerschmidt (2005) positioned hegemonic masculinity ideals within a patriarchal gender system, serving to maintain power over women and men considered of lower status (e.g., based on factors such as class or race). Other authors have also recognised that hegemonic ideals in this context were embodied primarily by white, heterosexual, highly educated and upper-class men (Courtenay, 2000b; Hearn et al., 2012; Jewkes et al., 2015). While it is now well-established that individuals are not passive receivers of cultural expectations and there are individual differences in 'masculine' behaviours, Connell and others have argued that upholding hegemonic masculine ideals remains profoundly influential in serving to maintain men's positions within social hierarchies and groups (Connell & Messerschmidt, 2005; Courtenay, 2000b). From this perspective, the gendered contexts in which people actively engage have been recognised as a profound influence on an individual's experiences and behaviours, including those related to health (Connell, 2012; Creighton & Oliffe, 2010).

Particularly in high-income countries, including the USA, UK and Australia, research has indicated that boys and men experience culturally-prescribed social pressure to endorse traditionally masculine health-related beliefs, including independence, self-reliance, and stoicism (Addis & Mahalik, 2003; Connell, 2012; Courtenay, 2003; Pleck, 1995; Seidler et al., 2016). To display the opposite (and traditionally normative 'feminine') behaviour of caring for one's health and seeking help would be to deny or reject traditional constructions of masculinity (Courtenay, 2000b). As a result, men who display a high level of conformity to traditional masculine norms or experience gender-role conflict have been found to be less likely to engage in help-seeking behaviours for concerns including depression, substance use and stressful life events (Addis & Mahalik, 2003; Galdas et al., 2005; Yousaf, Grunfeld, et al., 2015). They have also been found to display more negative perceptions toward engaging in psychological therapy, particularly for fear of the potential for coercion and stigma (Levant et al., 2009, 2011; Seidler et al., 2016; Yousaf, Popat, et al., 2015; Yousaf, Grunfeld, et al., 2015). Given, in part, reduced frequency of health-positive behaviours, men have statistically displayed higher risks of developing chronic conditions (e.g., heart disease, cancer) and early mortality due to causes including substance use, physical violence and suicide, in comparison to women (White et al., 2011; Yousaf, Grunfeld, et al., 2015).

Gender and masculinity theorists have also recognised that healthcare systems and institutions exist within gendered contexts and can play a role in constructing individuals' health experiences and behaviours (Connell, 2012; Courtenay, 2000a; Doyal, 2001; van Wijk et al., 1996). For example, a large body of research has found that in 'western' countries, women are more likely than men to have physical health conditions mis- or under-diagnosed and mental health conditions including depression and anxiety, over-diagnosed (Floyd, 1997; van Wijk et al., 1996). Misattributions regarding the causes of ill-health are especially common for women living with chronic pain conditions, who have been found to receive higher rates of psychogenic causal diagnoses and poorer quality healthcare than men, despite higher rates of help-seeking by women (Hoffmann & Tarzian, 2001). Researchers have conceptualised these differences in health diagnoses and treatment in the context of culturally-prescribed perceptions of women as the ‘sicker’ or ‘weaker’ gender and men as the ‘stronger’ gender (Courtenay, 2000a). Such views can lead to unconscious biases resulting in a tendency for women to develop a greater awareness of their health and willingness to engage in health services, but a higher perceived tendency to ‘complain’ and over-report symptoms; in contrast, men tend to have decreased awareness of their health and are more likely to remain ‘stoic’ in the face of illness (Hoffmann & Tarzian, 2001; van Wijk et al., 1996). In line with these findings, research has found that when men access health services, they tend to experience shorter visits, fewer and briefer health explanations, and less information regarding health risks and changing behaviours (Courtenay, 2000a, 2005; Govender & Penn-Kekana, 2008; Weisman & Tietelbaum, 1989). Therefore, while complex gender interactions exist regarding common perceptions of men and women’s health and their subsequent access to timely and quality care, masculinity norms have been attributed to more frequent delays among men in addressing health needs and accessing healthcare; especially for mental health concerns (Connell, 2012; Wilkins et al., 2008).

Contrary to early stereotypes that men do not seek help, more recent research has identified that the number of Australian men seeking help for mental health concerns has increased substantially in the last 15 years (Harris et al., 2015; Seidler et al., 2018). However, statistically, men continue to display high dropout rates from medical and mental health services and report that services frequently fail to fully engage them (Johnson et al., 2012; Pederson & Vogel, 2007). Factors contributing to low levels of engagement have been hypothesised to include a limited focus on men’s mental health in clinician training programs, deficit approaches to working with masculinities, and the potential for a ‘nurturance model’ approach (focusing on expressing emotional vulnerability) to trigger gender role conflict in some men (Addis & Mahalik, 2003; Seidler, Rice, Ogrodniczuk, et al., 2018).

However, health-related help-seeking in men has been identified as a complex and dynamic process that also varies substantially across individuals (Addis & Mahalik, 2003; Galdas et al., 2005). Ongoing developments in the field of gender and health research have noted the growing emergence of ‘multiple masculinities’, with increasing numbers of men contesting traditional norms and choosing to enact positive health practices (Anderson & McCormack, 2018; Connell & Messerschmidt, 2005; Creighton & Oliffe, 2010; Schofield et al., 2000; Sloan et al., 2010). In addition to gendered contexts, factors including men’s close interpersonal relationships (e.g., peer, partner and parental) can also impact health-related choices and behaviours (Creighton & Oliffe, 2010). Furthermore, in contexts where the health issue is perceived as normative (i.e., a common or shared experience), help-seeking is encouraged by others, or there is the opportunity to reciprocate or ‘give back’, men may be more likely to seek support for physical and mental health (Addis & Mahalik, 2003). Overall, more recently, authors have called for services to adopt “tailored, strengths-based and gender-sensitive approaches” (Seidler et al., 2018, p. 406) to maximise engagement, retention, and beneficial treatment outcomes among men (Johnson et al., 2012; Seidler et al., 2017).

This thesis drew upon masculinity theory to consider how socially-constructed gendered expectations may impact men’s experiences of grief and support after pregnancy loss and neonatal death. For example, as discussed in Section 1.2.3.4, the frequently identified theme in previous qualitative research of men’s role as a ‘supporter’ to their partner following pregnancy loss has previously been contextualised as a result of gendered “male role” expectations (Bonnette & Broom, 2012, p. 248; Miron & Chapman, 1994). In particular, the nationwide survey for Study 2 included two masculinity subscales to determine whether traditionally ‘masculine’ behaviours/expectations of self-reliance and ‘toughness’ were associated with men’s grief scores after pregnancy loss and neonatal death.

2.1.7.3 *Father-inclusive practice guidelines*

As discussed in Section 1.2.3.1, woman-centred care is an essential part of maternity and perinatal health services to ensure that the safety and wellbeing of birthing women and their babies are prioritised and upheld. However, given the frequency of men’s active involvement during pregnancy and childbirth – particularly in high-income countries – it is important to also integrate family-centred and father-inclusive approaches, where appropriate, to ensure the family unit as a whole can access support as needed (Fletcher et al., 2014). Healthcare approaches aimed at fathers are particularly important, in light of statistics demonstrating that one in 10 fathers experience depression and/or anxiety before or after the birth of their baby and that the highest risk of men’s suicide occurs during the perinatal period (Darwin et al., 2021; Healthy Male, 2020; Quevedo et al., 2011; Shorey & Chan, 2020).

Father-inclusive practice aims “to value and support men in their role as fathers, actively encourage their participation in programs, and ensure they are appropriately and equally considered in all aspects of service delivery” (Commonwealth of Australia, 2009, p. 9). However, research has recognised that implementing father-inclusive practice can be challenging, with various barriers reported by fathers, families and perinatal health professionals. For example, at an individual level, fathers may be “reluctant” clients due to perceptions of a maternal bias in service delivery (Fletcher et al., 2014). At a practice level, organisational policies, staffing structures and training can influence how practitioners engage with fathers. Generally, birth data collection excludes information on fathers, and there are not enough appropriate services to manage concerns regarding family and domestic violence and intervention with aggressive presentations (Department of Social Services, 2012; Zanoni et al., 2013). Finally, at a broader policy level, the availability and uptake of social benefits and parental leave differs for mothers and fathers (Alio et al., 2011; Cullen et al., 2011; Feeley et al., 2013); with 95% of primary parental leave in Australia taken by women (ABS, 2017).

Despite these difficulties, several facilitators to father-inclusive practice have also been identified to guide recommendations for health services, supportive intervention, and projects. While there are few published references in this area (particularly in the Australian context), key recommendations from Fletcher and colleagues (2014) and a recent report resulting from an Australian project by Healthy Male (2020) include:

- Adopting father-inclusive language, referring specifically to 'fathers' and including images of men in print/digital materials;
- Co-designing supportive initiatives with men/fathers who have diverse lived experiences;
- Including education on working with fathers in health-related undergraduate and postgraduate training courses;
- Actively encouraging men to attend reproductive appointments;
- Providing fathers-to-be with tailored antenatal education and information that addresses their needs and the needs of their families;
- Routinely screening new and expectant fathers for emotional wellbeing, including anxiety/depression, particularly for those experiencing infertility, loss of a baby or a traumatic birth;
- Ensuring availability of parental leave and flexible work arrangements, which are actively encouraged and modelled by organisational leaders.

In light of these suggestions and the increasing imperative to adopt family- or father-centred care (that is inclusive of all family structures, including single parents and gender and sexuality diverse parents), the design of this research, including advertisements for participation, survey and interview questions asked, themes explored, and resulting recommendations incorporated multiple aspects of father-inclusive practice. This approach aimed to maximise the potential involvement of men in the research, as well as produce outcomes that were relevant, helpful and appropriate to informing future research, projects and service provision. In the context of pregnancy loss and neonatal death more specifically, this framework was also used to explore how father-inclusive current pregnancy, birth, and loss and grief support services were, according to participants. In Studies 2 and 4 particularly, questions regarding participants' perceptions of feeling included in health and support services were purposively asked, and examined as a key part of the analysis.

2.1.7.4 *Models of support*

In a health context, research examining models of support has acknowledged that various types of support can be protective for individuals' physical and mental health outcomes. These include informational support, practical/tangible support, emotional support, and social support (Cutrona & Suhr, 1992; Glanz et al., 2008). Informational support refers to providing knowledge or facts, for example, through advice or feedback, to guide one's actions. Practical/tangible support refers to providing physical goods or services to address a need. Emotional support refers to expressions of care, concern, empathy, or sympathy received from others. Finally, social support refers to the benefits of belonging to a group, including receiving companionship or comfort from shared social experiences (Cutrona & Suhr, 1992; Glanz et al., 2008; Ko et al., 2013). Each form of support may serve a different function depending on the individual's need; in addition, not all offers of support will address public health goals or the recipient's ideals (Myers et al., 2021; Taylor, 2011). However, receiving social support is generally considered beneficial, through potential pathways including reducing biological inflammatory responses, encouraging positive health behaviours, and supporting emotional wellbeing through social connection (DiMatteo, 2004; Reblin & Uchino, 2008).

In relation to bereavement more specifically, it is important to acknowledge that not all individuals require or want professional support and intervention for their grief. While developed specifically in the context of palliative care, the Public Health Model of Bereavement Support (Aoun et al., 2012) outlines three ‘tiers’ relating to bereavement risk and need for support. The first tier (low risk group) may benefit from support predominately from family/friends to manage ‘normal’ bereavement; the second tier (moderate risk group) may benefit from support provided by wider community networks such as volunteer and peer support groups; and the third tier (high risk group) may benefit from support provided by mental health professionals (e.g., counsellors, psychologists) to manage symptoms of complicated bereavement (Aoun, 2020). The Public Health Model of Bereavement Support aims to provide an overview for providing cost-effective allocation of bereavement services, as well as tailored support to individuals based on need. In relation to pregnancy loss and neonatal death, public health approaches have recognised a need for community education and a ‘whole-hospital’ approach to support. Such an approach includes offering various opt-in services to bereaved parents such as annual remembrance services, psychoeducation, peer support groups, and referral to external specialised mental health assistance for those parents/families who experience persistent grief reactions (Mulvihill & Walsh, 2014).

With this framework in mind, this thesis sought to recognise and explore the various types of support available to men after pregnancy loss and neonatal death, including informational, practical/tangible, social, and systems/policy-level supports. As an overarching aim, I focused on identifying gaps in current supports in response to men’s expressed individual preferences and needs. I also acknowledged that in the context of highly varied and individualised grief experiences, it was likely that not all men would desire formal (or any) supports after pregnancy loss and neonatal death, and in addition, there would not be a 'one size fits all' approach to best practice support for men. These considerations were important in forming the final recommendations and conclusions from the research.

2.2 Study 1: Systematic review

In the initial stages of planning this program of research, a general review of the literature (outlined in Chapter 1) identified few previous studies exploring men's experiences of pregnancy loss and neonatal death, along with a lack of psychological theories to adequately describe their grief and contributing factors. In addition, at the time of study planning, no previous comprehensive systematic reviews had been conducted on men's grief following pregnancy loss *and* neonatal death, nor on factors contributing to grief (for men or women) following pregnancy loss and neonatal death. Therefore, the objective of Study 1 was to provide a solid foundation to begin to inform a more comprehensive understanding of men's experiences of grief and factors contributing to grief following pregnancy loss and neonatal death. A formal (and reproducible) systematic review method was chosen over a traditional narrative review to reduce the risk of bias and systematic error in the selection and synthesis of data and provide increased confidence in the findings.

2.2.1 Study design

The design of Study 1 was broadly guided by the Joanna Briggs Institute's series of papers on "Systematic Reviews, Step by Step" (Aromataris & Pearson, 2014). This approach was taken to ensure the features of the review aligned with internationally-approved definitions and standards of conduct. As outlined by Aromataris and Pearson (2014), the steps followed for this study were:

1. Clearly articulate the research objectives and questions (guided by the Population, Intervention, Comparison, Outcome [PICO] mnemonic; see Appendix 4);

2. Clearly identify inclusion and exclusion criteria to determine the eligibility of studies, stipulated *a priori* in the form of a protocol (see Appendix 5);
3. Conduct a rigorous search across relevant academic databases to identify *all* relevant studies, published and unpublished;
4. Complete a formal appraisal of the reporting quality of included studies, and report any exclusions based on quality;
5. Conduct appropriate analysis of the data extracted;
6. Present a synthesis of findings extracted from eligible studies;
7. Transparently report the methodologies used.

To further ensure quality in the research development and process, a research librarian with expertise in systematic reviews and psychology was consulted to review research questions, refine search terms/grids, and select appropriate academic databases to search. The four academic databases chosen (PubMed, PsycINFO, CINAHL and Embase) were deemed most relevant to the broad fields of health, psychology and nursing, under which research on pregnancy loss and neonatal death would be most likely to be classified.

Also aligning with internationally-recognised quality standards for systematic reviews, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed to guide and report the search and study inclusion/exclusion process. While the PRISMA guidelines were updated in 2020 (Page et al., 2021), the 2009 version of the guide (Moher et al., 2009) was followed for this study, as this was the most recent edition at the time of the research.

2.2.2 Quality rating and data analysis

Following initial study screening and selection according to the pre-specified inclusion and exclusion criteria, the reporting quality of the included studies was guided by the Critical Appraisal Skills Program (CASP) checklists (2017). The CASP checklists were chosen to guide the critical appraisal process due to the availability of checklists for multiple study designs; the final sample of included studies comprised qualitative and cohort studies, and one Randomised Controlled Trial (RCT).

The approach to data synthesis was guided by the data available in the included studies. Due to the mixed methodologies of the included studies and the exploratory nature of the research questions, the main approach to combining data took the form of a narrative synthesis; first to describe the experiences of grief, and second, to describe the factors contributing to grief. While the quantitative data available did not allow for meta-analysis, descriptive statistics (Means and Standard Deviations) could be collected from nine of the included quantitative studies to summarise the data relating to measures of grief after pregnancy loss/neonatal death. These data could be compared to historic normative data (Lasker & Toedter, 2000) to determine the severity of men's average grief scores (low, mid or high) across the included studies.

The synthesis of factors contributing to grief enabled a thematic approach, as the identified factors from included studies fell broadly into four categories: (1) individual factors, (2) interpersonal factors, (3) community factors, and (4) public policy/system factors. This categorisation resulted in the development and proposal of an emerging model of men's grief, which aligned with an adaptation of Bronfenbrenner's (1979) Ecological Systems Theory. As a result, this model of men's grief and contributing factors was used as a theoretical basis to guide the subsequent studies (see Chapter 3 for the published version of the systematic review, including a full description of the emerging model).

2.3 Study 2: National survey

Informed by the results of Study 1, Study 2 aimed to explore the individual, interpersonal, community and policy/system factors relating to men's grief after pregnancy loss and neonatal death in more depth, focusing particularly on under-explored factors and testing associations between these factors and men’s grief. In particular, it was identified in Study 1 that no previous studies had comprehensively explored the impact of a full range of individual, interpersonal, community or systems-related factors on grief in a single model, and none had explored factors relating to different grief styles. In addition, very few studies had been conducted in the Australian context; those that had comprised small sample sizes and/or had limited reach (e.g., confined to a single State/Territory or major city). Specifically, this study aimed to explore the factors associated with grief intensity following pregnancy loss and neonatal death, as well as the factors associated with intuitive and instrumental grief styles, in a sample of Australian men.

2.3.1 Study design: Web-based survey

The design of this study was a cross-sectional web-based survey hosted by the online platform *SurveyMonkey*. Compared to traditional paper-based or telephone surveys, web-based approaches have many advantages, including fast application, rollout and access to data; cost-effective data collection, entry and analysis; wide potential reach and access to specific or difficult-to-reach populations; convenience (participants can complete anytime, anywhere); and a higher degree of self-disclosure, particularly for sensitive topics (Albaum et al., 2015; Cantrell & Lupinacci, 2007; Duffy, 2002; Parsons, 2007; Sax et al., 2003; van Gelder et al., 2010). In the context of limited involvement of men in pregnancy loss and neonatal death research to date, web-based survey methodology was chosen for this study to (a) maximise potential reach (availability nationwide, including in major city and regional locations), and (b) provide an option to remain anonymous, and a convenient approach to collecting data on this sensitive topic of grief and loss. However, various potential limitations to online research methods also exist and required specific methodological considerations.

Two central concerns with web-based surveys are the potential for sampling bias and incomplete/non-response errors. It has been flagged that individuals who participate in self-selected web-based research do not necessarily accurately represent target population demographics, as participation may be biased toward individuals who have more extreme or invested responses (Duffy, 2002; Sax et al., 2003). In addition, given that participants complete the survey in an unknown environment, there will always be a degree of uncertainty regarding the accuracy of responses, as well as a higher likelihood of incomplete responses or missed items (Parsons, 2007; Sax et al., 2003). This research adopted quality control suggestions from previous research to assess the potential for sampling bias and incomplete response errors. Specifically, strategies included (1) collecting comprehensive demographic data as part of the survey for later analysis of any confounding variables (Duffy, 2002); and (2) requiring mandatory responses to essential survey items before participants could progress to the next page and submit their responses (Sax et al., 2003).

2.3.2 Survey content

The opening page of the survey provided the full study information required for informed consent. As mentioned above, participants then responded to a range of demographic questions and questions regarding the type of pregnancy loss/es or neonatal death/s they had experienced. If they had experienced more than one kind of loss, participants were asked to select one of their choice to focus on for the survey, with an option to comment later on other loss/es they may have experienced. Skip logic, a feature in *SurveyMonkey* that changes what question or page a respondent sees next based on how they answer the current question, was incorporated to tailor the survey questions to refer to the type of loss on which participants chose to focus. The remainder of the survey contained a combination of quantitative self-report measures – both standardised psychometric measures and author-developed – and qualitative open-ended questions, to assess men’s grief and factors potentially contributing to grief. A full description of the included measures is provided in

Chapters 4 and 5. However, an overview and rationale for the measures selected is outlined below. Appendix 12 contains a copy of the full survey.

2.3.2.1 *Grief measures*

Men’s grief was measured using the 33-item version of the Perinatal Grief Scale (PGS-33; Potvin et al., 1989). The PGS-33 is the most commonly used grief measure in studies examining parents’ grief after perinatal loss, assessing bereaved parents’ thoughts and feelings related to the death of their baby (Maniatelli et al., 2018; Toedter et al., 1988, 2001; Yan et al., 2010). While the PGS-33 has been widely accepted as a valid and reliable measure of perinatal grief (Lasker & Toedter, 2000), some studies (e.g., Barr, 2006; Conway & Russell, 2000; Franche & Bulow, 1999; Huffman et al., 2015) have noted that it may have limited validity among people (particularly men) who display instrumental, rather than intuitive, styles of grief as a number of the items are generally more directed toward outward grief expressions (e.g., crying, feeling a need to talk about the baby, feeling frightened). Early versions of the scale were also validated on samples comprising predominately of women (Toedter et al., 1988), and men have generally scored substantially lower on grief than women in previous studies using this measure (e.g., Alderman et al., 1998; Cope et al., 2015; Volgsten et al., 2018). While other measures of grief have been used in a pregnancy loss or neonatal death context, including the Grief Experience Inventory (GEI; Habler, 1988), the Texas Revised Inventory of Grief (TRIG; Faschingbauer et al., 1977), and the Revised Impact of Miscarriage Scale (RMIS; Huffman et al., 2014), these have either not been validated as extensively at the PGS in relevant samples, and/or also contain predominately intuitive-style items. Given the lack of available alternative measures to assess men’s grief, the PGS-33 was deemed the most appropriate for this study, in conjunction with an additional measure to assess grief style.

In addition to the above motivations, Study 1 identified that while men displayed highly varied styles of grief, no previous quantitative studies had included measures of grief that differentiated between instrumental and intuitive styles. In combination with the PGS-33, this study therefore also included the Grief Patterns Inventory-Revised (GPI-10; Lange et al., 2020; Martin & Wang, 2006). The GPI-10 includes 10 items to assess an individual's tendency toward an intuitive or instrumental grief style, with scores in the mid-range indicating a 'blended' style of grief. Including this measure allowed for additional analyses to explore the factors associated with different styles of grief in men and provided a comparator to the PGS-33.

2.3.2.2 *Factors contributing to grief*

Using the Socio-Ecological Model of Men's Grief from Study 1 as a theoretical basis, a range of measures reflecting individual, interpersonal, community and public policy/system factors were included to test the accuracy of this model and further explore which factors had the strongest associations to men's grief in an Australian sample. A particular priority of this study was to include measures of under-explored factors and more comprehensive measures of factors which had only previously been identified from single-item measures, or qualitatively.

Individual-level factors referred to characteristics immediate to the individual, including demographics, personality and attachment styles. For example, qualitative studies included in Study 1 indicated more intense grief reactions among men who described a strong attachment to their unborn/newborn baby (Armstrong, 2001; Bonnette & Broom, 2012; McCreight, 2004; Murphy, 1998; Obst & Due, 2019a; Samuelsson et al., 2001; Wagner et al., 2018). In quantitative studies included in Study 1, men's attachment to their babies had only been previously explored through proxy measures, including increasing gestational age of the baby (Cope et al., 2015; Franche, 2001; Huffman et al., 2015; Puddifoot & Johnson, 1999;

Rich, 2000), whether men had viewed an ultrasound image of their baby (Puddifoot & Johnson, 1999), and whether men had held their baby after birth (Wilson et al., 2015). In recognition of the various ways men can form attachments with their unborn/newborn babies (e.g., through everyday interactions), a more comprehensive measure of attachment, the 16-item Paternal Antenatal Attachment Scale (PAAS; Condon et al., 2013; Condon, 1993), was therefore included in this study.

Interpersonal-level factors referred to the influence of men's interactions with immediate others, including their partner, family and friends. One of the most consistent themes arising at this level in qualitative studies concerned (heterosexual) men's role as primarily a 'supporter' to their partner. In most studies, the 'supporter role' was positioned as a factor that interfered with men's grief by taking precedence over their own emotional needs (Bonnette & Broom, 2012; McCreight, 2004; Miron & Chapman, 1994; Obst & Due, 2019b; O'Leary & Thorwick, 2006; Samuelsson et al., 2001; Wagner et al., 2018). However, a small number of studies also described benefits in adopting this role, particularly for instrumental grievers who found a sense of purpose in providing this support (Armstrong, 2001; Hamama-Raz et al., 2010). To provide opportunity for a more nuanced exploration of the impact of the 'supporter role' on men's grief, two author-developed measures were included, asking participants to rate on a five-point Likert scale their agreement with (1) experiencing their role as a 'supporter', and (2) the extent to which they believed the 'supporter role' interfered with and/or altered their grief.

Study 1 also highlighted that men's experiences of receiving support from family/friends varied greatly. Included qualitative studies detailed positive and negative experiences and indicated a need for men to receive practical (tangible) and emotional supports (Abboud & Liamputtong, 2005; Murphy, 1998; Obst & Due, 2019a; Samuelsson et al., 2001; Wagner et al., 2018). Again, no previous quantitative studies had included a comprehensive measure of men’s support experiences. In line with overarching frameworks regarding models of support (outlined in Section 2.1.7.4), the seven-item Crisis Support Scale (CSS; Elklit et al., 2001) was chosen for use in this study as a comprehensive measure of support, including items relating to the availability of others to listen, provide emotional support, and practical help.

Community-level factors in the Socio-Ecological Model referred to the influence of wider cultural norms and attitudes toward men, grief and pregnancy loss/neonatal death. At the community level, factors identified in Study 1 included disenfranchisement of men’s grief and the impact of gendered attitudes/expectations on men’s expression and management of grief. These themes were explored only by qualitative studies and not measured in quantitative studies. In the context of men experiencing disenfranchised grief, participants in included studies described experiences of stigma and silence (particularly surrounding miscarriage and stillbirth; Kelley & Trinidad, 2012; Meaney et al., 2017), as well as dismissal or minimisation of their grief and/or role as a father, which led to increased distress and feelings of isolation (McCreight, 2004; Obst & Due, 2019a; Wagner et al., 2018; Weaver-Hightower, 2012). To address these themes, four five-point author-developed Likert scale measures were included to assess the extent to which men felt their grief was recognised by others (including their partner, family/friends, community, and healthcare professionals). These simple author-developed rating measures were selected, as existing measures for ‘recognition of grief’ could not be located.

In addition, gendered expectations noted in qualitative studies described experiences of needing to appear ‘strong’ and therefore hide outward grief expressions from others, which prevented many men from seeking support and added to a feeling of disenfranchisement (Abboud & Liamputtong, 2005; Bonnette & Broom, 2012; Campbell-Jackson et al., 2014; McCreight, 2004; Murphy, 1998; Obst & Due, 2019a; O’Leary & Thorwick, 2006; Wagner et al., 2018). While multiple scales exist in the literature to measure individuals' alignment to expressions of masculinity (e.g., see: Thompson et al., 1992; Thompson & Bennett, 2015), the selection of measures for this study was guided by evidence to support the validity/reliability of the scales, as well as the relevance of scale items to the themes identified in Study 1. Reflecting gendered pressures experienced by men to cope with their grief in isolation, the *Self-Reliance* subscale from the Conformity to Masculine Norms Inventory (CMNI; Mahalik et al., 2003) was included in this study. In addition, the *Toughness* subscale from the Male Role Norms Inventory-Short Form (MRNI-SF; Levant et al., 1992, 2013) was also included to address social expectations to be 'strong' or 'tough' in the face of loss. Both the CMNI and MRNI-SF are widely used measures in the field of masculinities and have been found to have sound psychometric properties (Thompson & Bennett, 2015). While using the full scales would provide a more detailed measure of participants' masculine ideologies, the subscales were deemed the most relevant to the themes identified in Study 1 and chosen to reduce respondent burden.

Finally, policy/system-level factors referred to the influence of wider systemic structures and institutional policies on the grief experience. Study 1 identified two important policy/system level factors: (1) leave provisions and psychosocial support men received from their workplace after their loss, and (2) perceived inclusion as a man/father in the hospital during/after the birth of their baby. These two factors were identified from themes in qualitative studies and had not been measured previously in quantitative studies. Studies suggested that many men felt isolated in the woman-centred nature of the hospital environment and community bereavement support services (McCreight, 2004; Samuelsson et al., 2001; Turton et al., 2006) and frequently returned to work soon after the death of their baby as access to bereavement/parental leave was not readily available (Obst & Due, 2019a; O'Leary & Thorwick, 2006; Weaver-Hightower, 2012). To further explore the association between these experiences and the intensity of men’s grief, participants in this study were asked if they were employed at the time of their pregnancy loss or neonatal death and whether they had contact with a hospital as part of the loss experience. If they responded ‘yes’ to these questions, a series of author-developed follow-up categorical response questions were displayed. In relation to the workplace, participants were asked: how soon they returned to work, whether they informed their employer of their loss, (if yes) whether they were offered leave, and (if yes) what type of leave they were offered. If they had contact with a hospital as part of their loss experience, they were also asked about the extent to which they felt included (from *not at all* to *extremely* on a five-point Likert scale) and whether they were offered information on grief for fathers (yes/no). Two optional open-ended questions were also provided for participants who wished to provide further details on their experiences of returning to work or inclusion in the hospital (details below).

2.3.2.3 *Open-ended questions*

In recognition of the highly varied nature of grief for individuals and to further explore under-researched factors, a range of optional open-ended questions were also included in the survey. In survey research, open-ended questions can be advantageous in providing researchers with a deeper understanding of participants’ perspectives, which may lead to a more valid understanding of their experiences (Boruchovitch & Schall, 1999; Harland & Holey, 2011). This was deemed especially important in the context of a lack of previous research on men’s experiences of pregnancy loss and neonatal death.

Firstly, open-ended questions were included to explore aspects of men’s experiences of returning to work following their loss, as this area had been particularly under-explored by previous research. Men were asked one of two optional open-ended questions, depending on whether they indicated that they had returned to work following their loss. Men who had returned to work were asked: ‘In your opinion, could your workplace have offered anything else to make your transition back to work easier?'. Men who did not return to work were asked: 'Can you tell us why you did not return to work?'.

Two open-ended questions also asked participants for further details about their experience of support at the hospital, in line with the aim of the wider program of research to aid the development of men-specific recommendations in this setting. If participants attended a hospital as part of their loss experience, they were asked: "What was, or would have been, most helpful for you at the hospital?" and "Do you have any further comments about your experience at the hospital?".

To further explore men's experiences of potential stigma and added disenfranchisement identified in Study 1, following rating their perceived levels of recognition from their partner, family members, friends, community and health professionals, they were asked: "Do you have any further comments about these questions [on recognition for grief]?". In addition, in line with the aim to explore the impact of loss types on experiences, if participants had experienced more than one pregnancy loss or neonatal death, they were asked whether they would like to comment about other loss/es in terms of grief, support, or anything else they felt is important. This question was also specifically incorporated from consultation feedback (outlined in Section 2.3.3 below).

Finally, in recognition that the selected measures may not capture every important aspect of participants' grief experiences, participants could provide additional feedback on the survey content via two optional open-ended questions at the end of the survey. Questions were: "Is there anything else you would like to add/say in regards to your experience following pregnancy/neonatal loss that you feel this survey has not covered?" and, "Do you have any feedback on this survey?". While it is acknowledged that the findings from open-ended questions are potentially biased toward participants who self-select to respond to these questions (Holland & Christian, 2009), and can be limited in context and understanding if responses are brief (Boruchovitch & Schall, 1999), the potential benefits of this additional data were deemed worthwhile by the research team and reference group members.

2.3.3 Consultation and piloting

While selecting measures for inclusion in the survey was guided by the Socio-Ecological Model of Men's Grief and the evidence base from the literature, extensive consultation was also sought from the research reference group to guide the survey design, wording, and selection of measures. Initially, preliminary discussions were held with individual members of the reference group concerning the types of measures used and questions to be asked, in line with the findings from Study 1. In general, there was a high level of support from members about focusing the survey on factors included in the Socio-Ecological Model of Men's Grief. However, a key suggestion in the early stages was to ensure the length of the survey remained as short as possible, as members felt that motivation to complete the survey would be low if it went beyond 20-30 minutes. This feedback was a key driver to minimising the number of full-scale measures included in the survey. With this initial feedback, a full survey was drafted and entered into the online platform.

In the two successive stages of consultation, members of the reference group assisted with piloting the first and second drafts of the survey before it was finalised for distribution. Individual members of the reference group reviewed updated drafts of the survey in full and were invited to provide suggestions for revision. Major suggestions for revisions included:

- Asking participants who had experienced multiple pregnancy losses and/or neonatal deaths to focus on one loss for most of the survey. Questions in the original draft survey were not originally targeted to a specific loss and were therefore confusing to answer if the individual had experienced multiple losses. Additionally, the reference group indicated that there should be choice regarding the type of loss participants choose to focus on – that is, it need not necessarily be their *most recent* loss but could be the one that impacted them the most;

- Deleting ‘do you have a history of mental health concerns?’, given various understandings of what constitutes ‘mental health’. (*Note*: after discussion with the research supervisors, it was also decided that since mental health history was not identified as a factor from Study 1, it was not imperative to include);
- Adding a question about whether men informed their workplace of the loss, as anecdotal evidence suggested many men do not (and therefore would not have access to leave or psychosocial support) – if men did not inform their workplace, using skip logic to bypass further questions on the workplace;
- Given the length of the survey, provide an option for participants to ‘take breaks’ by saving their progress and coming back to complete the remainder of the survey later;
- Providing an option for participants to provide their email address to receive a copy/summary of the results of the research (further details about communicating study results to participants and dissemination of the research is discussed in Chapter 7).

All of the above suggestions were addressed in appropriate revisions to the final survey. Two members of the reference group also raised additional concerns regarding the wording and validity of some of the PGS-33 items. For example, they expressed confusion in the meaning of item 32, “I felt like a second-class citizen”, and felt that item 33, “It feels great to be alive”, would be difficult to answer given that the grief experience can be an up/down process and does not exist on an all-or-nothing spectrum. However, given that the PGS-33 is an established and validated measure of grief, the wording of problematic items was unable to be altered. Instructions for the scale include clarification that there are no ‘right’ or ‘wrong’ answers, and participants should provide a ‘best indication’ that feels right to them (Potvin et al., 1989).

Overall, although major concepts included in the original draft of the survey remained unchanged, the ordering, inclusion, and wording of questions, and final measures selected, were edited and refined according to the reference group members' feedback. The focus of changes was predominately to ensure sensitivity in language and ease of understanding for a range of potential audiences (e.g., acknowledging various educational levels and backgrounds). All reference group members approved the final survey before distribution.

2.3.4 Sampling procedure

In line with recommendations from the research reference group members, information about this study for recruitment was distributed predominately through the social media platforms, websites, and newsletters of national pregnancy loss and neonatal death community support organisations. These included Pillars of Strength, Bears of Hope, Sands Australia, Still Aware, Miracle Babies Foundation, SIDS and Kids SA, and the Australian Perinatal Loss Centre. This approach was not only used specifically to target the highly relevant audiences of these platforms (bereaved parents and families), but also aimed to ensure that participants who took part had an awareness of, and/or were already connected to, community support options should they experience emotional distress from responding to the survey. However, to maximise potential reach via passive snowball sampling, privacy limits were not placed on social media posts to allow sharing of the research by individuals who wished to do so.

In the context of previous research, which has noted difficulty recruiting bereaved men to pregnancy loss research, particular consideration was also given to the wording used to promote the study in line with family-centred and father-inclusive practice recommendations (see Appendix 1 for the Study Flyer). The Study Flyer was designed to specifically target men/fathers instead of 'parents' more generally. It utilised wording to highlight the lack of previous research on men, and appealed to the broader potential outcomes of study participation, such as improving future support services for men. I developed the hashtag #MenGrieveToo to be positioned as the main heading of the flyer, aiming to explicitly recognise men's grief, given that it has been historically under-acknowledged.

Inclusion criteria for participation in this study were that participants identified as men, were aged 18 years of age or older, and had experienced pregnancy loss or neonatal death in Australia within the last 20 years. It was acknowledged that this 20-year timeframe would potentially be open to recall bias, as well as differences in experience due to societal and policy changes over time which may impact the availability of support and inclusion in the healthcare system. However, due to the emotional saliency of their loss, several bereaved parents in qualitative research have been able to report vivid details of events at the time – including up to 16 years later (e.g., DeFrain et al., 1996) – and efforts were taken in this research to conduct an analysis by time since loss to determine whether there were major differences in men's reports of their grief and support over time. In addition, this timeline was ultimately chosen to maximise the potential participant pool.

2.3.5 Data analysis

Study 2 involved using statistical analyses to explore associations between the quantitative measures of men's grief and various contributing factors. An informal review of men's responses to the open-ended questions was also undertaken to locate general themes of interest for Studies 3 and 4. A brief overview of the specific approach to analysis for Study 2 is outlined below, with further details also provided in Chapter 4.

2.3.5.1 *Statistical analysis*

Statistical analyses were performed using SPSS Statistics (Version 25). Once the online survey was closed, survey data was exported directly from *SurveyMonkey* into SPSS and cleaned in preparation for analysis. Consultation was sought with a health research statistician to assist with planning and conduct of the statistical analyses. In line with the research aims, it was suggested that three statistical models could be built. Specifically, each model would be used to explore associations between factors relating to grief (according to the socio-ecological model) and: (1) total grief scores, as measured by the PGS-33, (2) intuitive grief scores, measured by the GPI-10, and (3) instrumental grief scores, also measured by the GPI-10.

Given the variety of measures included in the study, which were selected *a priori* according to the Socio-Ecological Model of Men's Grief, a multivariable modelling approach to linear regression was deemed appropriate. Specifically, a generalized linear modelling approach was recommended to account for including multiple continuous and categorical measures in the study. In addition, given the nested form of the factors included in the Socio-Ecological Model of Men's Grief, a stepwise approach, including a backward elimination method (Sainani, 2014), was also recommended. Further details about this approach to analysis are provided in Chapter 4.

2.4 Study 3: Men's experiences of returning to work after pregnancy loss or neonatal death

Initial analysis of men's responses to the open-ended questions in the nationwide survey for Study 2 revealed that for many participants, returning to work after their loss and/or gaining access to approved leave to grieve the death of their baby was a substantial challenge. In addition, when conducting Study 2, recommendations from the 2018 Senate Inquiry into the Future of Stillbirth Research and Education in Australia were under discussion for policy change at Federal and State levels. Part of these discussions was a proposal to introduce up to 12 months of unpaid leave for all parents (mothers *and* fathers) who experience a stillbirth (e.g., see: Ireland, 2020). While a small number of previous studies had mentioned men's experiences upon returning to the workplace as part of wider explorations of the pregnancy loss experience (e.g., Campbell-Jackson et al., 2014; Miller et al., 2019; Obst & Due, 2019a; O'Leary & Thorwick, 2006; Watson et al., 2019; Weaver-Hightower, 2012), none had focused specifically on the types of leave or psychosocial supports available. Given the political climate at the time, an additional paper summarising findings from the nationwide survey on men's experiences of returning to work was deemed an important and timely contribution to the scant research literature in support of advocacy efforts toward positive social change.

Study 3 is presented in Chapter 5. The findings of this paper detail the results of a conventional content analysis of participants' responses to the open-ended survey questions relating to their experiences of returning to the workplace and descriptive statistics/chi-square tests to summarise the types of workplace leave offered to participants across loss types. A general outline of content analysis is provided below.

2.4.1 Content analysis

Content analysis was used to analyse participants' responses to the open-ended questions relating to their experiences of returning to work after pregnancy loss and neonatal death in the nationwide survey. Content analysis aims to "provide knowledge and understanding of the phenomenon under study" (Downe-Wamboldt, 1992, p. 314) and involves using a systematic process to classify text responses into categories that are representative of similar patterns or meanings. In the context of limited existing theory and research on men's experiences of grief, a conventional approach to content analysis was taken to describe participants' experiences (Hsieh & Shannon, 2005). In addition, an inductive approach was used whereby themes were identified from the text data itself, without imposing preconceived ideas from theory or previous research findings. The process of conducting conventional content analysis, outlined by Hsieh and Shannon (2005), was followed. Further details about the process undertaken is provided in Chapter 5.

2.5 Study 4: Qualitative interviews

While men who had experienced a TOPFA only represented 13% of the total sample in Study 2 (*N*=30), a review of these men's responses to the open-ended questions in the survey suggested that they experienced specific challenges regarding grief, including added societal stigma and judgement from others toward the decision to terminate the pregnancy. Previous research among women who have experienced TOPFA echoes these findings (France et al., 2013; Hanschmidt et al., 2018; Irani et al., 2019) and has also indicated high levels of grief and trauma symptomatology among parents, potentially continuing for years following the loss (Kersting et al., 2005; Nazaré et al., 2014). While a small body of studies had previously focused on men's experiences of miscarriage and stillbirth, very few studies had specifically examined men's experiences of grief and support following TOPFA. Therefore, the final study for this program of research sought to address this gap.

2.5.1 Study design

This study was qualitative in design, involving individual semi-structured interviews with participants. An interview protocol was developed to guide the interviews (see Appendix 6). Questions in the protocol were informed by the major concepts and themes identified in Studies 1 and 2, as well as our previous studies on men's experiences of pregnancy loss (Obst & Due, 2019a, 2019b), and a small body of literature which had explored men's experiences of TOPFA (e.g., Carlsson & Mattsson, 2018; Kecir et al., 2020; Sun et al., 2018). In addition, the interview protocol was tailored for each participant according to their responses to the Study 2 survey. For example, if they had indicated in the survey that they were not employed at the time of their loss, this was verified in the interview and subsequent questions regarding return-to-work experiences were not asked.

2.5.2 Sample and procedure

At the end of the Study 2 survey, participants were offered the opportunity to express interest in participating in a follow-up interview to explore their experiences of grief and support after their loss in more depth. A total of 126 participants expressed interest in an interview and provided an email address for follow-up contact. Of these, 21 had experienced a TOPFA. Emails were sent to these participants, thanking them for participating in the survey and providing details on the interview study (see Appendix 7 for the follow-up email), including the Participant Information Sheet (Appendix 2) and Consent Form (Appendix 8). Eleven (52%) of these participants responded to the email to confirm their interest in participating in an interview. The remainder were sent a second follow-up email two weeks later; non-response was stated to be taken as an indication that they no longer wished to participate in an interview. None of these remaining survey participants responded to the second email.

Interview dates and times were organised over email with each of the remaining 11 participants. One participant who had originally responded to the follow-up email with interest later declined to participate, as he felt it would be too emotionally distressing. In line with the distress protocol outlined in Section 2.1.6, follow-up correspondence was provided to ensure this participant’s safety, and details of 24/7 telephone support services were provided to him. Interviews were completed with the remaining participants, resulting in a final sample of ten (see Chapter 6 for further details).

2.5.4 Data analysis

Following transcription of the interviews, thematic analysis was used to analyse the data (Braun & Clarke, 2006, 2013, 2019). Thematic analysis is a widely used and flexible form of qualitative data analysis, which involves identifying, analysing and reporting reoccurring patterns or themes within text-based data (Braun & Clarke, 2006). Further details on the process of TA are provided in Chapter 6. While I completed the initial phases of data analysis, the research supervisors and research participants were involved in the final analysis phases to improve the consistency and trustworthiness of the final thematic structure. As a criteria for publishing this study in the *Journal of Clinical Nursing*, the consolidated criteria for reporting qualitative research (COREQ) guidelines were also followed as a quality control measure (see Appendix 9).

2.6 Synthesis of information

In addition to synthesising the findings from qualitative and quantitative data within the individual studies for this thesis, an important final step for the program of research was to complete a cross-study synthesis to develop overarching conclusions and recommendations to inform future service provision for men (Kavanaugh et al., 2011). Specifically, the synthesis process involved conducting a comparative analysis of the main findings from each of the four studies, focusing broadly on the identification of common themes and patterns of convergence or divergence between the experiences and needs expressed by men, factors identified as contributing to grief, and available bereavement care support services. As part of this process, the synthesis enabled the identification of current services that matched men’s needs, as well as remaining gaps regarding aspects of men’s grief that may have been previously overlooked or unknown. This final and additional layer of data synthesis facilitated an in-depth analysis regarding the theoretical and practical implications of the findings (Kavanaugh et al., 2011). Results from this synthesis, including suggestions for future service provision and research, are presented in the discussion (Chapter 7).

CHAPTER 3. PAPER ONE

Men’s grief following pregnancy loss and neonatal loss: A systematic review and emerging theoretical model

3.1 Preamble

Given a lack of existing psychological theories to comprehensively describe men’s grief and contributing factors, the first study of this thesis was a systematic review exploring men’s experiences of grief, and factors contributing to grief, after pregnancy loss and neonatal death. The aim of this study was to provide a solid theoretical foundation to inform a more comprehensive understanding of men’s grief, through a formal and reproducible method. This Chapter presents the paper that resulted from this study, which was accepted for publication in January of 2020 with the academic journal *BMC Pregnancy and Childbirth*. Please note that the references for this paper are formatted in Vancouver style, as per requirements for publication with *BMC Pregnancy and Childbirth*. A separate reference list for this paper is therefore provided at the end of the manuscript.

3.2 Statement of authorship

Title of Paper	Men’s grief following pregnancy loss and neonatal loss: A systematic review and emerging theoretical model
Publication Status	☑ Published ☐ Accepted for Publication ☐ Submitted for Publication ☐ Unpublished and Unsubmitted work written in manuscript style
Publication Details	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, 11. https://doi.org/10.1186/s12884-019-2677-9

Principal Author

Name of Principal Author (Candidate)	Ms Kate Obst

Contribution to the Paper	Conceptualised the study, formulated research questions and search terms, performed searches, completed analysis on all articles, interpreted data, conceptualised the model, wrote the manuscript and acted as corresponding author.		
Overall percentage (%)	85%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	2 February 2022

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Associate Professor Clemence Due		
Contribution to the Paper	Supervision and input regarding development of research questions search terms and research protocol, selection of articles for inclusion in the review, and analysis of a sub-set of data. Contributed to data interpretation and conceptualisation of the emerging model. Provided editorial and structural feedback on the manuscript.		
Signature		Date	26 January 2022

Name of Co-Author	Dr Melissa Oxlad		
Contribution to the Paper	Input regarding development of research questions, search terms and research protocol, involved in selection of articles for inclusion in the review. Contributed to data interpretation and conceptualisation of the emerging model. Provided editorial and structural feedback on the manuscript.		
Signature		Date	27 January 2022

Name of Co-Author	Professor Philippa Middleton		
Contribution to the Paper	Input regarding study design, search terms and research protocol, and selection of articles for inclusion in the review. Contributed to data interpretation and conceptualisation of the emerging model. Provided editorial and structural feedback on the manuscript.		
Signature		Date	1 February 2022

3.3 Published paper

Abstract

Background: Emotional distress following pregnancy loss and neonatal loss is common, with enduring grief occurring for many parents. However, little is known about men's grief, since the majority of existing literature and subsequent bereavement care guidelines have focused on women. To develop a comprehensive understanding of men's grief, this systematic review sought to summarise and appraise the literature focusing on men's grief following pregnancy loss and neonatal loss.

Methods: A systematic review was undertaken with searches completed across four databases (PubMed, PsycINFO, Embase, and CINAHL). These were guided by two research questions: 1) what are men's experiences of grief following pregnancy/neonatal loss; and 2) what are the predictors of men's grief following pregnancy/neonatal loss? Eligible articles were qualitative, quantitative or mixed methods empirical studies including primary data on men's grief, published between 1998 and October 2018. Eligibility for loss type included miscarriage or stillbirth (by any definition), termination of pregnancy for nonviable foetal anomaly, and neonatal death up to 28 days after a live birth.

Results: A final sample of 46 articles were identified, including 26 qualitative, 19 quantitative, and one mixed methods paper. Findings indicate that men's grief experiences are highly varied, and current grief measures may not capture all of the complexities of grief for men. Qualitative studies identified that in comparison to women, men may face different challenges including expectations to support female partners, and a lack of social recognition for their grief and subsequent needs. Men may face double-disenfranchised grief in relation to the pregnancy/neonatal loss experience.

Conclusion: There is a need to increase the accessibility of support services for men following pregnancy/neonatal loss, and to provide recognition and validation of their experiences of grief. Cohort studies are required among varied groups of bereaved men to confirm grief-predictor relationships, and to refine an emerging Socio-Ecological Model of Men’s Grief.

PROSPERO registration number: CRD42018103981

Keywords: men, fathers, grief, stillbirth, miscarriage, neonatal loss, systematic review

Background

The loss of a pregnancy through miscarriage or stillbirth, and the death of a baby within the first 28 days of life, are typically unexpected and highly distressing events for parents. In addition to processes of grief and bereavement, both pregnancy loss and neonatal loss can be complicated due to the additional loss of hopes for raising a child, and potential ambiguity regarding status as a parent [1-4]. Grief following both forms of loss can be described as disenfranchised [5]. This is due to a lack of social recognition for the unborn baby as a living individual, along with an absence of cultural norms and understanding about how to mourn the death of a baby [2, 6]. Societal norms may minimise the loss, particularly in the case of miscarriage [7].

Background and context

Global estimates indicate that miscarriage occurs for approximately one in four recognised pregnancies, while every year, 2.6 million babies worldwide are stillborn, and a further 2.8 million die within the first week of life [8-11]. The majority of these losses occur in low and middle income countries [11]. However, pregnancy/neonatal loss also remains a significant health burden in high income countries, where despite advances in medical technologies, rates of stillbirth have remained stagnant for over two decades [12-14].

Definitions of pregnancy loss according to gestational age vary considerably across countries, with over 30 different stillbirth classification systems identified across the literature [10, 15]. The World Health Organization (WHO) recommends a definition of stillbirth as a loss after 28 weeks’ gestation, whereas in the United Kingdom (UK) a stillbirth is classified after 24 weeks, and in the United States of America (USA), Canada and Australia, after 20 weeks [16-20]. Losses prior to these gestations are considered a miscarriage. Despite this variability, there is currently limited evidence to suggest that grief following pregnancy loss is affected by gestational age [3, 21-25].

Previous literature on grief following pregnancy loss and neonatal loss

Growing recognition of the impact of pregnancy/neonatal loss has led to increased research interest into the psychological and emotional burden on bereaved parents and families [26-28]. There is widespread consensus that grief is a multifaceted and highly individual process, although there may be general similarities. For example, early models of grief described common ‘stages’ of grief from shock or denial through to acceptance or recovery [29, 30]. The Dual Process Model of coping with bereavement [31] described an ongoing oscillation between ‘loss orientated’ (emotional) and ‘restoration oriented’ (problem-solving) coping strategies. Specific to bereaved parents, the continuing bonds model recognises the need for ongoing connections through symbolic objects, rituals, and sharing memories [32, 33]. Finally, research on gender and grief has found that due to social expectations surrounding how men should behave, men are generally less likely to outwardly display emotional reactions. Men may also experience more difficulty than women in seeking or accepting help for mental health concerns, grief, and adjustment to loss [34-36].

Following pregnancy/neonatal loss, men engage more frequently than women in compensatory behaviours (such as increased substance use), score higher on avoidance scales, and experience difficulty in approaching or accessing support services [37-41]. Despite these difficulties, the majority of previous research and subsequent pregnancy/neonatal loss bereavement care guidelines have been focused primarily on the experiences and needs of heterosexual mothers [42-45]. Fewer studies and recommendations relate to men’s experiences of grief and subsequent support needs. Given the potential for detrimental health and wellbeing outcomes among men following pregnancy/neonatal loss, it is essential to further understand how men grieve, and the factors that contribute to worsened or improved outcomes [21, 46, 47]. Recently, three reviews were published in areas relating to men’s experiences of pregnancy/neonatal loss. However, two of these were scoping reviews rather than systematic [48, 49], and the other thematically synthesised only qualitative studies on men's lived experiences of miscarriage [50]. This systematic review aimed to provide a comprehensive summary and appraisal of existing qualitative and quantitative literature on men's grief, following both pregnancy loss and neonatal loss. The study objectives were to identify (1) how men experience grief following pregnancy loss and neonatal loss, and (2) the factors and/or predictors that contribute to men's grief.

Methods

Data sources and search strategy

Following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [51], a systematic literature search of four online databases (PubMed, PsycINFO, Embase, and CINAHL) was completed in October 2018. Initially, preliminary searches were undertaken across the databases to identify potential subject headings and keywords. Following this, the final search strategies were developed in collaboration with an experienced research librarian (see Appendix 10 for search strategies).

Study selection

Inclusion criteria were qualitative, quantitative, or mixed methods studies, published between 1998 and October 2018, reporting the results of primary data on men's grief and/or predictors of grief following pregnancy loss or neonatal loss. By definition, this included the death of a baby at any stage in-utero, or up to 28 days after live birth. Exclusion criteria were articles not published in English, abstracts, editorials or opinion pieces, discussion or review articles not reporting primary data, and studies using a comparator (e.g., women) that did not present the data pertaining to men separately. Studies were also excluded if they investigated the grief experiences of men who had experienced an elective abortion or termination for viable foetal anomaly, as there is literature to suggest that these types of losses may lead to different psychological outcomes compared to other forms of pregnancy loss [52, 53].

Study yield

The database searches identified 1,529 potentially eligible studies. A further 23 articles were sourced manually from database-identified articles and systematic reviews [27, 37, 38], resulting in a total of 1,552 articles. Following removal of duplicates and screening, a total of 46 studies were selected for inclusion in the final analysis and were agreed upon by all authors (See Figure 1 for the PRISMA flow diagram). A random subset of 10% of potentially eligible studies was co-screened by all authors. Interrater agreement was high (K = .72 – .96, p <.05) with any discrepancies resolved by consensus discussion.

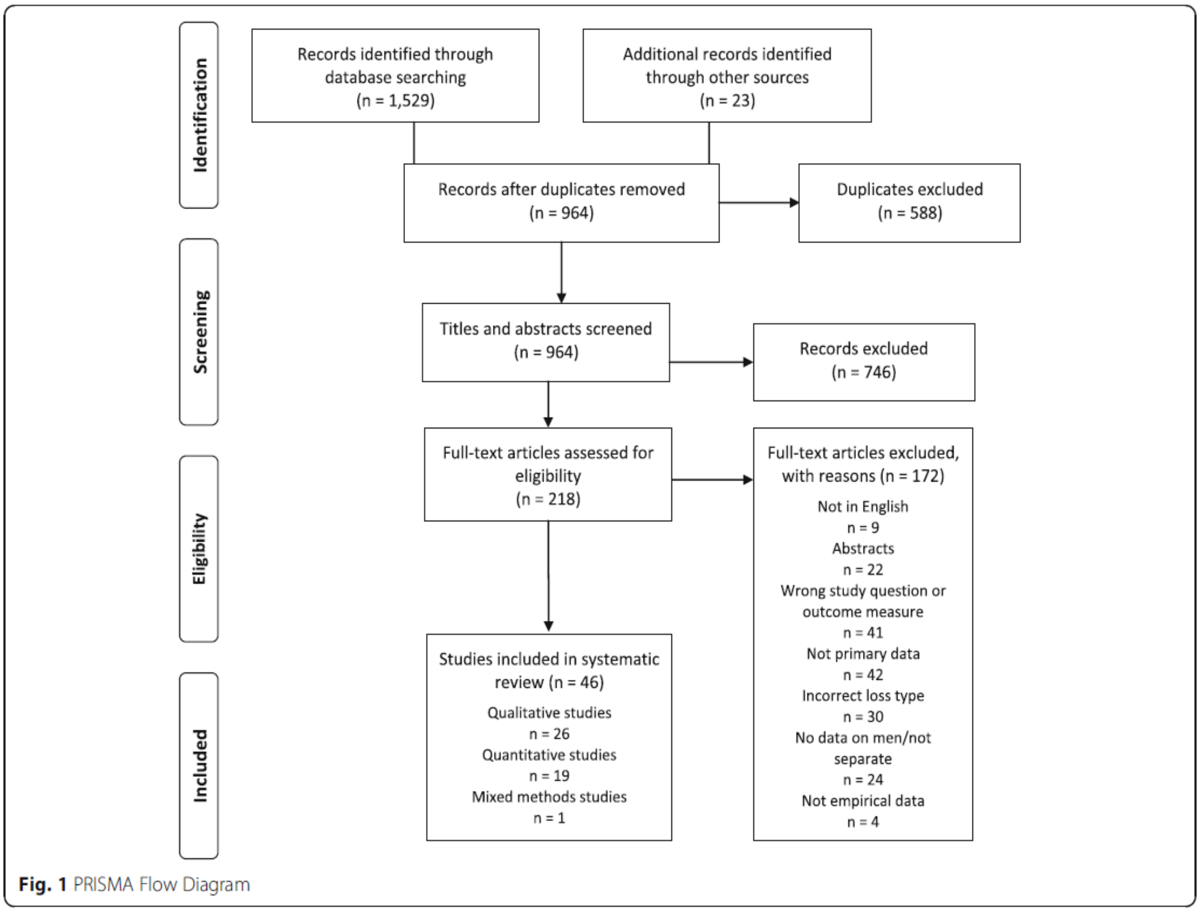

Fig. 1 PRISMA Flow Diagram

Figure 1. *PRISMA Flow Diagram*

Data extraction and study appraisal

The findings of the included articles were extracted by the first author using a predesigned data extraction form. The second author then cross-checked this information. The table items included research setting/country, date of publication, study design, number and characteristics of participants, key findings on men’s grief experiences, measures of grief, and/or predictors of grief. Study quality and risk of bias were assessed using the Critical Appraisal Skills Program (CASP) quality appraisal checklists [54] for qualitative studies, cohort studies, and randomised control trials (RCTs) where appropriate. The first author reviewed and rated all of the included studies, and the second author cross-checked a random sample (5%) of the same studies. Discrepancies between the reviewers were resolved through group discussions.

Results

Description of studies

Design

Nineteen papers were quantitative, 26 qualitative, and one used a mixed methods design [55]. For ease of discussing results in this paper, the mixed methods study was classified as qualitative, as the emphasis of reporting was clearly on this form of data. Thirty-nine studies were peer-reviewed papers, and seven were unpublished theses [56-62]. All but one of the included quantitative studies were variations of cohort designs, most commonly using structured questionnaires to assess grief. The remaining study was a RCT, examining the effectiveness of nurse-care and self-care interventions on grief following miscarriage [63]. Qualitative studies predominantly used individual semi or unstructured interviews. However, two studies used a postal [55] or online questionnaire [64], one used focus groups [65], and one was an autoethnography [66]. Details of each of the 46 studies can be found in Appendix 2. Table 1 provides an overview of studies by research design.

Focus

Twenty-one studies investigated grief experiences following miscarriage (definitions which ranged between ≤ 20-24 weeks’ gestation), 10 following stillbirth, and 15 following a combination of loss types. Two papers explored experiences following termination of

Table 1. *Overview of included studies*

	Quantitative (*n* = 19)	Qualitative (*n* = 26)	Mixed Methods (*n* = 1)	Total (*n* = 46)
Year of publication				
1998-2002	7	5	-	12
2003-2007	5	6	-	11
2008-2012	2	7	-	9
2013-2018	5	8	1	14
Region of study				
Australia	5	5	-	10
United Kingdom	3	3	-	6
United States and Canada	8	13	1	22
Europe	3	4	-	7
The Middle East	-	1	-	1
Informant group				
Men	3	13	-	16
Men and women	15	12	1	28
Men and service providers	-	1	-	1
Men, women and service providers	-	1	-	1
Total study sample size*				
10 or under	1	9	-	10
11-50	3	16	-	19
51-100	3	-	1	4
101-200	6	1	-	7
201-300	2	-	-	2
301-500	2	-	-	2
500+	2	-	-	2
Number of male participants				
10 or under	1	18	-	19
11-50	6	7	1	14
51-100	4	-	-	4
101-200	4	1	-	5

201-300	-	-	-	-
301-500	3	-	-	3
Unspecified	1	-	-	1
Loss type				
Miscarriage	9	8	-	17
Recurrent miscarriage (3+)	1	1	-	2
Stillbirth	1	8	1	10
Neonatal death	-	-	-	-
Medical termination for nonviable anomaly	1	1	-	2
Combination (pregnancy and neonatal losses)	7	8	-	15
Primary outcome focus				
Grief	16	5	1	22
Other	3	21	-	24

*Numbers only report the number of participants who experienced a pregnancy loss or neonatal loss

pregnancy for nonviable (or lethal) foetal anomalies [67, 68]. No papers focused exclusively on neonatal death. Twenty-three studies (16 quantitative and seven qualitative) focused on grief as a primary outcome. The remaining included elements of grief secondary to general explorations of experiences of loss, including ‘meaning’ [69], ‘impact’ [46] and ‘emotional responses’ [70] among others [23, 57-59, 64, 65, 68, 71-83]. Two qualitative [73, 74] and two quantitative [24, 84] studies also investigated grief following pregnancy loss that continued into a subsequent pregnancy or after the birth of a child.

Participant characteristics

Twenty-two studies were based in the USA and Canada, 10 in Australia, six in the UK, and seven in Europe (six Swedish). One study was based in the Middle East [69], one interviewed African-American couples [77], and another two interviewed Australian couples who were born in the Middle East [71, 72]. The majority of participants across remaining studies were Caucasian, with those including mixed ethnicities providing little to no discussion on cultural or ethnic background. All studies were conducted in high-income countries, and male participants were heterosexual men who experienced pregnancy loss with a female partner. With the exception of six studies that did not specify men's marital status [64, 65, 79, 80, 85, 86], the majority of male participants were in a relationship with the partner they were with at the time of loss. Sixteen studies recruited only men [25, 46, 57, 58, 60, 61, 64, 66, 70, 75, 80-83, 85, 87]. The remaining studies included men as participants in conjunction with their female partner.

Samples sizes varied widely, from one (an autoethnography) [66] to 131 men [64] in qualitative studies, and nine [70] to 341 men [23] in quantitative studies (see Appendix 11 for details). Thirteen studies reported age and standard deviations (*SD*s) for male participants [23-25, 56, 60, 61, 73, 84, 87-91]. Across these, the average age of 1,052 men was 33 years (pooled *SD* = 8.74). The remaining studies either did not report male participant ages [64-66, 68, 71, 72, 78, 79, 82, 92], combined men's ages with women's [63, 69, 74, 76, 86, 93], or provided an average age and/or range [46, 55, 57-59, 62, 67, 70, 75, 77, 80, 81, 83, 85, 94-96]. The youngest participant was aged 20 years [70], and the oldest 61 years [57] at the time of study participation.

Quality of included studies

An assessment of quality was undertaken for each study using CASP checklists [54]. Study quality varied, however the overall standard was acceptable and therefore no studies were excluded based on poor quality. With the exception of 12 studies, [25, 55, 68, 81, 86, 88-90, 92, 94-96], almost all studies used convenience, purposive or snowball sampling to recruit participants. While ethically justified given the sensitive nature of the research, the results may therefore not be representative of all men bereaved to pregnancy/neonatal loss more broadly. This is further indicated by the narrow range of variability in participant characteristics. All studies adhered to appropriate ethical standards including obtaining informed consent, protecting participant anonymity through identification numbers or pseudonyms, and offering contact details of pregnancy/neonatal loss support services to bereaved parents in case of distress. However, 10 studies did not state whether institutional ethical approval had been sought or obtained [25, 46, 79, 82, 83, 86, 87, 91, 93, 94]. Two studies also acknowledged potential conflicts of interest relating to the first author being the developer of the intervention under investigation [63], and another employed by the bereavement service being evaluated [92]. Otherwise, no additional conflicts were declared by study authors or identified as a result of quality rating.

Qualitative studies were generally of a high standard, with methodologies and analyses (content [46, 55, 60, 64, 69], thematic [61, 65, 71, 72], grounded theory [59, 62, 68], autoethnographic [66], descriptive [83] and phenomenological [56-58, 73-75, 77-82]) clearly reported and justified in the context of 'exploratory' or 'understanding lived experience' research aims. Quantitative studies reported either correlational and regression analyses [24, 67, 76, 86, 88, 90, 92, 93], or group difference tests [23, 25, 76, 84, 87, 89, 91, 94-96], including significance testing of resulting relationships or differences. However, one small quantitative study reported only numbers and percentages of participants who endorsed a particular feeling relating to grief or service outcome [70], and another reported percentages of participants who had received certain support services following a loss [95].

With the exception of one study which employed author-developed measures of grief and support service satisfaction [70] the remaining quantitative studies employed standardised and validated measures for both predictors and grief [23-25, 67, 76, 84, 86-96]. However, there was an inconsistency in the use of grief measures and reporting grief. Although 13 studies used the Perinatal Grief Scale (PGS) as a primary measure of grief, some reported average total grief scores [67, 88, 90, 93, 95], others average subscale scores [84, 96], both [25, 87, 91], or subscale correlations to predictor variables [24, 89]. Finally, 17 studies also grouped together different types of loss as part of the investigation of grief (e.g., miscarriage and stillbirth, stillbirth and neonatal death, or all three types together) [24, 46, 57-61, 73, 77, 80, 83, 84, 86, 88-90, 93]. As a result, outcomes specific to these different loss groups may have gone unrecognised. Only two studies specifically discussed differences in support and grief between miscarriage and stillbirth [46, 61].

Findings relating to the grief experience

Quantitative studies

Thirteen quantitative studies used the PGS as the primary measure of grief [24, 25, 67, 84, 87-93, 95, 96]. Other grief measures included the Grief Experience Inventory-Loss Version (GEI-L) [94], the Revised Impact of Miscarriage Scale (RIMS) [23, 76, 96], the Miscarriage Grief Inventory [63], and the Texas Revised Inventory of Grief (TRIG-F) [86]. Although primarily a measure of stress rather than grief, three studies also used the Impact of Events Scale (IES) [67, 91, 94].

Of the 12 quantitative studies that provided raw grief scores for men, outcomes varied considerably both between studies and within them [23, 25, 67, 76, 84, 87, 88, 91, 93-96]. This was indicated by wide range and *SD*s. Average total grief scores for men in studies using the PGS varied from 36 [93] to 133.19 [95] from a possible range of 33 to 165. However, the majority of average total PGS scores across remaining studies were between 73 and 83, with *SD*s ranging between values of 16 and 22 [25, 87, 88, 91, 93]. Population norms suggest that total grief scores above 91 for the PGS are reflective of a high degree of grief [97]. The outcomes reported across studies here (with the exception of one study [96]) indicate that men typically are not scoring in the highly significant grief range. However, they are nevertheless scoring quite highly in general [25, 67, 84, 87, 88, 91, 93] (see Table 2 for a comparison of studies reporting total *M* and *SD* scores for the PGS). Similarly, for three studies using the RIMS as a measure of grief, outcomes also varied with subscale scores ranging from 0-57 [96], 5-24 [76], and subscale *SD*s up to 4.08 [23].

This variation in grief scores may be due to inconsistencies in the timing of grief measurement. Time since the loss varied from one week in one study [96], to 32 years in another [67]. Overall, it was not clear whether increased time since the loss led to reduced grief in men (see Table 2). However, some studies also noted that even when the losses had occurred many years in the past, participants' grief had not necessarily diminished with time [55, 67, 79, 83].

In nine of 10 studies which compared men and women, men's grief scores were significantly lower or less intense than those of women [67, 94, 96]. This was indicated by approximately 20 points of difference on the PGS and IES [88, 91, 93], and 3 points of difference on the RIMS [23, 76]. Importantly, however, some studies noted that the use of existing grief measures (including the PGS and RIMS) might not be valid for measuring men's grief experiences, particularly in relation to potential differences between internal versus external grieving styles [23, 84, 89, 95]. There were mixed findings in terms of overall scale scores across similar studies looking at grief following miscarriage, with Despair (internalised grief) scores higher in men than those for Active Grief (externalised grief) in two studies [87, 95], and lower in the remaining two [91, 96]. Across other grief measures, men scored highly on the Devastating Event (RIMS), Denial and Social Desirability (GEI-L), and Avoidance (IES) subscales [23, 76, 91, 94, 96]. This may represent some of the more inward responses to loss involved in some men's grief experiences.

Qualitative studies

In 14 qualitative studies, men reported that the loss of their baby was a significant life event, regardless of gestational or neonatal age [46, 57-62, 66, 73, 75, 79, 81, 82, 85]. However, other men in 10 studies (some overlapping with the above 14 studies) also reported less intense reactions, including stating that their partners experienced worse grief in comparison to them [56, 61, 69, 71-75, 78, 79]. Regardless of grief intensity, in 14 studies men seemed to face additional or unique tasks and challenges that complicated their experience, or delayed the timing of grief. These included a sense of helplessness or powerlessness (especially during labour) [66, 69, 75, 79, 81], and responsibilities such as caring for other children, completing paperwork, organising a funeral/burial, and informing family and friends [46, 57, 58, 61, 62, 66, 80-82].

Although the grief experience was highly varied, and subsequent grieving styles mixed, there was a general trend among male participants towards instrumental grieving, which included the use of active or problem-focused coping strategies [55-62, 65, 66, 70-75, 77-82]. ‘Keeping busy’ and ‘moving forward’ were common desires [55, 59, 73, 77, 78, 80], with men seeking out distractions including sporting activities or increased exercise [58, 59, 62], returning to work [57-61, 72, 74, 79, 80], completing household tasks [58, 61, 73, 81], and creative, hands-on outlets such as woodworking, painting or writing [57, 58, 66]. However, men in 10 studies also reported outward emotional grief expressions such as crying. Although, these were frequently kept private, with many men preferring to grieve independently and alone [46, 56-59, 62, 66, 81, 82, 85].

Findings relating to predictors of men’s grief

Of the included quantitative studies, 16 included an analysis on predictors of men’s grief and/or correlations to related factors [23-25, 67, 76, 84, 86-93, 95, 96]. As part of a wider exploration of grief, all qualitative studies also discussed factors that contributed (both positively and negatively) to men’s grief. Overall, a wide range of varied predictors/factors were considered, which fell broadly into four domains or levels: (1) individual/person-level factors; (2) interpersonal factors; (3) community/socio-cultural factors; and (4) public policy factors.

Table 2. *Comparison of total grief scores on the Perinatal Grief Scale*

Scale	**Study**	**Loss type**	**Time point** (*n*)	**Mean** (*SD*)	**Overall classification** (degree of grief based on normative data)^
Perinatal Grief Scale (total scores)	Barr (2004)	Stillbirth (≥ 20 weeks gestation) or neonatal death (≤ 28 days from birth)	One month post-loss (*n* = 72) 13 months post-loss (*n* = 69)	82.7 (20.73) 71.9 (24.57)	Mid Low
	Conway & Russell (2000)	Miscarriage (losses occurred between 5 and 16 weeks of gestation)	Within 3 weeks of loss (*n* = 32) 2-4 months post-loss (*n* = 16)	133.19 (18.98) 136.31 (24.11)	High High
	Franche & Bulow (1999)	Perinatal loss (losses occurred between 10 to 42 weeks of gestation)	Pregnant subsequent to loss group: 1-31.5 months post-loss (*n* = 24)	74.66* (7.16*)	Low
			Loss group (not currently pregnant): 2-19 months post-loss (*n* = 18)	75.11* (5.8*)	Low
	Johnson & Puddifoot (1998)	Miscarriage (< 24 weeks of gestation)	Within 11 weeks post-loss (*M* = 5.5 weeks; *n* = 158)	78.4 (22.7)	Mid
	Puddifoot & Johnson (1999)	Miscarriage (≤ 20 weeks of gestation) or stillbirth (> 20 weeks of gestation)	NR (*n* = 323)	80.98 (29.08)	Mid
	Rich (2000)	Ectopic pregnancy, miscarriage or stillbirth (losses occurred between 3 and 42 weeks of gestation)	2-60 months post-loss (*M* = 16.5 months; *n* = 114)	73.99 (18.47)	Low
	Serrano & Lima (2006)	Miscarriage (≤ 24 weeks of gestation)	Up to one year post-loss (*n* = 30)	72.23 (16.85)	Low
	Volgsten et al. (2018)	Miscarriage (up to 21+6 weeks of gestation)	1 week post-loss (*n* = 64) 4 months post-loss (*n* = 64)	44.5* (*SD*s NR) 37.5* (*SD*s NR)	Low Low
	Wilson et al. (2015)#	Stillbirth (from at least 20 weeks of gestation or over 400 g in weight)	6-8 weeks post-loss (*n* = 9) 6 months post-loss (*n* = 6) 13 months post-loss (*n* = 3)	82.8* (7.31*) 75.9* (7.02*) 63.9* (5.80*)	Mid Low Low

*Calculated based on reported subscale mean and *SD* scores; ^normative data as reported in Lasker & Toedter (2000); #grief reported for fathers who held their stillborn baby after birth; NR = not reported.

Individual factors

Attachment to the baby

One of the strongest factors found to impact upon grief at the individual level was men's attachment to the baby. In 11 qualitative studies, men who had developed a bond with their baby throughout the pregnancy described more intense grief following a subsequent loss [46, 58, 60-62, 73, 75, 79, 81, 82, 85]. However, in five studies some men stated that they did not feel that they had a relationship with the developing baby [61, 69, 75, 79], either because it was an early miscarriage, or they described little involvement during the pregnancy. Others also made a conscious attempt during pregnancy not to get attached, due to previous experience of loss or diagnosis of a life-threatening condition [74]. In these cases, grief was reported as less intense. Actions that increased attachment included spending time with the baby [66, 85], and attending ultrasound appointments to 'see' the baby and hear the heartbeat [46, 61, 62, 66, 73, 79, 82, 85]. Although estimates of grief were imprecise due to a small male sample size, one quantitative study measuring grief after seeing or holding the stillborn baby identified worsened grief for men [92]. Similarly, men in six qualitative studies who held or spent time with their baby following a stillbirth generally also reported high levels of grief [58, 62, 66, 77, 81, 85]. Importantly, however, the cause and effect relationship here is unclear. It may be that men who spent time with their baby were already more attached, and therefore more likely to experience worsened grief.

Seven quantitative studies explored men's attachment to the developing baby using measures including viewing an ultrasound [25], vividness of visual imagery [87], increasing gestational age [23-25, 67, 93], and holding or seeing the baby following stillbirth [92]. Men who viewed an ultrasound image had an average PGS total score 23 points higher than those who did not view any images [25], and men with a strong visual image of their baby as measured by the Baby Vividness of Visual Imagery Questionnaire ("vivid imagers") had an average PGS total score 40 points higher than those who did not [87]. Again, the causal relationship here is unclear.

Attachment may be related to gestational age, since a longer pregnancy could result in more opportunities for bonding. In five quantitative studies, increasing gestational age was associated with higher grief scores [23-25, 67, 93]. However, qualitative studies complicated this picture. In studies inclusive of multiple loss types, men who had experienced earlier losses did not describe less intense grief than those with later losses [46, 57-59, 61]. Studies on miscarriage also noted that men's grief responses were not dissimilar to the grief of men described in studies focused on stillbirth or neonatal death [62, 75, 82]. As such, the impact of gestational age on grief remains unclear.

Men's personality

Two studies on the same sample of bereaved parents in Australia [88, 90] investigated the relationships between grief and a general personality proneness to guilt (considering one's actions as regretful) and shame (attributing regretful actions to oneself). Overall, shame and guilt-proneness were found to explain 63% of the variance in grief (as measured by the PGS) in men, with shame-proneness accounting for 56% of the variance in men's grief 13 months following a stillbirth or neonatal death [88]. In the follow-up study [90], which conducted analysis within the couple, women's self-conscious emotions and grief tendencies did not appear to influence men's emotions and grief tendencies (although men's did impact upon women's). Franche [24] similarly explored the predictive value of self-criticism on grief after pregnancy/neonatal loss. Considered in combination with other obstetric and demographic variables, higher levels of self-criticism were significantly associated with higher scores on all subscales of the PGS in men ($p < .01$ for the Active Grief subscale, and $p < .001$ for Despair and Difficulty Coping subscales).

Demographic factors

Findings relating to the relationship between demographic factors and grief were mixed. Only one quantitative study [23] found age to be a significant predictor of grief following miscarriage, with men aged <35 years scoring higher on the Devastating Event subscale of the RMIS. The remaining quantitative studies including age as a predictor did not find a significant association [24, 93, 95], and qualitative studies did not specifically explore or discuss the impact of age on grief. However, the majority of men who participated in qualitative studies were generally aged 28 years or over, with the exception of two studies which reported minimum ages of 20 and 21 years [46, 77].

Ethnicity did not emerge as a significant predictor of grief, but this was rarely explored. One study comparing Swedish and American couples' experiences of miscarriage [76] found differences between the samples on one subscale of the RMIS (Loss of Baby). However, this difference was attributed to linguistic understanding and wording of the scale questions, rather than the grief experience itself. Other quantitative studies including a small number of culturally diverse participants (e.g., African American, Asian-Australian, Hispanic, Native American) either did not examine differences [23, 88-90, 93], or did not find any significant differences in grief [91]. Five qualitative studies had mixed ethnic samples (e.g., Jamaican, African-American, Hispanic/Latino), but none reported any differences in grief; although, their aim was not to do so [57, 60, 62, 73, 82]. Further, in two Australian-based studies of the same sample of participants with Middle-Eastern backgrounds, culture was not discussed as impacting upon grief [71, 72]. In one qualitative study based in Israel [69], high drop-out rates were noted due to (mostly) the husband's objection to participating, in the context of a typically "closed" religious society. Finally, in a study of low-income African-American parents, grief for men did not differ to those in other studies. However, "dealing with stressful life events", including economic hardship and other unrelated family deaths, were found to compound grief for both parents [77].

In one quantitative study [67], involvement in organised religious activity was inversely associated with Despair subscale scores on the PGS for men (p = 0.047). In eight qualitative studies, men who reported religious or spiritual beliefs also found this to be a source of comfort in coping with their grief. This was both from a meaning-making perspective (e.g., “what God does, He does it for the best”) [69], and from the additional social support that was received from religious/church communities [58, 59, 62, 73, 77, 81, 82]. However, the experience of loss for some men in two qualitative studies also led to questioning or challenging of their religious beliefs [66, 69].

Recurrent loss and living children

Findings relating to the impact of previous losses and number of living children on grief were also varied. In one quantitative study which examined men who had experienced recurrent miscarriage, grief and stress scores were high on both the PGS (*M*=72.23, *SD*=16.85), and IES (*M*=26.53, *SD*=13.76) [91]. In contrast, men with a history of loss in nine qualitative studies [46, 61, 62, 68, 71, 72, 78, 82, 83] did not report different or increased levels of grief. Yet, in four studies, men did report increased worry about future pregnancies [59, 62, 75, 78].

In two quantitative studies including subsequent pregnancy status as an indicator of grief intensity, no significant relationships were found between a group who were currently pregnant following a loss, and a group who had not had a subsequent pregnancy or child [84, 89]. However, in three qualitative studies examining experiences of grief into subsequent pregnancies/children, it was clear that men’s grief did continue, along with added concerns and vigilance due to the knowledge of potential risks [73, 74, 80]. Similarly, one of three studies examining the presence of living children at the time of loss found a relationship to worsened grief in men [23]. However, for the remaining two studies including this factor, it was unrelated [86, 89]. Four qualitative studies described how living children could both enhance the reality of the developing baby (thus worsening grief), *and* make coming to terms with the loss easier. This was attributed to enhanced appreciation for surviving children, reassurance about the possibility of successful future pregnancies, or providing a caring role to focus on [58, 75, 78, 81].

Interpersonal factors

Quality of the partner relationship

In 10 qualitative studies, men noted that the relationship with their partner could be either a positive or negative contributor to the grief experience [55, 57, 59-62, 70, 71, 74, 81]. For many participants, a lack of recognition for their grief from family, friends and healthcare professionals meant their partner became their main source of interpersonal support [59, 61, 81]. Although many men reported supportive relationships with "frank and honest communication" [81] resulting in a stronger couple bond that buffered the grief experience, many also experienced conflict or relationship strain due to incongruent grieving styles [55, 57, 59, 61, 62, 70, 74, 75, 81]. Where dissonant grieving styles or conflict were present, men reported a sense of alienation or frustration that added to their grief experience [55, 60, 61, 74]. However, despite early conflict, where couples learned to effectively navigate one another's grief, the relationship was ultimately strengthened [59, 62, 74].

The supporter role

Although not a factor quantified for measurement in any quantitative studies, one of the most consistently reported and important elements relating to men's grief across qualitative studies was being a 'supporter' to their female partner and family. Twenty-three qualitative studies identified an element of the supporter role from men's responses [46, 55-59, 61, 62, 65, 68, 69, 71-75, 77-82, 85]. In 21 of these, all male participants reported their primary role of being the supporter to their female partner. In the remaining two, the majority of men (five of nine [62], and 14 of 15 [75]) also reported this role. For men in five studies, the need to support their partner explicitly came from a perception that she had a more intense grief reaction in comparison to themselves [59, 61, 69, 74, 79]. In 15 studies, men described having to suppress or put aside their own grief to take on this role [46, 57-59, 61, 62, 68, 71, 72, 74, 75, 77, 81, 82, 85]. As a result, many of these men reported a feeling of being ignored or unrecognised as grievers, instead seen merely as the ‘support person’ [46, 61, 80]. In three studies, some men reported feeling as though this supporter role was helpful, as it gave them a meaningful task to focus on [69, 73, 75]. However, for other men in Hamama Raz et al. [69] and the remaining studies, this role ultimately served as a hindrance in allowing them to acknowledge, express and manage their grief and emotional responses [46, 56-59, 61, 62, 65, 68, 69, 71, 72, 74, 75, 79-82, 85].

Support and acknowledgement from family and friends

In 16 studies looking at support, 10 found family and/or friends to be a helpful facilitator to men’s coping following the loss [56, 57, 59, 66, 72, 73, 75, 79, 81, 82]. This was important, since many men explicitly reported a preference not to engage in formal counselling [78] and/or support groups [56, 61]. However, men’s experiences of support from family and friends varied greatly. In the one quantitative study that looked at family and friend support as variables, ‘talking with friends’ was associated with increased grief scores, along with ‘timing of talking to family’. However, there is no description of what is meant by this [93]. In the remaining qualitative studies, the majority of men also reported talking with either close family members or friends post-loss, which they found meaningful and helpful most of the time [56, 57, 59, 61, 75, 79, 81, 82]. Practical support immediately following the loss (e.g., making meals) was particularly appreciated by men in three qualitative studies [61, 72, 82]. For others “subtle” gestures of care from other male friends, including sharing their own stories or scheduling time/activities post-loss, were immense comforts [66, 81, 82]. However, seven qualitative studies also reported negative – or a total absence of –

interactions with family and friends [59-62, 73, 75, 80]. In two of these studies, men did not feel the need to discuss their grief with anyone other than their partners, or avoided talking to others about the loss, believing this would reduce the impact [73, 75]. In the remaining five, men desired support from family and friends, however stated that "no one" [80] was available to them due to a lack of understanding, avoidance, and/or discomfort [59-62]. Where there was a lack of acknowledgement or support from family and friends, reported grief experiences were worsened [60, 61, 80].

Support and acknowledgement from healthcare professionals

Similar to support from family and friends, the role of healthcare professionals was recognised in one quantitative study [70] and 13 qualitative studies [46, 56, 60-62, 64, 65, 68, 72, 73, 78, 81, 82] as essential to the bereavement process. However, among studies that examined healthcare provider support, findings were again mixed. In 10 studies, some men reported positive experiences with healthcare staff [46, 60, 61, 64, 68, 73, 75, 78, 81, 82]. Three studies noted that providers who worked "extra hard" to provide both medical and practical information to men were valued [81], and parents who experienced the support of specialist bereavement care teams, or follow-up telephone calls from care providers, commented positively on this [68, 78]. However, men in one quantitative study felt excluded from services and none were satisfied with the support they received from health professionals [70]. Likewise, other men in 11 of both the same and different qualitative studies also reported negative interactions with healthcare staff. This led to sadness, anger, or distress which worsened or prevented the grieving process [46, 61, 62, 64, 65, 70, 72, 75, 79, 81, 82]. Common issues included insensitive language or confusing medical terminology [79, 81, 82], a lack of answers or explanations [61, 62], a lack of practical information on how they could care for their female partner or organise a funeral/burial [46, 62, 72], and failing to recognise their distress and role as a father [46, 64, 65, 70, 75, 79]. It should be noted that the majority of studies reporting negative experiences with health care providers/the hospital focused on miscarriages as opposed to later-term losses, with the exception of three which focused exclusively on stillbirth [64, 65, 81]. Two studies exploring healthcare support following both miscarriage and stillbirth also noted differences in care between these types of losses, with miscarriages receiving considerably less support in comparison to stillbirths [46, 61].

Community factors

Disenfranchisement of grief following pregnancy/neonatal loss

A lack of community acknowledgement and understanding for grief following pregnancy loss was explicitly identified by male participants in seven qualitative studies from the USA [58, 65, 66, 82], Ireland [46, 78] and Australia [61]. Across these, men discussed widespread taboo, stigma and silence surrounding miscarriage and/or stillbirth which worsened their grief. Experiences of disenfranchisement included questioning their identity as fathers due to confusion surrounding whether their pregnancy was understood as a baby or not [46], only discussing their loss if/when prompted by another bereaved parent [78], and hurtful comments from others which minimised their grief or encouraged them to “move on” from the loss [61, 82]. Overall, this sense of disenfranchisement due to a lack of community acknowledgement for pregnancy loss led men to experience increased distress and feelings of isolation [46, 58, 61, 66, 82]. This factor was not explored in quantitative studies.

Male role expectations and attitudes toward men’s grief

Tying in closely with the ‘supporter role’ theme, a pressure to conform to masculine role expectations toward how men should grieve was expressed in 19 qualitative studies. These were based in Australia [61, 72, 85], the UK [79], the USA [55-60, 62, 65, 66, 74, 80, 82], Ireland [46], Sweden [81] and Israel [69]. No quantitative studies explored this factor. In 13 studies, male participants specifically discussed the need to be “strong”, and a perceived expectation to hide their grief [46, 56-59, 61, 62, 72, 74, 79, 80, 82, 85]. Men reported that these expectations had a direct negative impact on their grieving process, as they felt prevented from displaying their emotions in front of others, seeking support, and/or working through their grief [46, 57, 61, 65, 66, 74, 80, 82, 85]. This expectation to hide their emotions also meant that the impact of the loss on these men was frequently disguised from family, friends and healthcare professionals. This led to a generalised lack of recognition for their grief, and a further sense of disenfranchisement, above that which already exists for grief following pregnancy/neonatal loss generally [60, 61, 82].

Public policy factors

Woman-focused maternity care and support services

A general focus on woman-centred care in the hospital environment and existing support services was identified as a factor impacting grief by nine qualitative studies, but not in quantitative studies [46, 60, 61, 64, 66, 70, 80-82]. A general community attitude that pregnancy and subsequent loss was primarily a "woman's experience" [80] was explicitly expressed by men in three studies [46, 60, 80]. Men also reported feeling overlooked or ignored in the context of existing healthcare and support services. For example, in the hospital environment, both following loss and during subsequent pregnancies, men felt "out of place" [81], "marginalised" [46] and sometimes, as though they "barely existed" [61]. Similar sentiments were echoed in the context of support services/groups which were delivered primarily by women and focused on "'traditionally feminine' modes of grieving" [60, 61, 66, 80]. Men in five studies expressed a desire for recognition [80-82], as well as a need for increased male involvement in care and support services [46, 61]. Indeed, in studies where male friends and family were available to men, or healthcare staff sought to specifically involve them in pregnancy care and support services, grief improved [46, 60, 61, 64, 66].

Workplace policies: bereavement leave

Another consistent theme at a policy level was the availability of paternity or bereavement leave for men following pregnancy/neonatal loss. Returning to work following loss was explicitly discussed in 11 qualitative studies [57-62, 66, 74, 79, 80, 82] and one quantitative study [86]. For the majority of men, particularly those who described a more instrumental grieving style, work provided a distraction from their loss, and was used as a strategy to cope with their grief [57-60, 74, 79]. However, four qualitative studies, which examined men's experience of returning to work in more depth, identified varied outcomes [61, 66, 80, 82]. In three of these studies, men were not provided with the same opportunities as their female partners to take paid leave from work following their loss [61, 66, 80]. This led to physical and emotional exhaustion, along with difficulties in concentration and keeping up with tasks. In one quantitative study [86], men also reported difficulty returning to work. In contrast, the burden of grief was eased for men in two studies who were offered extended paid leave or extensions on work-related deadlines [61, 82].

The emerging model: a socio-ecological theory of men's grief

Spanning the individual, interpersonal, community and public policy realms, the factors identified in this review align with a socio-ecological approach to understanding grief. We propose a preliminary model of men's grief, adapted from Bronfenbrenner's [98] ecological systems theory (see Figure 2). The original theory (focusing more broadly on development as opposed to grief) purported that an individual's development is impacted by four interacting levels in the environment: the microsystem (the immediate environment), the mesosystem (settings in which we actively participate), the exosystem (wider social setting), and the macrosystem (culture and belief systems) [98]. Like the original theory, the model of men's grief proposed here acknowledges that the grief experience does not exist in isolation. Rather, it is shaped by a complex system of interacting factors and levels. These include those relating to the individual, their relationships, the surrounding community, and governing policies. Each of these levels also interacts with one another in a bi-directional nature. For example, cultural norms and beliefs regarding men's roles – particularly in pregnancy – may play a vital role in informing the woman-centred focus of perinatal healthcare and bereavement leave policies (and vice versa). These norms can also impact the ways that individuals interact with one another in response to pregnancy/neonatal loss, as do these interpersonal interactions serve to support the overarching cultural norms. At the centre, the individual, their personality, knowledge, attitudes and skills are impacted by, and continually interact with, all of these contributors.

The overarching theme of this model is the concept of "double disenfranchisement", first introduced by Cacciatore and Raffo [99] in their study on lesbian maternal bereavement. The authors argued that given an additional lack of societal recognition for their status as legitimate mothers, lesbian women can experience an added level of disenfranchisement following pregnancy loss [99]. In a similar way, the lack of recognition that many men cited in this review for their position as grieving fathers indicates that they may also experience a sense of added or double disenfranchisement. Consequently, it is imperative that men's grief following pregnancy/neonatal loss is not viewed entirely as an individual response to the event, but as part of a wider socio-ecological process.

Discussion

Main findings and implications

This systematic review has summarised men's experiences of grief following pregnancy/neonatal loss, and identified factors that contribute towards grief. Evidence from this synthesis and the proposed Socio-Ecological Model of Grief highlights potential ways to support men, including access to multi-level strategies.

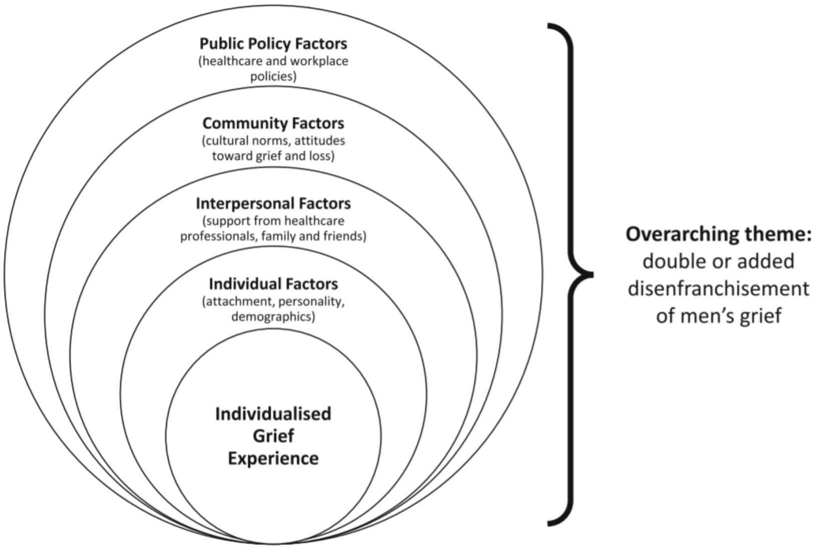

Fig. 2 Socio-Ecological Model of Men's Grief

Grief

Both quantitative and qualitative studies revealed the highly varied and individual nature of men’s grief. Although men’s grief was less intense compared to women’s in some quantitative studies [23, 67, 76, 88, 91, 93, 94, 96], qualitative studies identified the significant impact of loss on men. Given grief is a normal and expected process following a loss, it is unsurprising that some men experienced such significant effects. In contrast to stereotypes that men intellectualise or rationalise their grief, studies also found that men do grieve on an emotional level. They may also oscillate between problem-focused coping and emotional expressions of grief, as reflected in the dual-process model of coping [31]. However, men’s experiences also appeared to be consistent with the theory of disenfranchised grief [5], with a general silence surrounding pregnancy loss contributing to feelings of isolation and worsened grief. Compared to women overall, men may also face different challenges that can worsen grief. This finding is consistent with previous research on gender and grieving which suggests that grief can be impacted by, but is not dependent on, gender [100].

Predictors of grief

A wide range of factors have the potential to influence men’s grief. At an individual level there are mixed findings relating to demographic factors, suggesting that these have not been well-explored. Similarly, personality constructs may play a key role in predicting grief [24, 88, 90], although further research is required to confirm causality. However, in contrast to early assumptions that men only develop an attachment to the developing baby as gestation increases, results suggest that attachment at any level is an important predictor of grief [58, 62, 79, 81, 82].

Men’s interactions with others seem to play a pivotal role in how they experience grief. The quality of the couple relationship contributed to either a positive source of support that helped the grief process, or a negative source of added stress which increased the impact of the loss [55, 57, 59-62, 70, 71, 74, 81]. Grief was eased when friends and family were available to support men, and were understanding of their loss [56, 57, 59, 61, 75, 79, 81, 82]. Furthermore, a positive experience with the healthcare system led to both reduced grief and increased support group participation [60], whereas insensitive treatment led to psychological distress and worsened grief [64].

These findings relating to individual and interpersonal factors are similar to studies focused on women’s experiences of grief following pregnancy/neonatal loss. For example, findings on demographic factors have also been inconsistent. Involvement in religious activity and strength of religious faith have been inversely associated with grief in some studies [101, 102] but not others [103]. Similarly, maternal age both has [23, 101], and has not [24, 104], been found to be a significant predictor of grief. However, while the impact of cultural diversity is yet to be explored in men, cross-cultural studies with women highlight a range of culturally-specific understandings and practices relating to the loss of a baby that can impact upon grief [105, 106, 107, 108, 109]. Finally, social support and experiences with the healthcare system have been linked to both immediate grief and long-term psychological health for women [1, 110-113].

Alongside the potential for mixed styles of grieving, individual-level supports should consider these factors to provide tailored and appropriate support options to suit men's individual needs. For example, individual counselling or support groups may not be appealing to all men. Rather, previous research has recommended creative options including activity-based supports, evidence-based online supports, opportunity for peer contact, or including male support workers in hospitals [21, 46, 47]. Joint couple bereavement counselling could also be considered where necessary. As a minimum, it is important to provide explanations to bereaved parents about incongruent grieving between partners, and skills to navigate potential issues. There is an ongoing need for healthcare professionals to provide sensitive and empathetic care to both members of a couple relationship. This includes adopting appropriate, jargon-free language, providing explanations relating to the cause of loss when available, and follow-up calls specifically to men in the weeks or months following a loss. Practical information on how best to support their partner, alongside recognising and managing their own grief, was also desired by men [46, 62, 72].

Community attitudes concerning the legitimacy of parents' grief following pregnancy/neonatal loss, along with gendered expectations relating to how men should behave in the face of loss, are important in shaping men's experience. A lack of recognition for grief following pregnancy/neonatal loss resulted in disenfranchisement [5], with men frequently reporting a feeling of being overlooked as grieving fathers [46, 58, 61, 66, 82]. Policies relating to woman-centred care and bereavement leave in the workplace also impacted grief. Where pregnancy was seen as an issue relating exclusively to women, and men consequently felt excluded from the loss experience at the hospital, their grief was worsened [46, 61, 81]. A small number of studies also suggested that men were frequently not afforded adequate workplace leave to manage their grief following a loss [61, 66, 80]. In line with recent investigations which have highlighted similar social and economic consequences of stillbirth [27, 114], there is potential to re-examine current paternity and bereavement leave policies [66, 80].

These findings imply that beyond individual and interpersonal supports, there is also a need to educate the community about the impact of pregnancy/neonatal loss on men, as well as promoting their strengths to seek and accept, rather than avoid, support. More generally, similar recommendations have been made in the men's physical and mental health literature, where stigma surrounding male help-seeking frequently serves as a barrier to accessing appropriate health-related supports [34-36]. Strategies are also needed to develop male-inclusive healthcare practices, and promote the meaningful engagement of men as equal partners throughout pregnancy and childbirth. In the broader postnatal health context, engagement of fathers has demonstrated improved long-term physical and mental health outcomes for women, men and babies [115, 116].

Limitations and future research

Although inconsistencies concerning grief between quantitative and qualitative studies highlight the varied nature of men's experiences, some authors have questioned the ecological validity of current grief measures [23, 84, 89, 95]. The PGS, for example, was initially developed and validated in a sample of mainly bereaved mothers (women n = 138 and men n = 56) [117]. As such, some of the items and subscales have been criticised for measuring more traditionally 'feminine' (or intuitive) expressions of grief, which may under-recognise more 'masculine' (or instrumental) expressions and responses. Across included studies that provided separate subscale analyses of grief, the greatest differences between men and women occurred on the Active Grief subscale. This reflects outward expressions of grief and emotions, which men often display less frequently than women [25, 91, 95, 96], and may indicate a selection bias in qualitative studies toward men with more extreme grief responses. However, some men in qualitative studies also expressed less extreme reactions to the loss, indicating representation of a range of experiences [56, 61, 69, 71-75, 78, 79]. Given the correlational nature of findings on viewing an ultrasound [25], it also remains unclear as to whether viewing an ultrasound results in more intense grief, or whether men who were already more attached to their baby were more likely to attend the ultrasound appointment. This concept requires further investigation.

Overall, quantitative studies seem to have captured part of the picture about grief, focusing predominately on individual and interpersonal factors as key contributors to the grief experience. Further studies are needed to explore the unique facets of men's grief following pregnancy/neonatal loss (e.g., helplessness, marginalisation, and the expectation to 'be strong'), as well as the broader socio-cultural and public policy factors. This might include a more comprehensive measure of attachment to the baby and workplace functioning, or quantitative measures of marginalisation from the healthcare system, and the expectation to 'be strong' and conform to masculine norms. Once these factors are well understood, there will be scope to develop and validate a grief measure with increased sensitivity toward these elements, as well as the more instrumental-orientated grief styles [23, 80, 84].

None of the included studies focused exclusively on men's grief following neonatal loss. Furthermore, those which did include men experiencing neonatal loss did not specifically identify disenfranchisement as a contributing factor. This may be due to increased recognition for the baby's life, given survival outside of the womb. However, in studies on neonatal loss not eligible for inclusion [4, 118, 119], parents reported feelings similar to those following miscarriage or stillbirth. These included loneliness and isolation from friends and family, as well as a profound "silence concerning the death" [4]. There is a need for updated research to explore men’s experiences of grief following neonatal loss, and to identify any unique factors impacting grief.

Finally, participants in the included studies were predominately Caucasian, heterosexual males. As ever, there is a need for research among diverse samples of men. This includes gay and transgender men whose pregnancy and loss experiences may involve unique or added challenges [120, 121], single and separated men who experience relationship breakdown following a loss, and culturally and socio-demographically diverse men. The emerging Socio-Ecological Model of Men’s Grief following pregnancy/neonatal loss also requires refinement and confirmation through cohort studies which includes these diverse populations. A comprehensive longitudinal study following men throughout pregnancy, and then during and following a pregnancy/neonatal loss, would also be useful to explore the causal pathways for risk and protective factors of grief.

Conclusions

A Socio-Ecological Model of Men’s Grief implies a need for multi-level strategies, rather than individual bereavement supports alone. Tailored support is needed for instrumental grievers, and to address the unique challenges men face. Additional strategies may also include community campaigns to change attitudes toward grief and loss and promote the strengths, rather than weaknesses, of traditionally normative “masculine” traits including resilience and strength to seek assistance. Appropriate workplace policies and health systems that validate and engage men throughout pregnancy, childbirth, and in the event of loss, are also required. A focus on men’s grief and subsequent support does not seek to reduce the significance of the loss for their female partners. Rather, a lack of validation as equal partners in the pregnancy and loss process has led to increased difficulties in coping for men, and being afforded acknowledgement for their grief [82, 85]. As such, this review provides a helpful synthesis on the existing literature for men’s grief following pregnancy/neonatal loss, and a solid theoretical foundation from which future research and recommendations can be built.

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CHAPTER 4. PAPER TWO

Factors contributing to men's grief following pregnancy loss and neonatal death: further development of an emerging model in an Australian sample

4.1 Preamble

Building on the findings of the systematic review presented in Chapter 3, the second study of this thesis involved a nationwide online survey to further explore the individual, interpersonal, community and policy/system factors relating to men's grief following pregnancy loss and neonatal death in a sample of Australian men. This study focused particularly on investigating previously under-explored factors that may contribute to men's grief and used generalized linear modelling to explore associations between these factors and men's grief. This Chapter presents the paper that resulted from this study, which was accepted for publication in January of 2021 with the academic journal *BMC Pregnancy and Childbirth*. Please note that the references for this paper are formatted in Vancouver style, as per requirements for publication with *BMC Pregnancy and Childbirth*. A separate reference list for this paper is therefore provided at the end of the manuscript.

4.2 Statement of authorship

Title of Paper	Factors contributing to men's grief following pregnancy loss and neonatal death: further development of an emerging model in an Australian sample
Publication Status	☑ Published ☐ Accepted for Publication ☐ Submitted for Publication ☐ Unpublished and Unsubmitted work written in manuscript style
Publication Details	Obst, K., 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). https://doi.org/10.1186/s12884-020-03514-6

Principal Author

Name of Principal Author (Candidate)	Ms Kate Obst

Contribution to the Paper	Conceptualised the study and developed the survey, including devising research questions, selection and development of included measures, and piloting/revision to form the final survey. Prepared the survey for online distribution and recruited participants. Completed data cleaning and analysis, and organisation and presentation of the data and final results. Wrote the paper and prepared the manuscript for journal submission.		
Overall percentage (%)	85%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	2 February 2022

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate in include the publication in the thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Dr Melissa Oxlad		
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Signature		Date	27 January 2022

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Contribution to the Paper	Assisted with conceptualisation of the study and development of the survey. Contributed to organisation and presentation of the data and final results. Contributed to editing the draft manuscript.		
Signature		Date	26 January 2022

Name of Co-Author	Professor Philippa Middleton		
Contribution to the Paper	Assisted with conceptualisation of the study and development of the survey. Contributed to organisation and presentation of the data and final results. Contributed to editing the draft manuscript.		
Signature		Date	1 February 2022

4.3 Published paper

Abstract

Background: Historically, men's experiences of grief following pregnancy loss and neonatal death have been under-explored in comparison to women. However, investigating men's perspectives is important, given potential gendered differences concerning grief styles, help-seeking and service access. Few studies have comprehensively examined the various individual, interpersonal, community and system/policy-level factors which may contribute to the intensity of grief in bereaved parents, particularly for men.

Methods: Men ($N = 228$) aged at least 18 years whose partner had experienced an ectopic pregnancy, miscarriage, stillbirth, termination of pregnancy for foetal anomaly, or neonatal death within the last 20 years responded to an online survey exploring their experiences of grief. Multiple linear regression analyses were used to examine the factors associated with men's grief intensity and style.

Results: Men experienced significant grief across all loss types, with the average score sitting above the minimum cut-off considered to be a high degree of grief. Men's total grief scores were associated with loss history, marital satisfaction, availability of social support, acknowledgement of their grief from family/friends, time spent bonding with the baby during pregnancy, and feeling as though their role of 'supporter' conflicted with their ability to process grief. Factors contributing to grief also differed depending on grief style. Intuitive (emotion-focused) grief was associated with support received from healthcare professionals. Instrumental (activity-focused) grief was associated with time and quality of attachment to the baby during pregnancy, availability of social support, acknowledgement of men's grief from their female partner, supporter role interfering with their grief, and tendencies toward self-reliance.

Conclusions: Following pregnancy loss and neonatal death, men can experience high levels of grief, requiring acknowledgement and validation from all healthcare professionals, family/friends, community networks and workplaces. Addressing male-specific needs, such as balancing a desire to both support and be supported, requires tailored information and support. Strategies to support men should consider grief styles and draw upon father-inclusive practice recommendations. Further research is required to explore the underlying causal mechanisms of associations found.

Trial registration: N/A

Keywords: Pregnancy loss, Neonatal death, Miscarriage, Stillbirth, Termination of pregnancy, Foetal anomaly, Men, Grief

Background

Despite continued global advancements in reproductive healthcare, both pregnancy loss and the death of a newborn baby within the first 28 days following birth (neonatal death) continue to be devastating realities for many families. The pervasive psychological and emotional impacts of parents' grief following pregnancy loss and neonatal death are now well-recognised [1-4]. Parents frequently report experiences of stigma, shame and disenfranchisement through minimisation of their loss from others, which can complicate their grief [5-9]. Men's experiences of pregnancy loss and neonatal death have been under-explored in comparison to women. However, a growing body of research has highlighted the importance of investigating men's perspectives, given potential gendered differences concerning grief, help-seeking and service access [10-17]. For example, quantitative studies comparing heterosexual couples' experiences following pregnancy loss and neonatal death suggest that men typically experience less intense and enduring levels of grief than women [18-23]. However, a smaller number of studies have found similar grief intensity between men and women [24, 25], or even higher levels of grief in men [26]. Broader research on grief also demonstrates potential differences in grief styles for men and women, with a general classification made between instrumental (action-focused coping) and intuitive (emotion-focused coping) styles [27]. Following pregnancy loss and neonatal death, studies suggest that men may engage in more instrumental grieving styles, which includes using activities, distraction or problem-solving approaches to grief, as opposed to intuitive styles which use emotion-focused approaches including outward displays of crying, talking about grief, or seeking social support [9, 16, 28-35].

Our recent systematic review of men's grief following pregnancy loss and neonatal death emphasised the importance of examining grief from a holistic, socio-ecological perspective to understand the varied factors which can contribute to men's experiences (see Figure 1) [36]. At the individual level, factors contributing to men's grief include demographic elements (e.g., age, religion, ethnicity), pregnancy loss/neonatal death history and number of living children. Regardless of gestational/newborn age of the baby, previous research also suggests that attachment is a particularly strong predictor of men's grief intensity. Although early quantitative research measured 'attachment' using increasing gestational age or whether or not men viewed an ultrasound of their developing baby [20, 22, 23, 37, 38], qualitative studies have suggested that a broader exploration of prenatal attachment (e.g., through everyday interactions with the developing baby) may be more important in determining the intensity of men's grief response [10, 12, 13, 16, 30, 32, 34].

At the interpersonal level, men's interactions with others have been found to have implications for shaping their grief experience. Qualitative studies have pointed to the importance of whether men felt acknowledged as a grieving father from family, friends and healthcare professionals; where there was a lack of recognition for men as grieving fathers, grief intensity worsened [9, 10, 12, 33, 39]. Throughout the qualitative literature, heterosexual men's role primarily as a 'supporter' to their female partner, has remained a consistent and dominant theme. This role has often been reported as hindering men's expressions and experiences of grief [10, 12, 13, 16, 33, 34, 40]. However, a smaller number

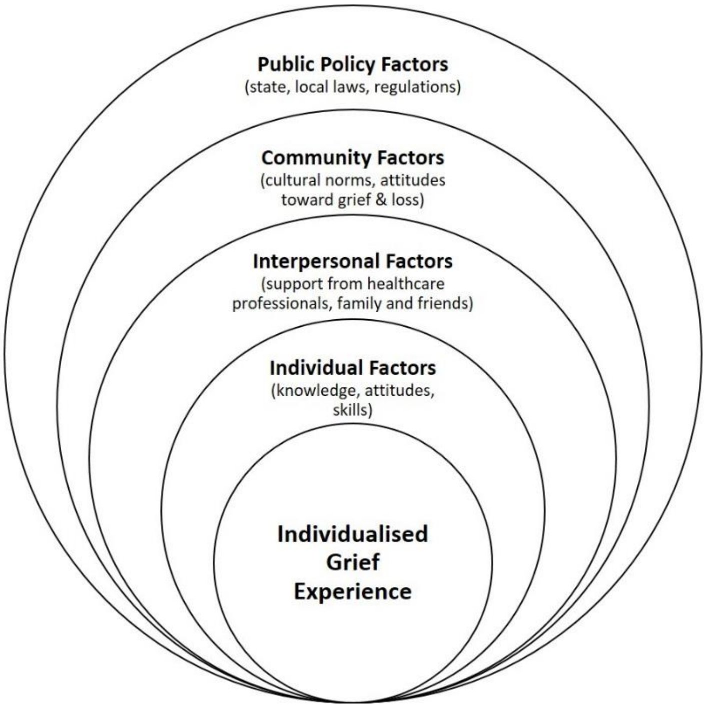

Figure 2. *Socio-Ecological Model of Men's Grief*

Socio-ecological Model of Men's Grief, demonstrating the factors contributing to men's grief following pregnancy loss and neonatal death at the individual, interpersonal, community and public policy levels. This image was generated by the authors for a previous publication [36].

of studies have suggested potential benefits of this role, particularly among people who are instrumental grievers, for whom this role could provide purpose [30, 41].

At the broader community level, qualitative studies have also consistently noted that men's experiences are shaped by social attitudes concerning the legitimacy of parents' grief, as well as gendered expectations surrounding how (or if) men should openly display emotion [9, 10, 12, 16, 29]. These were related to masculinity ideals, which often prescribed being strong or stoic in the face of loss [12, 13, 16, 32, 33].

Finally, at the system/policy level, parents' experiences within the healthcare system following pregnancy loss or neonatal death have been established as fundamental to shaping bereaved parents' grief experience [4, 9, 42]. For some men specifically, the context of woman-centred care in hospital (when applicable to the type of loss) has been found to be isolating and can worsen grief outcomes [10, 12, 34]. Also in relation to systems issues, research indicates that policies regarding bereavement leave within workplaces typically differ for men and women, with some men reporting less access to paid leave following their loss than women [10, 29, 33]. As many men have reported returning to work soon after pregnancy loss or neonatal death, bereavement leave policies may play a role in grief outcomes [36].

In addition to the research on factors relating to men's grief, several studies have explored various factors relating to grief intensity in women following pregnancy loss and neonatal death [43-50] and couples [23, 38, 51-53]. Most of these studies have examined individual, interpersonal, community or system-related factors separately, rather than together in a single model. Similarly, with the exception of Riggs et al. [17] who explored relationships between grief, psychological distress, stigma, help-seeking and social support, the studies outlined above concerning factors related to grief for men have also focused on specific variables such as the duration of pregnancy or viewing an ultrasound image. Importantly, no previous research has considered factors relating to different styles of grief, which may be important, given that studies have suggested gendered grieving styles [27]. Using the Socio-Ecological Model of Men's Grief developed in our previous systematic review as a basis [36], this study aimed to quantify and further explore the factors which contribute to men's grief, with a particular focus on previously under-explored determinants. Specifically, we sought to determine the factors associated with grief intensity following pregnancy loss and neonatal death, as well as the factors associated with intuitive and instrumental grief styles.

Methods

Participants

Ethical approval for the study was granted by the University of Adelaide Human Research Ethics Committee on the 5th of June, 2019 (approval code HREC-2018-273). Participants were Australian men who had experienced the loss of a baby at any stage of gestation to miscarriage, ectopic pregnancy, medical termination of pregnancy for nonviable foetal anomaly (TOPFA), stillbirth or neonatal death. Inclusion criteria were that participants were aged 18 years of age or older and had experienced pregnancy loss or neonatal death in Australia within the last 20 years. Although potentially open to recall bias, this timeframe was selected to maximise the potential pool of eligible respondents. Of 277 participants who commenced the survey, 228 completed all items and were included in the final sample reported here (completion rate = 82%). There were no apparent differences between completers and non-completers on demographic characteristics. At the time of survey completion, participants were aged between 19 and 60 years (*M* = 36, *SD* = 7.4). At the time of loss, they were aged between 18 and 58 years (*M* = 32, *SD* = 5.5*)*. See Table 3 for a summary of participant characteristics at the time of survey completion.

Procedure

A web-based survey was developed by the authors (see Appendix 12), hosted by the online platform *SurveyMonkey*. This survey was developed for the purposes of the current study, and has not been published elsewhere. Extensive piloting was undertaken with members of a reference group (including Australian fathers and mothers who had experienced pregnancy loss/neonatal death, grief counsellors and pregnancy loss/neonatal death support workers and researchers) as part of the broader program of research to form the final survey. The survey was developed with extensive consultation and piloting. Initially, preliminary discussions were held with individual members of the reference group concerning the types of measures used and questions to be asked in line with the Socio-Ecological Model of Men's Grief. With this feedback, the first author drafted a full survey. In the two successive rounds of piloting, members of the reference group reviewed updated drafts of the survey in full and were invited to provide suggestions for revision. Although major concepts remained the same, the ordering, inclusion and wording of questions and final measures selected, were edited and refined according to feedback to ensure both sensitivity and ease of understanding.

Table 3. *Participant characteristics*

	Category	***N* (%)**
Ethnicity	Australian	194 (85%)
	Other^	34 (15%)
Sexual orientation	Heterosexual	224 (98%)
	Bisexual	3 (1.5%)
	Homosexual	0 (0%)
	Transgender	0 (0%)
	Rather not answer	1 (0.5%)
Highest level of education	High School	54 (24%)
	Technical and Further Education (TAFE)/Trade	83 (36%)
	Undergraduate Degree	58 (25%)
	Postgraduate Degree	33 (15%)
Marital status	Married	186 (82%)
	In a relationship	35 (15%)
	Divorced	1 (0.5%)
	Separated	4 (1%)
	Never married/single	2 (2%)
Area of residence*	Major city	131 (58%)
	Inner regional	64 (28%)
	Outer regional	28 (12%)
	Remote/very remote	4 (2%)
Number of losses	One	138 (61%)
	Two–three	15 (7%)
	Four–five	47 (21%)
	Six or more	28 (12%)
Loss type reflected on for the survey	Ectopic pregnancy	5 (2%)
	Termination of pregnancy for foetal anomaly (TOPFA)	30 (13%)
	Miscarriage	69 (30%)
	Stillbirth	77 (34%)
	Neonatal death	47 (21%)
Time since loss	Less than one year	65 (28%)

	1-2 years	40 (18%)
	3-5 years	59 (26%)
	6-10 years	43 (19%)
	11-15 years	10 (4%)
	16-20 years	11 (5%)

^Other ethnicities reported by participants include: European (8%), Asian (2%) and New Zealander (2%).
*Based on Australian Bureau of Statistics classification of remoteness.

Potential participants were invited to take part in the survey via advertisements through Australian pregnancy loss and neonatal death support and advocacy organisations. These included Pillars of Strength, Bears of Hope, Sands Australia, Still Aware, Miracle Babies Foundation, SIDS and Kids SA, and the Australian Perinatal Loss Centre. Following ethics approval, these organisations were contacted by the first author via email or telephone to discuss the study. All organisations agreed to share a study flyer and information through either social media platforms (primarily Facebook), newsletters, and/or organisation websites.

The study flyer contained brief information about the survey and the online survey link, which opened to a covering page with a preamble providing potential participants with detailed information about the study. After reading the study preamble, participants provided passive consent, a method of consent approved by the University of Adelaide Human Research Ethics Committee, by choosing to commence the survey and submit their responses. In recognition of the sensitivity of the topic and potential for participants to experience emotional distress in reflecting on their experience of loss, a comprehensive distress protocol was developed and articulated to participants. This included providing contact details for national pregnancy loss telephone support lines at the beginning and end of the survey. No concerns regarding participant distress were raised during the research.

The survey took approximately 30 minutes to complete. Depending on participant responses, skip logic was incorporated to hide questions which were irrelevant to individual experiences, often resulting in a shorter completion time (M=22 mins). The number of items/questions presented to participants who completed they survey therefore ranged between 110 and 130. Participation in the survey was voluntary and anonymous. Data collection occurred between June and August 2019. Data were exported from the online SurveyMonkey platform and stored on a secure university-approved network at the University of Adelaide.

Measures

Participants completed questions relating to demographic characteristics (age, ethnicity, education, occupation, sexual orientation, marital status, religion, and postcode), along with questions about their pregnancy and loss history. Definitions for the death of a baby during pregnancy or shortly following birth vary, with gestational cut-offs for classification differing between countries. In Australia, a miscarriage is defined as the death of a baby in-utero before 20 weeks' gestation and occurs for approximately 20% of pregnancies [54]. In 1-2% of pregnancies, an ectopic pregnancy occurs when the fertilised ovum implants outside of the uterus, most commonly in the fallopian tube [54-56]. A stillbirth is defined as the loss of a baby from at least 20 weeks' gestation or over 400g in weight, occurring for 7.1 per 1,000 births [57]. Neonatal death refers to the death of a newborn infant within the first 28 days of life and occurs for 2.5 per 1,000 live births [57]. A congenital anomaly is diagnosed in approximately one in 22 pregnancies in Australia [58]. National data on TOPFA is not collected in Australia; however, it has been estimated that approximately 10-13% of parents elect to medically terminate a pregnancy diagnosed with foetal anomaly, particularly when the diagnosis is considered life-limiting or fatal [59]. Where more than one type of pregnancy loss or neonatal death had been experienced, participants were asked to reflect on only one type of their choice for the remainder of the survey. An option to comment on other losses was provided at the end of the survey. Participants then completed a mix of questions developed by the authors as well as standardised measures.

In line with the literature on the ‘supporter role’ relating to men’s grief [10, 12, 13, 16, 36, 40, 60], two author-developed measures were included to determine the extent to which men perceived this to be their role, and whether they felt it interfered with their grief. Participants responded to these questions on a five-point Likert scale from 1 = *strongly disagree* to 5 = *strongly agree*. Higher scores indicated that men perceived their role to be a supporter to their female partner and family after the loss and that their supporter role had a larger impact on their ability to grieve. Scales were also developed to determine the extent to which participants felt their grief was recognised by others, namely: their partner, family, friends, health professionals, and the wider community. For these, participants responded on a five-point Likert scale from 1= *not at all* to 5 = *extremely*. Higher scores were indicative of higher levels of recognition for their grief. Participants were also asked a series of questions about their experiences of returning to work, including whether they were offered leave, and what type of leave they were offered (detailed results under review for publication elsewhere). If they had contact with a hospital as part of their loss experience, they were also asked about the extent to which they felt included (from 1 = *not at all* to 5 = *extremely*; where higher scores indicated a greater sense of inclusion), and whether they were offered information on grief for fathers (yes/no). The six included standardised measures are outlined below.

Paternal Antenatal Attachment Scale (PAAS): A modified version of the Maternal Antenatal Attachment Scale (MAAS), the PAAS assesses both the quality and strength of the subjective experience of the father’s attachment to the developing baby [61, 62]. Comprising 16 items forming two subscales (*Quality of Attachment* and *Time in Attachment*), the PAAS is answered using five-point Likert scales, where higher scores indicate stronger attachment to the baby. Although only a small number of papers have used the PAAS, relationships have been found with related measures including relationship quality, mental health, increasing gestational age, and father identity [63, 64]. Previous research also supports the reliability and validity of the PAAS, with reports of high internal consistency (Cronbach's alpha = 0.83) [62]. For this study, the final question of the scale "If the pregnancy was lost at this time (due to miscarriage or other accidental event) I expect I would feel…" was omitted, given that participants had experienced a pregnancy loss or neonatal death. Internal consistency of this 15-item version in this study was also high (Cronbach's alpha = 0.83).

Perinatal Grief Scale-33 (PGS-33): Designed to quantify bereaved parents' grief based on emotional responses, the PGS-33 assesses thoughts and feelings associated with perinatal loss [65]. The overall scale comprises three subscales: *Active Grief* (outward expressions of grief including crying, sadness and missing the baby), *Difficulty Coping* (difficulties with daily activities and relating to others) and *Despair* (feelings of hopelessness and worthlessness). Participants rate each item on a five-point Likert scale ranging from 1 = *strongly agree* to 5 = *strongly disagree,* with higher scores indicating more intense grief. The PGS-33 is the most common grief scale used among the perinatal loss literature and has been extensively evaluated, with psychometrically sound properties reported (including Cronbach's alphas between 0.92 and 0.96) [66, 67]. Internal consistency for the full measure was also high in this study (Cronbach's alpha = 0.94). Although questions remain surrounding the accuracy of using the PGS among men, as it may not be sensitive to instrumental grieving styles [36], given a current lack of alternative grief measures specifically for men following pregnancy loss/neonatal death, we decided that in conjunction with the Grief Patterns Inventory (described below), this was the best available measure to adopt.

Grief Patterns Inventory-Revised (GPI-10): A measure developed to assess an individuals' general grieving pattern, the GPI indicates a tendency toward either an instrumental or intuitive grieving style. The original measure comprised 24 items containing true-false responses; however, a revised version containing ten items (five items each for the instrumental and intuitive styles) was used in the current study to reduce respondent burden

[68, 69]. A pilot study of the 10-item version reported moderate inter-correlations between subscale items, along with a significant negative correlation between the intuitive and instrumental subscales (*r* = -.525) [68]. Although alpha coefficients were not reported for the 10-item version, research demonstrates acceptable internal consistency for the original version (Cronbach's alphas ranging between 0.71 and 0.76) [70]. In this study, a similar level of internal consistency was found (Cronbach's alpha = 0.71). Items are rated on a five-point Likert scale from 1 = *Strongly Disagree* to 5 = *Strongly Agree,* with instrumental items reverse-scored. As such, potential total scores ranged from 10 to 50, with lower scores indicating a more instrumental style, and higher scores indicating a more intuitive style. As applied previously [69], categorisation of grief styles was made as follows: 10-23 = instrumental; 24-36 = blended; 37-50 = intuitive.

Crisis Support Scale (CSS): The CSS is a measure of social support received from family and friends following a traumatic event (in this case, pregnancy loss/neonatal death). Comprising seven items relating to the availability of others, emotional support, and practical help, respondents rate their agreement to the items on a seven-point Likert scale, ranging from 1 = *never* to 7 = *always*. In the original scale, participants responded to two time points: just following the event (T1) and the present time (T2). However, for this study, participants were only asked to provide responses for the support that was available to them most of the time following their loss. Higher scores indicate higher levels of social support. Validation studies indicate robust psychometric properties for the scale across a range of trauma populations, including bereaved parents of infants (Cronbach's alphas ranging between 0.67 and 0.82; in this study, Cronbach's alpha was 0.69) [71].

Conformity to Masculine Norms Inventory (CMNI): Developed based on Mahalik's model of gender role conformity, the CMNI assesses the extent to which an individual male does or does not conform to the actions, thoughts, and feelings reflected by broad masculinity norms [72, 73]. The original scale consists of 144 items forming 11 distinct factors. However, to reduce participant response burden, only one subscale comprising five items from the overall measure was included for this study, to determine respondents' tendencies toward *Self-Reliance*. This subscale was chosen in line with previous literature which suggests men often feel the need to hide their grief from others, preferring to cope in isolation [10, 12, 13, 16, 29, 33]. The questions included: "I never ask for help", and "It bothers me when I have to ask for help". Respondents rated the degree to which they agreed with these statements on a four-point Likert scale from 1 = *strongly disagree* to 4 *strongly agree*, with higher scores indicating a stronger tendency toward being self-reliant. Widely used in the literature, many studies have reported construct validity for the CMNI, along with discriminant validity between its subscales and high internal consistencies (Cronbach's alpha of 0.85 for the *Self-Reliance* subscale; in this study, Cronbach's alpha was 0.86) [73].

Male Role Norms Inventory Short Form (MRNI-SF): A measure of masculinity ideology developed by Levant et al. [74], the original MRNI comprised 57 items with seven subscales. In 2011, a 39-item revised form was proposed, followed by a 21-item short-form in 2013. For this study, the *Toughness* subscale from the MRNI-SF was used, as items closely aligned with the recurrent theme of needing to be 'strong' or 'tough' reported by men following pregnancy loss in previous literature [10, 13, 16, 32, 33]. The subscale comprises three items, including: "When the going gets tough, men should get tough". Responses are given on a seven-point Likert scale from 1 = *strongly disagree* to 7 = *strongly agree.* Higher scores indicate higher levels of endorsement of traditional masculine ideology [75]. Research has demonstrated sound psychometric properties for the MRNI-SF, including subscale alphas ranging from 0.79 to 0.90 [75]. In this study, Cronbach's alpha for the 3-item *Toughness* subscale was 0.61.

Data analysis

Analyses were performed using SPSS Statistics (V.25). Data were summarised using descriptive statistics and relationships between the variables were assessed using generalized linear modelling with a multiple stepwise approach, including a backward elimination method outlined by Sainani [76]. The generalised linear model is a flexible form of usual linear regression used to compare the effect of several variables which may have error distributions other than a normal distribution on a continuous outcome variable. Using a link function to relate the response variable to the linear model, it provides a maximum likelihood estimation of the model parameters rather than assuming a linear-response model [78]. As recommended for multivariable modelling [77], a priori selection of variables for this study was guided by the Socio-Ecological Model of Men's Grief identified in our previous systematic review [36]. Given the nested form of the socio-ecological model, variables were entered into the regression models in four (stepwise) stages. Assumptions required for generalised linear modelling were assessed prior to analysis; all necessary assumptions were satisfied. Individual-level variables were entered first, and a backward elimination process was carried out until all variables were statistically significant at the 0.5 level as recommended by Harrell [77]. This process was repeated with each of the interpersonal, community and policy/system-level variables until all had been entered into the model (see Table 4 for the variables entered at each level).

While we acknowledge the debates surrounding the use of *p*-values in making decisions regarding variable selection [79,80], the cut-off for inclusion of 0.5 (rather than the traditional choice of $a = 0.05$) used for variable selection in this study is considered to be a reasonable and conservative estimate for a multivariable model [77]. Also, to reduce the risk of bias from sparse data, backward elimination is recommended to achieve a suitable number of degrees of freedom for the model given the number of observations in the study; a general rule is that degrees of freedom should be no more than the number of observations divided by ten to reduce the risk of bias [77]. Without the use of backward elimination, our models would have violated this rule. Ultimately, our approach resulted in a suitable number of degrees of freedom for each model in this study.

Table 4. *Variables entered into the multiple linear regression analyses*

Stage entered into the model	**Variables**
Stage 1 (individual variables)	Loss type; Grief style[a]; PAAS *Time in Attachment*; PASS *Quality of Attachment*; Whether men attended obstetric appointments; Whether men viewed an ultrasound image of their baby; Age at time of loss; Ethnicity; Importance of religion; Number of previous losses; Number of surviving children at time of loss
Stage 2 (interpersonal variables)	Marital satisfaction; Extent of agreement to the statement: “My role following the loss was to support my partner and family”; Extent of agreement to the statement: “I was unable to grieve, because I was too busy supporting everyone else”; Total CSS score; Extent of acknowledgement from partner; Extent of acknowledgement from family; Extent of acknowledgement from friends
Stage 3 (community variables)	Extent of acknowledgement from community; CMNI *Self-Reliance* subscale total score; MRNI *Toughness* subscale total score
Stage 4 (policy/system variables)	Extent of acknowledgement from healthcare professionals; Degree to which participants felt included in the hospital[b]; Whether employment leave was offered to men; Whether other psychosocial supports were offered to men

Note: [a]Entered only into model 1 (dependent variable = PGS total score); [b]Classified into a high/low level of inclusion based on original Likert scale responses (scores 1-3 = low level of inclusion and 4-5 = high level of inclusion)

Statistical power

There are no consistent rules for sample size requirements in linear regression [81]. However, various general recommendations have been made about minimum sample size, or sample size depending on the number of independent variables included in the model. While one general rule recommends a minimum of 100 participants regardless of the number of independent variables [82], others suggest 50 plus the number of independent variables [83], or at least 100 for less than three independent variables or 300-400 for nine or 10 independent variables [84]. Tabachnick and Fidell also suggested a sample size of $50 + 8k$, where k is equal to the number of independent variables [85]. Employing recommendations to consider a minimum sample size of 50 plus the number of independent variables [83, 85], with a sample size of 228 and the number of independent variables included in the models at any one stage not exceeding 16, the current study had sufficient statistical power.

Results

Descriptive statistics

Descriptive statistics for continuous variables are presented in Table 5. Overall, grief scores were high, with the average score sitting above the minimum cut-off considered to be a high degree of grief according to population norms (cut-off = 91) [67]. In particular, the highest mean grief scores occurred on the Active Grief subscale (indicating feelings of sadness and missing the baby), and the lowest scores occurred on the Despair subscale (indicating feelings of worthlessness and hopelessness). On average, men experienced the lowest average grief following early losses (<20 weeks' gestation); however, the standard deviation (*SD*) was high and the mean score still represented a high degree of grief. The average grief score following late loss (≥20 weeks' gestation) was the highest, followed by neonatal death; again, however, the ranges were wide and *SD*s were high, indicating substantial variation in scores. Although the mean grief score was slightly lower for losses which occurred more than 10 years ago, there was a negligible association between time since loss and total grief scores (F(2,215) = .556, *p* = .574).

According to the GPI, average scores were significantly higher for the intuitive grief items compared to the instrumental grief items (*t* (223) = 4.611, *p* <.001). Men's total reported attachment to their baby was also generally high. Specifically, scores on the *Quality of Attachment* subscale were also significantly higher than those on the *Time in Attachment* subscale (*t* (223) = 38.9, *p* <.001).

Men felt the most acknowledgement for their grief from their partners, and the least acknowledgement from the wider community and healthcare professionals. Average agreement concerning the extent to which men felt they had a supporter role following the

Table 5. *Descriptive statistics for continuous variables*

	N	Mean	Range	*SD*
Total PGS score according to loss type				
Early loss (<20 weeks' gestation)*	82	93.4	47-152	23.2
Late loss (≥20 weeks' gestation)^	90	109.7	65-158	19.8
Neonatal death	46	107.0	65-151	23.4
Total PGS score according to time since loss				
Last 5 years	156	103.2	49-158	23.3
6-10 years ago	42	104.8	47-151	23.6
11-20 years ago	20	98.2	65-141	21.1
Individual-level variables				
Age at loss (in years)	225	32	17-58	5.5
Time since loss (in years)	228	4.3	0-20	55
PGS total score	218	103	47-158	23.0
Active Grief subscale	222	42.8	22-55	6.3
Difficulty Coping subscale	226	32.7	12-53	9.8
Despair subscale	226	27.2	11-54	9.1
GPI – Intuitive	225	19.6	8-24	3.8
GPI – Instrumental	227	17.6	5-25	4.1
PAAS total score	224	58.5	35-72	8.0
Quality of Attachment subscale	224	30.1	15-35	3.6
Time in Attachment subscale	228	19.7	5-28	4.5
Interpersonal-level variables				
Marital satisfaction at time of loss	228	4.8	1-5	0.6
Acknowledgement from partner	228	3.9	1-5	1.0
Acknowledgement from friends	228	3.0	1-5	1.1
Acknowledgement from family	228	3.4	1-5	1.2
CSS total score	226	30.9	10-48	8.3
Extent of agreement to: "My role following the loss was to support my partner and family"	228	4.5	1-5	0.8
Extent of agreement to: "I was unable to grieve, because I was too busy supporting everyone else"	228	3.3	1-5	1.3
Community-level variables				
Acknowledgement from community	228	2.1	1-5	1.1
CMNI Self-Reliance subscale	227	13.1	5-20	3.1
MRNI Toughness subscale	228	11.7	3-21	3.7
Policy/system-level variables				
Perceived extent of inclusion in the hospital	189	3.6	1-5	1.3

Acknowledgement from healthcare professionals	228	2.7	1-5	1.3

*Includes ectopic pregnancy, miscarriage and TOPFA at less than 20 weeks' gestation
^Includes TOPFA and stillbirth at or over 20 weeks' gestation

loss was high. However, agreement regarding the extent to which this role impacted men's ability to grieve was in the mid-range.

Multiple linear regression models

Multiple stepwise linear regression analyses were performed to determine which variables were associated with total grief (PGS total score), intuitive grief, and instrumental grief (GPI scores). Results for the three resulting models are presented below.

Model 1: Total grief (PGS)

Fourteen variables were below the 0.5 significance cut-off for inclusion in the final model for men's total grief scores, and seven of these had confidence intervals which did not contain zero (see Table 6). When adjusting for all other factors, men who lost a baby to miscarriage had a mean total PGS score of 16.5 points less than men who experienced a neonatal death. However, the confidence interval was wide, indicating a low level of precision in this estimate; this may be due to large variability in grief scores across loss types. Narrow confidence intervals, indicating higher levels of certainty, were observed for history of loss, time in attachment and overall support. Specifically, a higher number of previous pregnancy losses/neonatal deaths were associated with higher levels of grief, as were lower levels of overall support and increased time in attachment. Higher grief scores were also associated with lower levels of acknowledgement of grief from friends, as well as higher levels of agreement to the statement: "I was unable to grieve, because I was too busy supporting everyone else". However, the opposite was observed for acknowledgement from family, with men experiencing higher levels of grief with more acknowledgement. Again, though, confidence intervals were wide for these factors, indicating less certainty in the precision of the estimates.

Table 6. *Multiple stepwise linear regression for PGS total score (n = 204)*

	B	95% CI	SE *B*	*β*	*p*
Variables					
Loss focus					
Ectopic pregnancy	-4.09	(-18.78 – 10.60)	7.49	-.02	.59
TOPFA	-6.41	(-14.08 – 1.26)	3.91	-.09	.10
Miscarriage	**-16.48**	**(-23.01 – -9.95)**	3.33	-.32	<.001
Stillbirth	1.42	(-4.57 – 7.42)	3.06	.03	.64
Neonatal death	Ref	-	-	-	-
PAAS *Time in Attachment*	**2.10**	**(1.60 – 2.61)**	.26	.44	<.001
Age at loss (in years)	0.39	(-0.05 – 8.37)	.23	.09	.09
Number of previous losses experienced	**1.84**	**(0.18 – 3.49)**	.85	.10	.03
Marital satisfaction at the time of loss	-3.60	(-7.01 – 0.19)	1.74	-.10	.04
Agreement to the statement: My role following the loss was to support my partner and family”	-2.48	(-5.45 – 0.49)	1.52	-.09	.10
Agreement to the statement: “I was unable to grieve, because I was too busy supporting everyone else”	**3.45**	**(1.45 – 5.45)**	1.02	.21	<.01
CSS total score	**-.69**	**(-1.12 – -0.26)**	1.02	-.24	<.01
Extent of acknowledgement of grief from family	**3.39**	**(0.74 – 6.05)**	1.36	.16	<.01
Extent of acknowledgement of grief from friends	**-2.89**	**(-5.75 – -0.03)**	1.46	-.13	.05
Extent of acknowledgement from wider community	-1.92	(-4.44 – 0.59)	1.28	-.11	.13
CMNI *Self-Reliance*	.47	(-0.32 – 1.25)	.40	.07	.25
Workplace leave					
Employment leave offered	21.44	(-11.11 – 53.99)	16.61	.47	.19
Employment leave not offered	21.12	(-11.61 – 53.86)	16.70	.39	.21
Did not inform employer of loss	Ref	-	-	-	-
Other workplace supports					
Other supports offered	-23.42	(-56.45 – 9.60)	16.85	-.49	.17
Other supports not offered	-25.75	(-59.17 – 7.66)	17.05	-.58	.13
Did not inform employer of loss	Ref	-	-		-

Model 2: Intuitive grief (GPI)

Thirteen variables met the 0.5 significance cut-off for inclusion in the final model for intuitive grief, although only one had a confidence interval which did not contain zero (see Table 7). Lower reported levels of acknowledgement from healthcare professionals were associated with higher intuitive grief scores.

Table 7. *Multiple stepwise linear regression for intuitive grief (n = 210)*

	B	95% CI	SE *B*	*β*	*p*
Variables					
Ultrasound viewing					
Ultrasound viewed during pregnancy	1.5	(-0.01 – 3.03)	.77	.15	.05
Ultrasound not viewed during pregnancy	Ref	-	-	-	-
Ethnicity					
Other	1.17	(-0.12 – 2.35)	.60	-.13	.05
Australian	Ref	-	-	-	-
PAAS *Quality of Attachment*	.10	(-0.02 – 0.22)	.06	.12	.09
Age at loss (in years)	.07	(-0.02 – 0.16)	.05	.07	.10
Number of surviving children at loss	-.20	(-0.67 – 0.27)	.24	-.05	.40
Agreement to the statement: “My role following the loss was to support my partner and family”	-.37	(-0.90 – 0.15)	.27	-.08	.16
CSS total score	.06	(0.4 – -0.01)	.04	.15	.10
Extent of acknowledgement for grief from family	.26	(-0.24 – 0.76)	.26	.11	.31
CMNI *Self-Reliance*	-.14	(-0.29 – 0.02)	.08	-.12	.08
MRNI *Toughness*	-.05	(-0.17 – 0.06)	.06	-.07	.37
Workplace leave					
Employment leave offered	4.98	(-1.2 – 11.16)	3.16	.73	.11
Employment leave not offered	4.93	(-1.3 – 11.19)	3.19	.62	.12
Did not inform employer of loss	Ref	-	-	-	-
Other workplace supports					
Other supports offered	-3.38	(-9.72 – 2.95)	3.23	-.57	.29
Other supports not offered	-3.78	(-10.19 – 2.63)	3.27	-.67	.25
Did not inform employer of loss	Ref	-	-	-	-
Extent of acknowledgement from healthcare professionals	**-.46**	**(-0.84 – -0.08)**	.20	-.18	.02

Model 3: Instrumental grief (GPI)

Sixteen variables met the 0.5 significance cut-off for inclusion in the final model for instrumental grief; of which, eight had confidence intervals which did not contain zero (see Table 8). While increased quality of attachment was associated with a slight decrease in men's grief scores, higher scores on time in attachment were associated with an increase in grief. Although the supporter role itself was not associated with instrumental grief, men who perceived their supporter role as interfering more with their ability to grieve experienced higher levels of instrumental grief. Lower grief scores were associated with higher levels of total support. More specifically, higher perceived acknowledgement of men's grief from their partner was associated with a reduction in grief. Higher endorsement of masculine ideals on the CMNI *Self-Reliance* subscale was associated with higher levels of instrumental grief. Finally, men who did not inform their workplace of their loss had higher levels of grief in comparison to those who did; this was regardless of whether workplace leave was offered to those who informed their employer. However, the confidence intervals for these workplace factors were wide, indicating a degree of caution should be exercised regarding the strength of these relationships.

Discussion

Main findings and implications

This study, using multivariable linear regression analyses, explored relationships between men's grief following pregnancy loss/neonatal death and a range of previously identified socio-ecological factors [36]. In relation to the severity of men's grief (as measured by the PGS), men who had experienced previous losses, lower levels of social support and more time bonding with their baby during pregnancy had higher grief scores. Men who had lower marital satisfaction, little acknowledgement of their grief from friends, felt as though their role as a 'supporter' prevented them from grieving and experienced higher levels of

Table 8. *Multiple stepwise linear regression for instrumental grief (n = 210)*

	B	95% CI	SE *B*	*β*	*p*
Variables					
Loss focus					
Ectopic pregnancy	-.91	(-3.8 – 1.99)	1.48	-.03	.54
TOPFA	-.38	(-1.86 – 1.10)	.76	-.04	.62
Miscarriage	-1.12	(-2.43 – 0.20)	.67	-.12	.09
Stillbirth	.21	(-0.98 – 1.41)	.61	.02	.73
Neonatal death	Ref	-	-	-	-
Ethnicity					
Other	-.41	(-1.59 – 0.77)	.60	.06	.49
Australian	Ref	-	-	-	-
PAAS *Quality of Attachment*	**-.15**	**(-0.30 – -0.01)**	.07	-.15	.03
PAAS *Time in Attachment*	**.16**	**(0.04 – 0.27)**	.06	.17	<.01
Age at loss (in years)	-.84	(-0.17 – 0.01)	.05	-.12	.06
Importance of religion	-.25	(-0.57 – 0.08)	.17	-.11	.13
Marital satisfaction at the time of loss	.43	(-0.40 – 1.26)	.42	.07	.31
Agreement to the statement: “My role following the loss was to support my partner and family”	.49	(-0.05 – 1.03)	.27	.09	.07
Agreement to the statement: “I was unable to grieve, because I was too busy supporting everyone else”	**.51**	**(0.13 – 0.89)**	.20	.18	<.01
CSS total score	**-.08**	**(-0.16 – -0.01)**	.04	-.18	.03
Acknowledgement of grief from partner	**-.53**	**(-0.99 – -0.06)**	.24	-.17	.03
Acknowledgement of grief from friends	.27	(-0.26 – 0.77)	.24	.07	.29
CMNI *Self-Reliance*	**.19**	**(0.03 – 0.34)**	.08	.16	.02
MRNI *Toughness*	.07	(-0.04 – 0.19)	.06	.08	.22
Workplace leave					.09
Employment leave offered	**-2.01**	**(-3.63 – -0.39)**	.83	-.14	.02
Employment leave not offered	**-2.25**	**(-3.98 – -0.52)**	.89	-.15	.01
Did not inform employer of loss	Ref	-	-	-	-
Perceived degree of inclusion in the hospital					.33
High level of inclusion	-.103	(-1.39 – 1.18)	.66	-.04	.88
Low level of inclusion	-.48	(-1.82 – 0.85)	.68	-.11	.48
No contact with a hospital	Ref	-	-	-	-

acknowledgement from family also had higher grief scores; however, the precision of the strength of relationships for these factors was less certain. Men’s grief scores also differed depending on the type of loss experienced; however, again, the extent to which loss type impacted grief scores was also less certain.

Factors associated with men’s grief also differed depending on grief style. There was a high level of confidence that increased perceived support from healthcare professionals was associated with lower levels of intuitive grief. Results also indicated that viewing an ultrasound image of their baby during pregnancy, identifying with an ethnicity other than Australian, developing a higher quality of attachment to the baby during pregnancy, higher levels of overall social support, and lower endorsement of self-reliance could be relevant for intuitive grief. However, given the confidence intervals for these factors just crossed zero, further research is needed to confirm the direction of the associations. In relation to instrumental grief scores, men who had higher levels of social support, high quality of attachment to their baby during pregnancy, and acknowledgement of grief from their partner, had reduced instrumental grief. In contrast, perceptions of their supporter role interfering with their grief, higher tendencies toward self-reliance, as well as an increased amount of time spent bonding with their baby during pregnancy, were associated with higher levels of instrumental grief. Men who did not inform their workplace of their loss also had higher levels of instrumental grief than men who did, however the precision of these estimates was less certain. While it is possible that informing an employer leads to lower grief levels (e.g., through enhancing recognition of grief), this finding may also be reflective of the instrumental grief style itself, which typically involves coping in isolation and privacy [27].

These findings relating to grief styles imply that strategies to best support men may need to vary depending on men’s grieving style. For example, intuitive grievers may benefit from higher levels of healthcare professional support and acknowledgement in the hospital, whereas instrumental grievers may benefit more from external social supports and higher levels of partner acknowledgement for their grief. This idea is in line with research on grief styles, which suggests that intuitive grievers more frequently access professional counselling services, whereas instrumental grievers rely on informal social supports [27, 86]. However, this is not to say that counselling is unsuitable for instrumental grievers. Rather, traditional counselling services may need to better target and support the unique needs of instrumental grievers and use tailored marketing strategies to increase their appeal/accessibility among men [86-88]. In addition, receiving adequate informal social supports may be a useful first step to providing recognition and validation to instrumental grievers, which could then lead to accessing more formal support services where required.

Although men who had experienced an early gestation loss (before 20 weeks' gestation) had the lowest average grief score, their scores still met the cut-off for a high degree of grief. Standard deviations also indicated a wide variation in scores across loss types, supporting the view than grief is a highly individualised experience, not necessarily dependent on the gestational age of the baby [10, 12, 36]. Overall, men who experienced later-gestation loss (including stillbirth and TOPFA after 20 weeks' gestation) had the highest average grief scores. Such high levels of grief may be related to both the unexpected nature of stillbirth, specific challenges associated with TOPFA, and with the stigma and disenfranchisement that many bereaved parents experience [1, 5-8, 10, 17, 89, 90]. In comparison to a neonatal death, which may be due to known medical complications and managed through a Neonatal Intensive Care Unit (NICU), parents who experience stillbirth continue to report variation in care received and availability of support services [42, 93-96].

Men's role as a 'supporter' to their female partner has been a consistent finding across studies [10, 12, 13, 36, 39, 40, 60]. However, our findings suggest that this role in and of itself was not a substantial contributor to men's grief intensity. Instead, it was the extent to which men perceived the supporter role to interfere with their grieving that was significant, particularly for instrumental grievers. Assuming a supporter role is not necessarily a negative contributor to the grief experience but, where this role takes precedence over men's needs, it may become detrimental to their grief. It is therefore imperative that healthcare professionals are equipped to assist men to balance their desire and need to support their partner, while also addressing their grief and need for support. Healthcare professionals may assist men to achieve balance by not only providing them with tailored practical tips for supporting their partner but also acknowledging their grief and making efforts to provide active, ongoing support in the weeks/months following the loss.

In line with previous research, the degree of men's attachment to their baby during pregnancy was associated with grief [10, 16, 36]. Although viewing an ultrasound was associated with instrumental grief, broader measures of attachment, including both time in attachment and quality of attachment, had stronger associations with grief in general. These findings are in contrast to early research suggesting that viewing an ultrasound and attending obstetric appointments were the main drivers of men's attachment to a developing baby [24, 25, 37], demonstrating that many men develop a very early prenatal attachment to their baby.

Although the precision of the estimate was uncertain, one of the more unexpected findings was that higher levels of grief were associated with more acknowledgement from family. This relationship could be purely correlational, in that men who experienced higher grief sought more acknowledgement and support from family members. However, it could also be that although men received support from their family, the type of support received did not address their needs. For example, previous research suggests that although family members may be available to support men, the support may not be effective. Challenges to providing effective support reported by men have included a lack of understanding or unhelpful comments despite well-meaning intentions [10-12, 32, 97], feeling as though they needed to support their family members through their grief [10, 13, 16, 32, 97, 98], not feeling comfortable discussing their feelings with family members (where family referred to people other than their female partner) [12], and a desire for practical support (e.g., cooking, cleaning, childcare) as well as emotional support [16]. In line with research exploring the impact of pregnancy loss and neonatal death on extended family members including siblings and grandparents [99-103], this finding supports a family-centred approach to providing information and support for loss and grief, so that all family members involved in the experience of loss are better able to support one another.

Strengths, limitations and future research

Previous research involving bereaved parents has noted difficulties in representing men’s perspectives, with female participants, more often than not, outweighing men [7, 9, 95, 103]. This study is one of the largest samples of men to have been surveyed on their experiences of grief following pregnancy loss and neonatal death in Australia. In line with father-inclusive practice recommendations [88, 104], targeting the research directly for ‘men/fathers’ specifically, rather than ‘parents’ collectively, was a successful approach. However, although the sample is sizeable, the convenience nature of sampling is open to potential bias in that participants may have been unique from other men who chose not to participate. For example, one third of participants in this study had experienced four or more previous losses. Participants were also recruited through advertisements disseminated by Australian pregnancy loss and neonatal death support organisations. This recruitment approach could constitute a sampling bias in that men who were not connected to these organisations would not have had access to the information to participate.

High levels of internal consistency were observed for the majority of included measures. However, a low Cronbach's alpha was observed for the *Toughness* subscale of the MRNI. Although this measure of 'toughness' did not emerge as a significant predictor in any of the models in the current study, it may still be an important factor to consider, as a low alpha value may indicate that this measure did not adequately capture men's experiences of needing to be 'strong' or 'tough' as reported in previous qualitative studies [10, 12, 13, 31, 36].

Future research could explore alternative ways to measure this construct and assess whether it is important in explaining men's grief.

Although the majority of men reflected on losses within the last five years, this study relied on retrospective accounts of grief which may be open to recall bias, especially for the small number of losses which had occurred up to 20 years ago. Although we found no substantial differences in grief scores according to time since loss in our sample, changes in individual, community and health system/policy level support over time are likely to shape men’s grief outcomes. For example, the Australian government recently announced policy changes to allow parents up to 12 months of unpaid leave following a stillbirth [105]. This change is a substantial step forward for recognition of parents’ grief after stillbirth, and may ease the burden of grief on men. However, this research was conducted before these changes and future research is recommended to monitor trends in uptake and impact upon grief. Longitudinal studies which follow men during pregnancy and in the event of a pregnancy loss or neonatal death would be useful to identify the factors associated with grief at the time of loss, as well as to trial support services which may be useful.

The cultural diversity of the sample was also limited. Although men who identified as Australian had slightly higher levels of intuitive grief, no other associations were identified in relation to ethnicity. There is an ongoing and pressing need to examine the experiences of culturally and linguistically diverse men following pregnancy loss and neonatal death, as well as men in some countries where pregnancy and childbirth are still very much considered ‘women’s business’ [33, 60, 106]. This is despite increasing evidence of the health benefits for both mother and baby when male partners are engaged in pregnancy and birth [106-110]. Finally, although this study was open to non-heterosexual men, only one participant identified as bisexual, and none as gay or transgender. Given research to suggest that gay and transgender men may face unique challenges concerning pregnancy, birth and loss [111-114], there is a need for research specifically targeting the experiences of these under-represented groups.

Conclusions

As this is one of the first studies to comprehensively explore multiple socio-ecological factors associated with men’s grief following pregnancy loss and neonatal death, many of the findings are relatively novel and require further research to understand the causal pathways underlying relationships. However, what is clear is that men often experience significant grief following a pregnancy loss or neonatal death. There is a need to initiate and trial support interventions targeted specifically to men and designed with consideration for the factors associated with men’s grief. Intervention strategies should engage individually with men both immediately in hospitals, and in the weeks/months following a loss, to ensure they have access to tailored support and services where these are needed. Intervention, particularly for intuitive grievers, could include formal brief assessment of men’s grief and mental health in the hospital and in the weeks/months following discharge (e.g., the Edinburgh Postnatal Depression Scale). Intervention, particularly for instrumental grievers, could also involve providing a follow-up telephone service specifically to men post-discharge from the hospital including referral to community-based supports where required, or delivering couples-based psychoeducation sessions to foster positive communication, mutual understanding of individual grief styles and information on supporting one another. At the service level, an intervention could include delivering father-inclusive training to healthcare professionals who work with couples experiencing pregnancy loss and neonatal death. To best assist men, genuine acknowledgement and engagement of men as equal partners throughout pregnancy, and in loss and grief, is required. Taking a public health or socio-ecological approach to understanding grief will also be beneficial in identifying target areas for strategies in all areas of men’s lives that may be affected by their grief.

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CHAPTER 5. PAPER THREE

Australian men's experiences of leave provisions and workplace support following pregnancy loss or neonatal death

5.1 Preamble

At the time of analysing data for Study 2, discussions were being held at Federal and State Parliaments in Australia regarding proposals to introduce up to 12 months of unpaid leave for all parents who experience a stillbirth. In addition, initial analysis of open-ended questions in the nationwide survey indicated that for some men, returning to work after pregnancy loss and neonatal death was a substantial challenge. Given no previous studies had focused specifically on the types of leave or psychosocial supports available to men after pregnancy loss and neonatal death, Study 3 analysed a subset of data from the nationwide survey relating to men's experiences of returning to work, using a combination of descriptive statistics and qualitative content analysis. This Chapter presents the paper that resulted from this study, which was accepted for publication in September of 2020 with the academic journal *Community, Work & Family*. Please note that the references for this paper are formatted in Vancouver style, as per submission for publication with *Community, Work & Family*. A separate reference list for this paper is provided at the end of the manuscript.

5.2. Statement of authorship

Title of Paper	Australian men's experiences of leave provisions and workplace support following a pregnancy loss or neonatal death
Publication Status	☑ Published ☐ Accepted for Publication ☐ Submitted for Publication ☐ Unpublished and Unsubmitted work written in manuscript style
Publication Details	Obst, K.L., Due, C., Oxlad, M., & Middleton, P. (2020). Australian men's experiences of leave provisions and workplace support following pregnancy loss or neonatal death. *Community, Work & Family*. https://doi.org/10.1080/13668803.2020.1823319

Principal Author

Name of Principal Author (Candidate)	Ms Kate Obst		
Contribution to the Paper	Conceptualised the paper. Completed data cleaning and analysis and prepared the organisation and presentation of data. Wrote the paper and prepared the manuscript for publication.		
Overall percentage (%)	85%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	2 February 2022

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Associate Professor Clemence Due		
Contribution to the Paper	Assisted with conceptualisation of the paper. Assisted with qualitative data analysis and contributed to organisation and presentation of the data and final results. Contributed to editing the draft manuscript.		
Signature		Date	26 January 2022

Name of Co-Author	Dr Melissa Oxlad		
Contribution to the Paper	Assisted with conceptualisation of the paper. Assisted with quantitative data analysis and contributed to organisation and presentation of the data and final results. Contributed to editing the draft manuscript.		
Signature		Date	27 January 2022

Name of Co-Author	Professor Philippa Middleton

Contribution to the Paper	Assisted with conceptualisation of the paper. Contributed to organisation and presentation of the data and final results. Contributed to editing the draft manuscript.		
Signature		Date	1 February 2022

5.3 Published paper

Abstract

This research note reports survey responses of Australian men (N=220) gathered as part of a larger study exploring men's grief following pregnancy loss and neonatal death. We explore the types of workplace leave offered to men and how men perceived leave and support provided by their employers. Almost all men (91%) informed their workplace of their loss, and 74% were offered some form of leave. The most common types of leave offered were compassionate/bereavement leave, and sick/carers leave. Supports included Employee Assistance Programs, referral to counselling, and flexible working arrangements. Open-ended responses highlighted five themes: *Emotional toll of returning to work*, *Need to be with and support partner*, *Recognition and understanding*, *Helpful distraction*, and *Pressure to return.* Not all men wished to take extended (or any) paid leave following pregnancy loss or neonatal death, though they believed leave should be available. It is essential that employers recognise men's bereavement following pregnancy loss and neonatal death, and that healthcare professionals support men's decisions about work.

Introduction

The death of a baby before or soon after birth is devastating for expectant parents. In Australia, one in four pregnancies ends in miscarriage, approximately 2,200 babies are stillborn, and up to 1000 babies die in neonatal intensive care each year (1,2). The impact of parents' grief is well recognised (3). However historically, pregnancy loss has been considered an issue concerning women, with men's roles considered primarily a 'supporter' to their female partner (4–8).

Men are increasingly involved in pregnancy and childbirth: attending antenatal screening, and participating in labour and parenting groups (9,10). These developments are positive for child and family outcomes, but are also key predictors of grief intensity following pregnancy loss and neonatal death (11–13). Although quantitative studies have typically found lower grief scores among men compared to women, grief levels are still high (14–16) and men interviewed in qualitative research have reported deep and enduring grief (4,8,17,18).

While parenting norms are changing, gendered differences in paid employment and childcare responsibilities remain prevalent (19). Men report difficulties in balancing family and work, with barriers including financial considerations, gendered expectations and workplace/employer resistance (20–23). While some research has explored the social and emotional impacts of pregnancy loss or neonatal death for men, the intersect of grief and working life has received less attention. Men typically report returning to work promptly following pregnancy loss (17,18). While some men find returning to work a welcome distraction after loss (24–26), others have reported physical and emotional exhaustion, and difficulties with concentration and managing workload (7,27–29). Overall, many men report that they are not offered equal leave opportunities as their female partners (7,17,29).

Workplace-related policies, including recognition of grief from employers and bereavement leave provisions for men, are therefore important (11).

In Australia, the 2018 Senate Inquiry into the Future of Stillbirth Research and Education in Australia highlighted the need for increased recognition of the economic and social impacts of stillbirth and infant loss (30). A lack of national standards concerning workplace leave following pregnancy loss was an important concern. Bereaved parents described inconsistent leave provisions which were often at employer discretion (30). The Inquiry found that in Australia, mothers and fathers of a stillborn baby (defined as over 400g or ≥20 weeks' gestation), or a baby who dies in the first 28 days following birth (neonatal death) may be eligible for 18 (shared) weeks of Paid Parental Leave (PPL), provided by the Australian Government (31). Where the mother takes parental leave, fathers may receive two weeks of Dad and Partner Pay, and/or a Stillborn Baby Payment (32,33). However, eligibility is subject to income caps and tests which exclude many employees, and other forms of loss (e.g., late-term miscarriage) (32). Where PPL is unavailable, two days' compassionate/bereavement leave may be granted, and/or employers may provide other forms of carers, sick or annual leave at an individual's request. However, many parents (including fathers) who contributed to the Inquiry noted that these combinations of leave were insufficient and relied on employer discretion (30). The Inquiry recognised a need for equity in leave provisions for mothers and fathers, recommending a review and further research. Early in 2020, new laws were proposed to provide mothers and fathers with up to 12 months of unpaid leave following stillbirth and infant death (34). In September 2020, these policy changes were accepted by government. Following a stillbirth parents will now be entitled to up to 12 months of unpaid parental leave (35).

This research note provides a preliminary investigation of Australian men's experiences of returning to work following pregnancy loss and neonatal death. We explore the types of workplace leave offered to men, and how men perceived current leave and support provided by their employers.

Study data and methods

Setting and design

This data was part of a larger program of research investigating men's experiences of grief following pregnancy loss and neonatal death. Pregnancy loss included ectopic pregnancy, miscarriage (<20 weeks of gestation), termination of pregnancy for nonviable foetal anomaly (TOPFA; at any stage of gestation) and stillbirth. Neonatal death included the death of a baby within 28 days of birth. The University of [removed for blind review] granted ethics approval for the research. Participants were men aged 18 years of age or older and fluent in English, who experienced a pregnancy loss or neonatal death in Australia within the last 20 years. Recruitment occurred via advertisements posted on the social media pages and newsletters of pregnancy loss and neonatal death support organisations.

Of 277 men who participated, 220 were employed at the time of loss and completed the full survey, comprising the current sample (see Table 9). At the time of participation, men were aged between 19 and 60 years (*M*=36, *SD*=7.3), and at the time of loss, between 18 and 58 years (*M*=32, *SD*=5.4). Where participants experienced multiple losses, they were asked to reflect on only one of these of their choosing.

Data sources and analyses

Survey

Between June and August 2019, men completed a web-based survey via SurveyMonkey. As part of a larger pool of questions, men were asked about their employment status at the time of the pregnancy loss or neonatal death. If employed, they were presented with a series of questions relating to their experiences of returning

Table 9. *Participant characteristics*

	Category	***N* (%)**
Age at loss	18-29	68 (31)
	30-39	130 (58)
	40-49	18 (8)
	50-59	1 (0.5)
	Missing	3 (2)
Ethnicity^	Australian	187 (85)
	Other	33 (15)
Education level	High School	50 (23)
	TAFE/Trade	80 (36)
	Undergraduate Degree	57 (26)
	Postgraduate Degree	33 (15)
Marital status	Married	180 (82)
	In a relationship	33 (15)
	Divorced	1 (0.5)
	Separated	4 (2)
	Never married/single	2 (1)
Losses experienced	One	132 (60)
	Two	45 (20)
	Three	22 (10)
	Four-five	11 (5)
	Six or more	10 (5)
Loss type reflected on	<20 weeks' gestation*	81 (37)
	≥20 weeks' gestation#	94 (42)
	Neonatal death	45 (21)
Time since loss	Less than one year	50 (23)
	One-two years	52 (24)
	Three-five years	60 (27)
	Six-10 years	42 (19)
	11-15 years	7 (3)
	16-20 years	9 (4)

^ Self-reported, in response to the question: to which ethnic background do you most identify?
* Includes ectopic pregnancy, miscarriage and TOPFA <20 weeks' gestation.
# Includes stillbirth and TOPFA ≥20 weeks' gestation.

(or not returning) to work, with categorical and open-ended response categories, including: "*How soon did you return to work following your loss?*", "*Did you inform your workplace of your loss?*", "*Were you offered any employment leave by your workplace?*", and, if yes, *"What types of employment leave were you offered?".* Finally, men were asked one of two optional open-ended questions, depending on responses to the previous questions. Men who had returned to work were asked: "*In your opinion, could your workplace have offered anything else to make your transition back to work easier?*" For men who did not return to work were asked: "*Can you tell us why you did not return to work*?".

Quantitative data were analysed in SPSS (V24.0). Descriptive statistics were used to explore the research questions. Chi-square tests were used to determine differences between loss types, categorised according to Australian cut-offs differentiating between losses <20 weeks of gestation and ≥20 weeks of gestation. Responses to open-ended questions were analysed using conventional content analysis (36). This approach was chosen as it aligned with the aim to describe men's experiences of returning to work following pregnancy loss/neonatal death, in the context of limited existing theory and previous research (36). Given limited literature in the area, an inductive approach was used whereby themes were identified from the text data itself, as opposed to being guided by theory or previous research findings. The first author manually generated the initial codes by highlighting words that appeared to reflect key concepts. Related codes were then grouped into themes, and reviewed by all of the researchers to ensure they remained reflective of the dataset. Author consensus was reached for the final themes.

Results

Quantitative data

Returning to work

Following their loss, men returned to work "within a couple of days" (18%, N=40), one week (13%, N=29), two weeks (23%, N=50), or one month (22%, N=49). Nineteen returned to work the next day (8%).

Men who lost a baby before 20 weeks' gestation returned to work sooner than men who lost a baby to stillbirth or neonatal death (Fisher's Exact test p<.001). Following losses before 20 weeks, most men returned to work "within a couple of days" (38%, N=31), whereas following stillbirth, most returned to work within two weeks (32%, *N*=30) to one month (34%, *N*=32), and following neonatal death, within one (29%, *N*=13) to three months (31%, *N*=14; see Figure 3).

Two men (who experienced miscarriage and stillbirth) did not return to work following their loss. Two men who experienced recent losses (TOPFA and stillbirth; one, and two months ago) had not yet returned to work, but planned to soon.

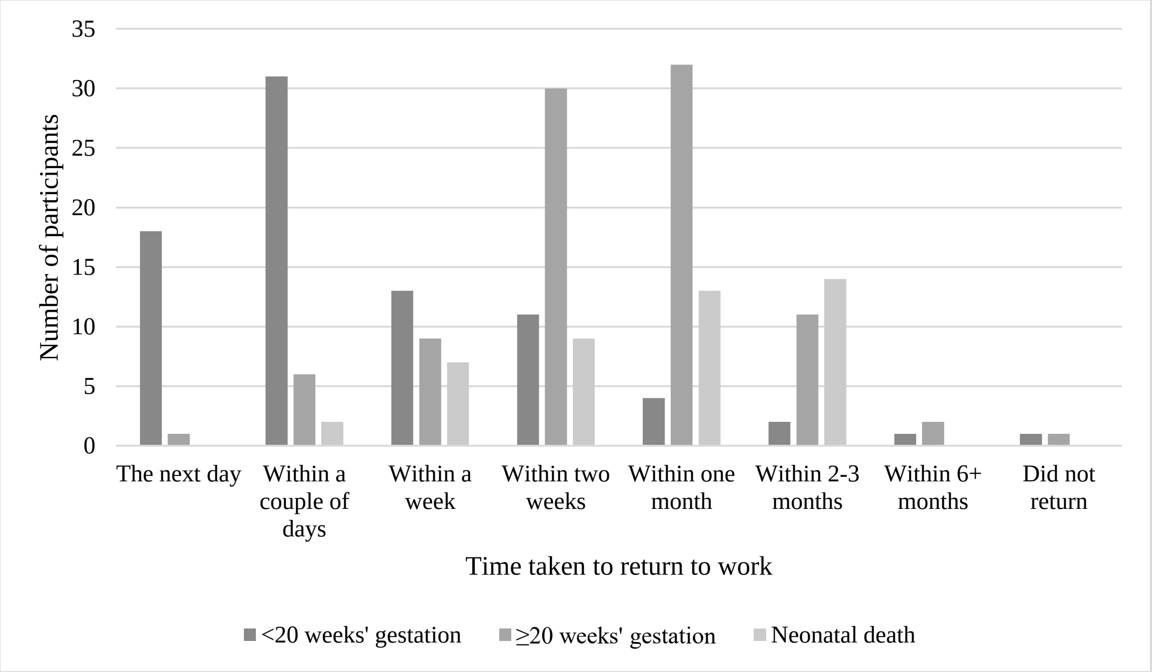

Figure 3. *Time taken to return to work by loss type*

Workplace leave

Most men (91%, *N*=198) informed their workplace of their loss, and of these, 74% (*N*=146) were offered leave by their employer. There was a significant association between loss type and whether men informed their workplace (Fisher's Exact test *p*<.001). Men who experienced a loss before 20 weeks' gestation were the least likely to inform their employer.

Men who experienced loss before 20 weeks' gestation were also the least likely to be offered workplace leave (67%, *N*=42), in comparison to 77% (*N*=71) and 75% (*N*=33) of men who experienced a stillbirth or neonatal death, respectively. However, the difference between loss type and leave offered was not statistically significant (X^2 (2, N=198) = 1.748, p=.44).

The types of leave offered to men were compassionate/bereavement leave (62%, N=91), sick/carers leave (42%, N=61), annual leave (19%, N=28), parental leave (17%, N=25), and leave without pay (14%, N=21). In all cases but parental leave, the leave offered therefore reduced available leave for other reasons (e.g., reducing available future sick leave). Parental leave (as an additional leave category) was offered to one man who experienced a loss before 20 weeks' gestation, 11 (14%) who experienced stillbirth, and 13 (29%) who experienced neonatal death.

Whether men were offered leave by their workplace did not differ significantly according to time since the loss occurred (X^2 (3, N=220) = 2.046, p=.56). For men who experienced losses within the last five years, 66 (41%) returned to work within one week following the loss, 71 (44%) returned within two weeks to one month, and 21 (13%) returned within two-six months. For men whose losses occurred six-20 years ago, 21 (36%) returned to work within one week following the loss, 28 (48%) returned within two weeks to one month, and nine (15%) returned within two-six months. Men who experienced losses more than five years ago were also not significantly less likely to take leave (Fisher's Exact test p>.05) or to be offered parental leave (X^2 (1, N=146) = 0.175, p=.67). In total, 19 men (18%) who experienced their loss within the last five years were offered parental leave, in comparison to six men (15%) who experienced their loss six to 20 years ago.

Additional workplace support

Beyond workplace leave, employers of 76 men offered additional support. This support included referral to an Employee Assistance Program (EAP) or counselling services (N=47), and flexibility in work hours/location (N=32). There was no significant difference between loss type and offer of additional supports (X^2 (2, N=198) = 5.208, p=.07).

Qualitative data

154 men responded to the open-ended question regarding whether their employer could have done anything else to aid their return to work. Some simply replied "yes" (*N* =12), or "no" (*N*=57). Only two men did not return to work; one was made redundant on the day of his loss, and the other was fired after requesting an extended period of leave. From 85 men who provided more in-depth responses to the first open-ended question, five key themes were identified.

The emotional toll of returning to work

Across loss types, returning to work took an emotional toll on men. Seventeen men reported feeling as though they were not their "normal self" or emotionally burnt-out, which led to decreased productivity and difficulty coping with their usual tasks/workload. One man who experienced stillbirth described:

> *"I feel I was forced back into my normal duties way too soon [...] because of that I am struggling more to cope now"*

Another man, who experienced TOPFA at 21 weeks, reported his choice to return to work early resulted in unresolved feelings of anger and "uncharacteristic outbursts at co-workers". Because of such experiences, 17 men – who were and were not offered leave following their loss – reinforced a desire for some or more paid leave. Even where leave was offered, 15 men also desired flexible hours or reduced workload, and six expressed a need for counselling.

Need to be with and support partner

In addition to their grief, 17 men said supporting their partner was a central concern. Although most of these men had access to some form of workplace leave, they also desired flexibility in work hours to "be with" their partner. For example, a man who experienced TOPFA at 24 weeks said:

> *"I tried to come back [to work] after two weeks but only lasted one week as my wife wasn't coping. I took a further four weeks."*

Six men, who experienced stillbirth or TOPFA, expressed gratitude for employers who "made allowances" for additional leave or ongoing flexibility to support their partner. Eleven men who also experienced stillbirth and TOPFA expressed a desire for flexibility. This flexibility was needed not only for the immediate aftermath, but also in the weeks/months following and in subsequent pregnancies.

Understanding and recognition

The level of support and understanding men received from their employers and co-workers impacted their grief and ability to return to work, regardless of loss type. Nineteen men described a lack of understanding from employers, while 21 described positive experiences with employers who recognised the significance of their loss. The nature of these experiences did not seem to vary substantially according to time since men's losses occurred. Men expressed dissatisfaction when employers were "not understanding or forgiving for time off", or made "little effort" to ask them how they were coping. Five men also experienced avoidance from co-workers or "awkward conversations" when their employers had not informed others of their loss. In contrast, men expressed appreciation for empathetic employers who provided leave, flexible work, or reduced workload (where desired). One man whose baby died in the neonatal period described:

> *"My workplace was extremely supportive, allowed me as much time as I needed before returning to work, and then tried their best to ensure my workload was not too overwhelming until I was ready to take on additional tasks."*

Work/routine as a helpful distraction

Five men, representing all loss types, commented positively on returning to work after leave. These men used work to provide routine or to distract themselves "from the pain" of the loss. “Keeping busy” was described as a useful coping mechanism. One man who experienced a miscarriage commented:

> *“It was my choice to get back to work the day after the curette and my partner said to go to work. It has been a great way for me to keep busy but also work through it mentally while working. I work outdoors in a semi-labour intensive job.”*

For these men, offers to take workplace leave were appreciated, however they did not feel these were necessary to accept. For example, one man who experienced stillbirth and was offered both parental leave and the support of an EAP described:

> *“[My workplace was] very supportive. I just wanted to get back into routine at the time so didn't take up the full offer of leave and support.”*

Pressure to return

Despite being offered leave, five men, who had all experienced their losses within the last five years, noted financial pressure as the primary reason for an early return to work, resulting in “burnout”, “breakdown”, and reduced productivity. For example, a man who experienced stillbirth noted:

> *“I needed the money so dragged myself back, however I felt I was not productive until weeks later.”*

Another man, who also experienced stillbirth, described:

> *“I felt and still feel that work felt like I should have gotten over it sooner. And I felt the pressure every week that I should be back at work even though the counsellor strongly felt it would not be good for me or my family.”*

Four men who were self-employed also reported pressure to return, as they had no access to leave or supports.

Discussion

This research note described findings from a national survey examining Australian men's experiences of returning to work following pregnancy loss or neonatal death. As with men's individual experiences of grief and support following pregnancy loss and neonatal death (11,18,25,26), experiences of returning to work varied. Quantitative data indicated that most men informed their employers of their loss and were offered some form of workplace leave. However, only 11% were offered parental leave, the remainder having to rely on various forms of existing bereavement, annual or sick/carers leave. Qualitative data echoed this; while some men reported receiving adequate workplace leave and understanding from their employers, others reported a lack of opportunity to take leave, and a lack of empathy from employers and colleagues.

Reported time taken to return to work following a loss also varied greatly, from the next day to six months. Although some men commented that they found returning to work to be a useful distraction from grief, others who did not have access to leave described that returning prematurely can take an emotional toll, leading to burnout and decreased productivity. In line with previous literature which has found that men often assume a 'supporter role' following pregnancy loss and neonatal death (4–6,11), qualitative data also indicated the importance of workplace leave and flexibility for men to be with and support their female partner. Although these themes were shared across loss types, quantitative data demonstrated that men who experienced losses before 20 weeks of gestation returned to work sooner, with less access to leave and support in comparison to men who experienced later-gestation losses. This is despite high levels of grief following miscarriage (8,17,25) as well as stillbirth and neonatal death, highlighting the need for specific leave regardless of loss type. Healthcare professionals could discuss returning to work with men to ensure they have adequate support.

While the results provide important insights into the role of workplace leave following pregnancy loss and neonatal death, the survey data were self-reported and retrospective. Although most losses occurred within the last five years, responses may be biased by recall error as well as policy variations in availability of workplace leave for fathers – particularly for losses which occurred up to 20 years ago. However, analyses did not indicate any significant differences between type and duration of workplace leave according to time since the loss. For this research, we did not collect information on employment industry at the time of loss, as this was not the main focus of the overall survey. For men who experienced multiple losses, we also did not collect information to determine which loss men were reporting on (i.e., first loss or a subsequent loss). These details would be valuable in future research, given potential differences in availability of workplace leave between industries, as well as the impact of multiple losses on the type and duration of men's leave requests. Only a small percentage of the participants responded to the open-ended questions, and those who did often did so only briefly, leading to a lack of context in qualitative data. Although the sample is sizeable, convenience sampling is open to bias in that participants may have been unique from other men who chose not to participate.

It is important to note that this survey was conducted prior to the Australian Government's recent policy change allowing parents who experience stillbirth up to 12 months unpaid parental leave. Future research will be necessary to monitor trends in men's uptake of this new leave provision and explore any barriers or facilitators to utilisation of such leave. This is particularly important since analysis in this research showed no difference in uptake or offers of workplace leave by time since loss, suggesting little has changed in this area in Australia in the past 20 years at least.

Conclusions

Understanding men’s preferences around returning to work can assist healthcare professionals and support organisations to best work with men in this area, as well as to advocate for workplace change relating to leave provisions. A national, standardised approach to leave provision and additional support is recommended, to ensure men’s grief is recognised and adequate support is provided upon return to work. The Australian Government’s recent policy changes in relation to providing parents with leave following stillbirth represent a substantial step toward achieving this. Employers may also benefit from training about providing empathy and additional support for men upon return to work. These approaches could not only ease the burden of grief for men and families, but also result in increased productivity and reduced periods of absenteeism.

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CHAPTER 6. PAPER FOUR

Men's experiences and need for targeted support after termination of pregnancy for foetal anomaly: A qualitative study

6.1 Preamble

In reviewing responses to open-ended questions for the nationwide survey, men who experienced a TOPFA seemed to experience specific challenges regarding grief, including stigma and judgement from others toward their decision to terminate the pregnancy in the context of their baby receiving a diagnosis of life-limiting foetal anomalies. Given very few studies had previously examined men's experiences of grief and support following TOPFA, this final study for the program of research aimed to address this gap. This Chapter presents the paper that resulted from this study, which was accepted for publication in April of 2021 with the *Journal of Clinical Nursing*. Please note that the references for this paper are formatted in APA style, as per requirements for publication with the *Journal of Clinical Nursing*. A separate reference list for this paper is provided at the end of the manuscript.

6.2 Statement of authorship

Title of Paper	Men's experiences and need for targeted support after termination of pregnancy for foetal anomaly: A qualitative study
Publication Status	☑ Published ☐ Accepted for Publication ☐ Submitted for Publication ☐ Unpublished and Unsubmitted work written in manuscript style
Publication Details	Obst, K., Due, C., Oxlad, M., & Middleton, P. (2021). Men's experiences and need for targeted support after termination of pregnancy for foetal anomaly: A qualitative study. *Journal of Clinical Nursing, 30(17-18)*, 2718-2731. https://doi.org/10.1111/jocn.15786

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Contribution to the Paper	Conceptualised the study and formulated interview questions. Recruited participations, conducted and transcribed all interviews. Completed data analysis and prepared results for presentation. Wrote the paper and prepared the manuscript for publication.		
Overall percentage (%)	85%		
Certification:	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.		
Signature		Date	2 February 2022

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

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Signature		Date	27 January 2022

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Signature		Date	1 February 2022

6.3 Published paper

Abstract

Aims and objectives: To explore men's experiences of termination of pregnancy for life-limiting foetal anomaly, including how healthcare providers, systems and policies can best support men and their families.

Background: While there is a sizable body of research and recommendations relating to women's experiences of grief and support needs following a termination of pregnancy for foetal anomaly, very few studies specifically examine men's experiences.

Methods: Semi-structured interviews were completed with ten Australian men who had experienced termination of pregnancy for life-limiting foetal anomalies with a female partner between six months and 11 years ago. Interviews were completed over the telephone and data were analysed using thematic analysis. COREQ guidelines were followed.

Results: Thematic analysis resulted in the identification of three over-arching themes, each with two sub-themes. First, participants described the decision to terminate their pregnancy as *The most difficult choice,* with two sub-themes detailing 'Challenges of decision-making' and 'Stigma surrounding TOPFA'. Second, participants described that they were *Neither patient, nor visitor* in the hospital setting, with sub-themes 'Where do men fit?' and 'Dual need to support and be supported'. Finally, *Meet me where I am* described men's need for specific supports, including the sub-themes 'Contact men directly' and 'Tailor support and services'.

Conclusions: Findings indicated that TOPFA is an extremely difficult experience for men, characterised by challenges in decision-making and perceived stigma. Men felt overlooked by current services, and indicated that they need specific support to assist with their grief. Expansion of existing infrastructure and future research should acknowledge the central role of fathers and support them in addressing their grief following TOPFA.

Relevance to clinical practice: Nursing/midwifery professionals are well situated to provide

men with tailored information and to promote genuine inclusion, acknowledgement of their grief and facilitate referrals to community supports.

What does this paper contribute to the wider global clinical community?

- This research provides new insights into the grief, healthcare and support experiences of men following termination of pregnancy for life-limiting foetal anomaly. Men experience unique challenges in comparison to women and require tailored information, direct support and active assessment and follow-up to both manage their grief and support their partner.
- Midwifery/nursing staff and other healthcare professionals need to consider men's experiences and needs throughout the processes of decision-making, birth and follow-up. In addition, healthcare systems and policies require a family-centred and father-inclusive approach to promote genuine inclusion and acknowledgement of men as equal partners in pregnancy and childbirth.

Introduction

Receiving news of a suspected anomaly is distressing for expecting parents, who frequently report intense emotional responses including shock, grief, anger, uncertainty and fear (Hodgson & McClaren, 2018; Pitt et al., 2016). Depending on the diagnosis, parents may also face the difficult decision of whether to medically terminate the pregnancy. Several international guidelines exist for support through decision-making and bereavement care following termination of pregnancy for life-limiting foetal anomaly (TOPFA). However, while there is a sizable body of research and recommendations relating to women's experiences of grief and support needs (e.g., Asplin et al., 2014; Irani et al., 2019; Atienza-Carrasco et al., 2019; Pitt et al., 2016), as well as a growing body of research focusing on men's experiences of grief and care following miscarriage and stillbirth (e.g., Bonnette & Broom, 2012; Miller et al., 2019; Obst & Due, 2019a), there are few studies specifically on men's experiences of TOPFA, particularly in the Australian context (Hodgson et al., 2016). This gap is important, given marginal to no differences identified between men and women's grief and trauma responses to TOPFA (Korenromp et al., 2005, 2007; Nazaré et al., 2014).

Background

International research indicates that although rates of TOPFA vary according to the type and severity of anomalies – as well as different laws between and within countries – a substantial proportion of expecting parents whose pregnancies are diagnosed with life-limiting anomalies choose to terminate (Schechtman et al., 2002). Most of these occur in the second trimester of pregnancy, with late terminations at or over 24 weeks of gestation generally remaining rare (0.55 per 1000 live births according to European data; Garne et al., 2010). In the United Kingdom (UK), approximately 2,700 terminations for foetal anomaly occur annually (Department of Health, 2014), while 77% of women in a large institutional sample from the United States (US) undertook TOPFA before 24 weeks' gestation (Schechtman et al., 2002). In Australia, national data is not collected on TOPFA; instead occurring at the state or territory level. In South Australia, the 2017 perinatal mortality rate including TOPFA was 9.0 per 1000 live births (SA Health, 2019). Where an anomaly is discovered after 20-24 weeks' gestation (depending on local/state-based laws), permission to medically terminate must be sought from registered medical practitioners, or be subject to independent review from multiple healthcare professionals or hospital ethics boards.

Despite the frequency of prenatal testing and diagnoses, international research on parents' experiences of TOPFA has indicated mixed experiences with grief, healthcare and decision-making support. While TOPFA could be considered an active decision, parents nevertheless experience intense and enduring grief, comparable to the experience of a spontaneous miscarriage or stillbirth (Hunt et al., 2009) with grief and trauma symptomatology potentially continuing for several years (Kersting et al., 2005; Nazaré et al., 2014). Following TOPFA, parents may experience additional fears of judgement due to ongoing contentions surrounding abortion and the fraught moral and ethical concerns which frequently accompany such decisions (France et al., 2013; Hanschmidt et al., 2018; Irani et al., 2019).

While research from the USA, Australia and Europe has recommended structured perinatal palliative care programs for families who choose to continue a pregnancy with foetal anomalies (Cortezzo et al., 2020; Flaig et al., 2019; Guimarães et al., 2019; O'Donoghue, 2019; Weeks et al., 2020), following TOPFA many parents have reported feeling inadequately supported. Specifically, concerns have included a lack of relevant information to inform decision-making, inconsistent levels of support during the termination and in follow-up, and perceived negative attitudes from healthcare professionals (Hodgson et al., 2016; Pitt et al., 2016).

Informed by research among bereaved parents, Australia/New Zealand, the UK and Ireland have published national bereavement care guidelines for pregnancy loss and neonatal death, including recommendations for TOPFA (Boyle et al., 2020; Health Service Executive, 2016; NBCP, 2020). However, while general recommendations refer to 'supporting bereaved parents and families', most of these documents include limited to no recommendations specifically concerning bereaved fathers.

A small number of qualitative studies from the UK (Robson, 2016), France (Kecir et al., 2020), Sweden (Carlsson & Mattsson, 2018) and Taiwan (Sun et al., 2018) have focused exclusively on men's experiences of TOPFA. Across these, men have reported intense emotional responses, with some unique challenges compared to women. Not dissimilarly to women, men's reactions to TOPFA include shock, fear, anger and sadness (Carlsson &

Mattsson, 2018; Kecir et al., 2020; Robson, 2016). However, throughout the subsequent decision-making and termination process, men frequently set aside or hide their emotions to adopt supportive roles, reporting a wish to remain strong to 'protect' their female partners (Carlsson & Mattsson, 2018; Kecir et al., 2020) whilst simultaneously acting as a parent, bystander, information-gatherer and joint decision-maker (Sun et al., 2018).

As a consequence of remaining strong, minimisation, internalisation and avoidance have been reported as common coping strategies (Kecir et al., 2020). These coping strategies are in line with an instrumental or activity-focused grief style, which research suggests men frequently display in response to the death of a baby (Obst et al., 2020b). Many men have also identified feeling excluded from medical care and support during TOPFA, with care focused primarily on women's physical and emotional needs (Robson, 2016; Sun et al., 2018). Where men have felt as though healthcare professionals have overlooked their position as a father, their emotional responses and grief are worsened (Kecir et al., 2020). Given the potential for specific challenges associated with men's grief and roles following TOPFA and a lack of recommendations regarding bereavement care for men, this study aimed to explore men's experiences of grief and support following TOPFA including how healthcare providers, systems and policies can best support men and their families.

Methods

Design

This study is part of a wider program of mixed-methods research investigating Australian men's experiences of grief following pregnancy loss and neonatal death (other results published elsewhere; see Obst et al. 2020a, 2020b; Obst et al., 2021). This study employed a qualitative design using individual interviews, underpinned by a realist ontological position whereby participants' accounts were assumed to be a direct reflection of their lived experiences. Given the exploratory aims of the research, interviews took a semi-structured approach using open-ended questioning. Questions were developed based on the authors' previous qualitative research on pregnancy loss and men's grief (Obst & Due, 2019a, 2019b), as well as previous research specifically on men's experiences of TOPFA (Carlsson & Mattsson, 2018; Kecir et al., 2020; Sun et al., 2018). Example questions included: "can you tell me about your reactions to the loss of your baby?" and "what was your experience like in the hospital during the termination and birth of your baby?".

Recruitment and data collection

Between June and August 2019, participants for this study contributed to a national online survey focusing on men's experience of grief following the death of a baby. Inclusion criteria were that participants were aged at least 18 years of age and had experienced a miscarriage (<20 weeks of gestation), stillbirth (≥20 weeks' gestation or birthweight of at least 400g), TOPFA, or neonatal death (within 28 days following a live birth) in Australia within the last 20 years. For the national survey, participants focused their responses on the type of loss they had experienced. If they had experienced multiple losses, they reflected on one loss of their choosing. Participants in the current study reflected on the experience of TOPFA and expressed interest in a follow-up interview to explore their responses in more depth. Interested participants were contacted via an email address they provided in the survey, with further details and a consent form for the current study.

The first author completed individual interviews between October 2019 and March 2020. Interviews were conducted over the telephone. Interviews times ranged between 50 and 100 min (*M*=78.3 min). With participants' permission, each interview was audio-recorded and transcribed verbatim using an orthographic method (Braun & Clarke, 2013). Confidentiality was maintained by allocating each participant a pseudonym and removing all identifying features from the transcripts.

This study followed the consolidated criteria for reporting qualitative research (COREQ) guidelines, a 32-item checklist for interviews and focus groups (see Supplementary File S1). In line with Tracy's (2010) criteria for excellence in qualitative research, the first author kept an audit trail to facilitate data analysis and enhance methodological rigour. This process involved taking notes after each interview to conceptualise potential codes and important aspects of participants' experience, as well as reflect on the interview process to make modifications to future interview questions as necessary. All participants were provided with the opportunity to review their transcript; five participants accepted the offer to do so, however no modifications were requested. Achieving data saturation was not a requirement for this research, as the concept of saturation does not align with the values and assumptions of reflexive thematic analysis (Braun & Clarke, 2019). Rather, Braun & Clarke (2019) recommend that data collection continues until sufficient meaning is able to be generated; while this requires subjective judgement, all authors felt this was achieved in our sample size of ten participants. Finally, in recognition of the researchers' potential to influence the interpretation of results, self-reflexivity (Braun & Clarke, 2013; Tracy, 2010) was engaged throughout the research. We are a team of women researchers experienced in research relating to reproductive health and loss and grief; none have direct experiences of TOPFA.

Ethical considerations

The University of Adelaide Human Research Ethics Committee provided ethical approval for the wider program of research, including this study (code: HREC-2018-273). Before participation in a research interview, participants provided signed informed consent. As recounting their experience of TOPFA had potential to raise emotional distress, a comprehensive list of supports (including 24/7 pregnancy loss telephone support lines) were provided to participants before and after the interviews. While some participants displayed emotional responses during the interviews, substantial emotional distress was not evident during the research. All participants expressed gratitude for the opportunity to share their experiences; many noted this was the first time they had openly discussed their perspectives with someone and doing so helped them.

Data analysis

Interview data were analysed using thematic analysis from a realist ontological position, whereby participants' responses were interpreted to directly reflect their lived experience (Braun & Clarke, 2013). The analysis process followed the six steps for thematic analysis outlined by Braun & Clarke (2006, 2013): (1) data familiarisation through transcribing, reading and re-reading the data; (2) generating initial codes from across the entire dataset; (3) searching for themes by collating related codes; (4) reviewing themes in relation to both coded extracts and the entire dataset, and creating a thematic map (see Figure 4); (5) defining and naming themes; and (6) writing up the final results.

The first author transcribed the interviews and completed the initial coding which was cross-checked by the second author. A deductive approach was taken initially to examine the entire dataset according to the research questions. After this, an inductive approach was taken to identify additional themes from the data. Initial themes were developed by the first author and then discussed and refined with all authors. To enhance the accuracy of the themes, an overview of the initial themes was sent to participants for member-checking (Tracy, 2010), to which eight participants responded (80%). All participants expressed that they resonated with most of the themes/sub-themes and agreed with the overall thematic structure, with only minor suggestions provided about nuances and varied experiences within the themes/sub-themes. A final thematic structure was achieved using participant feedback and further discussions between the authors; all authors agreed on the final themes.

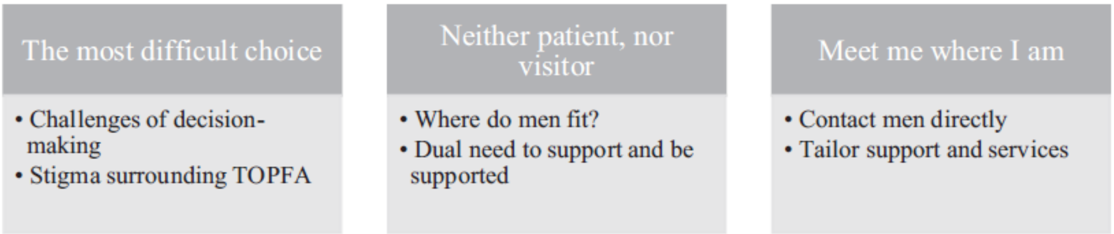
Results

Participants

Participants were ten heterosexual men who experienced a termination of pregnancy for life-limiting anomalies with a female partner in Australia. They were aged between 24 and 44 years at the time of the interview (*M* = 34 years, *SD* = 7.3) and time since TOPFA ranged from 11 months to six years (*M* = 24 months, *SD* = 18.6). For all participants, their baby's anomalies were diagnosed during the second or third trimester of pregnancy, and the terminations occurred between 19 and 37.5 weeks of gestation. Each pregnancy ended in induced labour (see Table 10 for further participant details).

Themes

A total of three overarching themes were identified across the interviews, each with two sub-themes (see Figure 4). Details of the themes are outlined below.



The most difficult choice

- Challenges of decision-making
- Stigma surrounding TOPFA

Neither patient, nor visitor

- Where do men fit?
- Dual need to support and be supported

Meet me where I am

- Contact men directly
- Tailor support and services

Figure 4. *Thematic map*

Theme 1: The most difficult choice

Participants described the decision to terminate their pregnancy after receiving the diagnosis of a life-limiting anomaly as "the hardest choice we've ever had to make" (Oliver). Although not all of the pregnancies were explicitly planned, every participant was involved in the pregnancy, attending ultrasound appointments with their partner and sharing "the excitement of telling everyone and preparing" (Jacob) for the baby's arrival. The diagnosis of an anomaly was a "shock" (Alan, Oliver, Henry and Patrick) for all participants; they described feeling "crushed/hollow" (Alan), "numb" (Henry and Jacob) and ill-prepared for such an outcome. On top of these emotional reactions, deciding to terminate was associated

Table 10. *Participant characteristics*

Name*	Age	State	Occupation	Education	Ethnicity	Marital Status	Gestational age at loss	Time since loss	Other children
Alan	37	Tasmania	Community/personal services worker	Undergraduate degree	Australian	Married	20 weeks	1 year	None
Brent	26	Victoria	Retail manager	Diploma	Australian	In a relationship	20 weeks	11 months	None
Oliver	30	Queensland	Manager	High school	European	Married	26 weeks	2 years	Two
Noah	30	New South Wales	Professional	Postgraduate degree	Australian	Married	21 weeks	1 year	One
Luke	36	New South Wales	Professional	Diploma	Australian	Married	37.5 weeks	22 months	One, and wife currently pregnant
Henry	44	New South Wales	Trade/technician worker	Undergraduate degree	Australian	In a relationship	24 weeks	18 months	One
James	24	Western Australia	Community/personal services worker	TAFE^/trade	Australian	Married	19+5 weeks	3 years	One, and wife currently pregnant
Corey	42	Victoria	Professional	Postgraduate degree	Australian	Married	19 weeks	6 years	Two
Jacob	31	New South Wales	Professional	Undergraduate degree	Australian	Married	20 weeks	18 months	Wife currently pregnant
Patrick	44	New South Wales	Machine operator/ process worker	TAFE^/trade	Australian	Married	19+5 weeks	1 year	One

**Note: Participant names are pseudonyms*

^*Technical and Further Education training* with many challenges, and participants described a need for clear information and support from healthcare professionals. For many, but not all participants, a perceived stigma surrounding termination of pregnancy also complicated their grief.

Sub-theme: Challenges of decision-making

The decision to terminate their baby was not clear or simple for any of the participants, however many ultimately felt it was the “right” (Oliver, Henry and Corey) or the “only” (Luke) decision given their baby’s anomalies. Many participants described spending a great deal of time considering their options, facilitated by personal research and numerous meetings with healthcare professionals to understand the diagnosis, prognosis and process of termination. Depending on local laws across different Australian states/territories, terminations later in pregnancy were also complicated by the need to seek special approval from medical professionals or hospital ethics boards. In all cases, approval and support to terminate from healthcare professionals was unanimous given the seriousness and rarity of the diagnoses. Oliver described:

> “…we were told in [state] that if you’re going for an abortion after the 22-week mark, you have to have it approved by a board of doctors at the hospital […] they have an ethics committee put together to justify it […] It was a unanimous decision made within 20 minutes of hearing the case. So, [we felt we were] making the right decision.” (Oliver)

For these participants, support from healthcare professionals and a quick, unanimous decision regarding the termination contributed to a feeling of making the right decision. However, although confirmation from healthcare professionals “made the decision clearer” (Noah) for many, it was by no means easier, with participants describing substantial emotional distress. Henry explained:

> “…to say it was soul-destroying probably doesn’t even begin to touch it […] even though it was incredibly, incredibly difficult, both my partner and I did actually feel like we made the right choice.”

All participants felt they had adequate information and support from healthcare professionals throughout the screening, diagnosis and decision-making process. Appreciation was expressed when information about their choices was provided in a professional, honest and sensitive way, and healthcare professionals were available to answer questions and did not rush them. Patrick explained:

> “I felt the doctor and the technicians were all very good. Because they didn’t try to […] you know, go, oh, it’ll be alright. They just went, look, it’s not good, you know, [baby]’s got a very low chance of surviving […] they gave us time to be in the clinic […] we were in there for probably 45 minutes or so before we could gather ourselves […] our obstetrician, he was good enough to be available for us to talk to, and, you know, unfortunately we just had to decide what to do.” (Patrick)

Despite support from healthcare professionals, participants felt they had limited time to prepare for the termination, only a couple of days to a week between the diagnosis and termination (or longer if hospital ethics board approval was required). A smaller number of participants also experienced feelings of guilt or self-blame associated with their decision, or uncertainty surrounding the cause of their baby’s anomaly. For example, Oliver described spending time with his baby after delivery, “apologising that […] we couldn’t be better for [baby], that we couldn’t fix it […] apologising for making that decision”. James also explained that he and his wife had to wait one month for the results of genetic testing and during this time they were left questioning whether “it was something wrong with us”. These participants indicated that it was important to receive clear explanations and support from healthcare professionals as reassurance, as well as timely results from genetic testing.

Sub-theme: Stigma surrounding TOPFA

Compared to other types of pregnancy loss, including miscarriage or stillbirth, many participants felt that TOPFA carried a degree of stigma or potential judgement from others due to varied opinions surrounding abortion. Several participants described telling people they had a stillbirth instead of a termination or withheld parts of their story to avoid adverse reactions from people who may not have agreed with their decision to terminate. Brent explained:

> "…not a lot of people knew that it was a medical termination like of our choice, they just knew that it was a miscarriage. And it was very select people, only because we didn't want people's opinions of it" (Brent)

Therefore, participants indicated that others can also reinforce feelings of guilt and self-blame noted above due to stigma. Some participants felt stigma also hindered their ability to seek support from general pregnancy loss services, as they worried that other bereaved parents would not view their loss in the same way. Henry described:

> "We didn't feel like any of the support groups were suitable for us to contact. It didn't fit for us, because we didn't feel like we could tell our whole story to the others."

Recognising a lack of societal understanding for TOPFA, Luke explained that he frequently tried to openly discuss his experience with others to raise awareness and break down the silence around the subject:

> "…it's not something that I've shied away from, um, you know, talking to people about doing a late-stage termination. It's probably not something that you ever hear. You know, you kind of hear about stillbirths and stuff like that, but um, yeah, it's not something that I've shied away from being open about."

However, not all participants felt that stigma was specific to TOPFA. Instead, others felt that there was a general societal taboo and lack of recognition for all kinds of pregnancy loss, which made it difficult to share their experience and feel understood by family and friends. Noah shared:

> "People who go through [pregnancy loss] almost feel shame to talk about it […] because of that stigma, it makes it hard for other people to acknowledge it. Or, or to try and be there for you, and to try and understand."

Regardless of whether stigma was perceived to be directed toward TOPFA or pregnancy loss generally, these experiences compounded grief for men and contributed to feelings of isolation and disenfranchisement.

Theme 2: Neither patient, nor visitor

In general, participants described receiving good support in hospital, with midwives and other healthcare professionals providing sensitive and thoughtful care to men and their partners, as well as opportunities to spend time with their baby and make memories. Having their baby acknowledged and validated in the same way as a full-term baby was extremely important to men and their partners. Jacob explained:

> "[The midwives] took so much care, treated [baby] like a term, newborn baby. Dressed her, made sure to get all her finger and toe prints so we could get, if we wanted to, casts and moulds made to remember her. Um, real gentle. Um, they gave us details for some services that do up like commemorative […] prints into these moulds […] with her name and a photo of her. Um, and just things like that that really quantify her and make her like a tangible person, not just a memory."

However, two participants whose losses occurred at less than 20 weeks of gestation (19 and 19+5 weeks) described less acknowledgement for their babies. Although these participants were provided with opportunities to spend time with their babies following birth, make memories and access chaplaincy/counselling services, their birth experiences differed to participants who experienced later-gestation losses, as in both cases, their babies were born into containers. Corey described:

> "I felt there was probably a lower level of care […] compared to someone who was delivering a full-term baby, or a baby who was going to survive […] both of us felt like we were sort of left off to the side a little bit […] when the baby was born and delivered, it was um, essentially into a plastic container, or a bucket, and the sound – I'll never forget the sound of

> her landing in that container. And just the feeling of the indignity for her for that was um, just something that's always stuck with me, and um, also with my wife" (Corey)

Despite many receiving good hospital care, participants also described a lack of support specifically targeted toward men, with most of the immediate and ongoing support options geared toward mothers rather than fathers. Overall, because participants were not officially a patient themselves, they felt there was difficulty surrounding assessment of men's needs and the provision of male-specific support.

Sub-theme: Where do men fit?

Participants' immediate priority throughout the experience of TOPFA was their partner's wellbeing, as she was experiencing the physical implications of pregnancy, termination and birth. As a result, many participants described giving little thought or acknowledgement to their own grief and needs. Noah described:

> "I just didn't give myself a second thought, for what it meant for me, or how it was affecting me, because she's the one carrying the baby […] I think that's natural when something's happening to someone, you want to do everything you can […] to be there for them. Look after them. And that really took over all the [following] three or four months, I'd say."

The hospital environment reinforced a focus on women. Although most participants felt they were included and part of the TOPFA experience, they generally felt a degree of separation and as though support specifically for them was lacking. This left men feeling uncertain about their role as 'grieving father' versus 'support person'. For example, some participants said they felt as though they were "an afterthought" (Alan) or a "secondary concern" (Oliver) compared to their partner. Henry explained:

> "In the hospital, I was certainly very much acknowledged in the room, I wasn't just an outsider […] but it was very much geared towards my partner and her experience. Only really the one pamphlet about men and a support group, which I really wasn't keen in that moment, or any moment following, to go and actually join." (Henry)

Similarly, while mental health assessments for mothers are commonplace in many hospitals, Oliver expressed concern that healthcare professionals did not consider his history of mental health difficulties:

> "I have clinically diagnosed anxiety disorder […] all of these mental health issues, are on my, in my records […] which, to me, is kind of concerning that after such a traumatic event as losing a son, the hospital didn't go, hang about, the dad has anxiety and depression, we should maybe do something about that. We should maybe follow-up on that, we should maybe get him to go in and see his local GP for a check-up."

Overall, participants described a need to recognise that TOPFA can have a profound and lasting impact upon men, and to find ways to address this in policy and practice. While participants in no way wanted to detract from their partner's needs, there was a consensus toward "consider[ing] dad part of the treatment plan" (Oliver) to ensure adequate support could be provided for both women and men.

Sub-theme: Dual need to support and be supported

Participants also expressed a desire to be a good support for their partner. However, many found it challenging to balance their wish to support their partner while also experiencing their grief. While some participants experienced good communication about their grief with their partners, others described hiding their feelings to protect their partner from further emotional distress. In these cases, they needed someone other than their partner to speak to about their grief. Patrick explained:

> "…that's why I went to the counselling, was to try to deal with my level of tolerance for work, and try to deal with [baby]'s passing, without burdening [wife]" (Patrick)

In the hospital, some men received pamphlets on men's grief and community supports. However, healthcare professionals often did not provide specific information or guidance to men on managing their emotions following TOPFA. Instead, most of the immediate focus was on their partner and her wellbeing. Oliver explained that although counselling was offered to him and his wife before hospital discharge, there was little focus on how he could support his wife and also address his grief:

> "I wasn't spoken to separately. It was a, [wife] and I sort of thing. When we were in the recovery room, the day after, um, they sent two counsellors in to speak to us together […] she spoke to [wife]. Unless I spoke up and said something in response to a question, she looked at [wife] […] So, I'm sitting there, and all I'm hearing is: I have to look after her. I have to support her. I have to make sure she's okay. I have to be strong enough to bear the weight of my own grief, as well as support the weight of my wife's [grief]."

In contrast, Patrick felt that healthcare professionals made a direct effort to speak with him and ensure he recognised his needs throughout the TOPFA process. This inclusion had a lasting, positive impact on his ability to acknowledge and deal with his grief:

> "…they kept on saying to me, you know, Patrick, you make sure you keep talking about this and don't sit there and feel as though you can't say anything […] because you're part of this process. It's not just your wife who's going through this […] you know, are you alright, are you okay? […] quite direct and ensured that they'd spoken to me […] I didn't want to take away from [wife], but I think what they did really helped."

Overall, participants expressed a need for tailored information about how to both support their partner *and* care for themselves. This information could be aided by nursing/midwifery staff or a support person with knowledge in grief taking them aside to "talk to [men] in their own language" (Jacob) and provide written resources or referrals to community services. Jacob summarised:

> "[I needed information on] ways to manage, you know, look after myself, but also look after [wife] because […] I definitely felt way out of my depth with how to help her […] and it just made me feel kind of useless."

Alongside a need for tailored information to support their partners, these experiences demonstrate that men must be included throughout TOPFA. Patrick's experience in particular demonstrates how efforts to include men can make a crucial difference in acknowledging men's grief and needs. While men expressed a desire to support their partner, there was also a clear need for specific guidance on how to acknowledge their grief and gain support for themselves.

Theme 3: Meet me where I am

As noted in the theme above, participants described many challenges in accessing support services in the aftermath of TOPFA. Along with little focus on men's needs in the hospital environment described in the second theme, follow-up specifically for men by healthcare professionals was lacking outside of the hospital environment. In addition, participants perceived many of the currently available support services to be unappealing, inappropriate to their needs as bereaved fathers, or difficult to access due to geographical/distance issues.

Sub-theme: Contact men directly

One of the largest gaps in current care highlighted by participants was a lack of active follow-up or referral to additional support services specifically for men in the weeks or months following TOPFA. Many participants said their partner received a follow-up telephone call from the hospital or had an appointment with their obstetrician or general practitioner (GP) in the weeks following TOPFA, however this was not offered or suggested directly to men. Corey explained:

> "We did have a follow-up appointment with [obstetrician]. Um, but that was primarily about the physical wellbeing of my wife […] he sort of talked a little bit about counselling to her but not, ah, not to me […] yeah that wasn't something I was involved in at all." (Corey)

Some participants also felt they were less likely to seek help in comparison to their partner because of societal expectations around what it means to be a man and support their family:

> "I could have asked, right? But maybe it's too hard to ask, too hard to reach out – again, from that whole, 'it should be fine, you're a man' sort of thing." (Noah)

Patrick also noted that he needed someone to give him “a bit of a push” to access services. In a context where men felt an expectation to support their partners and did not seek out services themselves (and where they did not feel there were any services available to them regardless), it could be important for the hospital or another affiliated service to directly contact men to offer support and referrals. For example, Oliver said:

> “There’s this sort of, societal thing, this pressure to be the bloke, be the dad […] I didn’t want to go and look for help after losing [baby] […] I needed someone to check on me, to push me to do something. And, that can’t be my wife. Because my wife is in the middle of it too.” (Oliver)

Participants also noted that the timing of support was important. In the early stages following TOPFA, most participants described being caught up in supporting their partner and taking care of practical responsibilities associated with their loss. At this early stage, many did not feel a need for support. However, once these responsibilities began to subside, and their partner’s distress was less acute, men’s grief began to surface. Noah explained:

> “And so [wife] went from needing my help to – well, not *not* needing my help, but, yeah, needing support, to being okay. And I kind of felt like I got left behind a little bit […] I hadn’t taken any of that time to actually understand and process what had happened for myself.” (Noah)

Given self-care for men frequently came secondary to caring for their partner, these experiences indicate that expression and acknowledgement of their grief may be delayed, requiring support at a later stage compared to women. However, as well as considering timing, participants frequently expressed that if they were contacted directly by a support person or healthcare professional, they may have been able to recognise their own needs and engage in available support services earlier. The timing and provision of support is complex and should account for individual differences in preferences and needs. While some men may respond to early offers of support, others may require check-in at a later stage. Determining the best course of action requires working with men on a case-by-case basis.

Sub-theme: Tailor support and services

Participants coped with their grief in many different ways. A trend toward instrumental coping was common, with many participants describing using sport or activities, finding new hobbies, or going back to work. The combination of physical exertion and a mental ‘break’ that these activities provided were described as beneficial to participants’ grieving processes. Alan explained:

> “I certainly did turn to surfing […] for that minute, you’re 100 percent focused, you’re not thinking of anything apart from the here, you know, literally the here and now. And then when you kick off you’ve got all those endorphins […] and it’s just, you don’t have time to dwell on the other stuff […] meditation is not a word I sort of gravitate towards but um, you really are somewhere where you can think, peacefully.” (Alan)

Although activities were helpful to distract participants from their grief, many noted that relying on distraction alone or “bottl[ing] it up” (Oliver, Jacob) was not helpful in the longer-term. Consequently, they expressed the importance of finding a balance between distraction and openly expressing their grief.

> “…exercise, doing things, were good in some ways but bad in another way in that I didn’t have my check-in balance […] so I kind of avoided it and did things to distract myself […] I was drinking a bit more […] I really was not being the best version of myself. Um, I was isolating myself from friends […] I just lost all patience […] my behaviour was destructive [and] I wasn’t myself” (Noah)

Others found talking about their experience or attending counselling helpful. However, talking options were not appealing to everyone, with some participants expressing that they “definitely wouldn’t be interested” (Brent) in counselling. For participants who engaged in psychological services, experiences were varied. For example, Patrick described how counselling helped him to understand the process of grief:

> "[Counselling helped me realise] that things aren't black-and-white […] [loss] affects everyone differently. And you've got to acknowledge what's happened and not just try to push through it. And remember it's not a straight line – you know, like a wave, it's going to go up and down and […] some days it's going to be a burden that you'll handle, and it'll be something you're confident in dealing with. And then the next day it won't be. And, um, you know, try to be mindful of your mood."

Others had less helpful experiences. These participants described a need for counsellors who were specialised in grief and bereavement and understood the unique challenges of TOPFA. James said:

> "We did go see a psychologist a few times. That was through work. Um, just one that your general work provides […] but we didn't think that it was very helpful [because] he wasn't really addressing the issue […] didn't really address, um, like coping mechanisms and things like that. It was just, try to distract yourself. My argument was yeah, you can only distract yourself for so long […] [baby is] all you think about, day in and day out."

All participants discussed a need for encouragement and guidance to find what works for them. Specific information from healthcare professionals on how other men have coped, or being connected directly with men who had experienced TOPFA or similar, could be helpful to offer suggestions. Where participants had others to talk to about coping with their loss, their grief was eased. For example, Patrick expressed feeling "lucky" that he had a support network of friends who have been through loss themselves and encouraged him to share his experiences with them:

> "…two friends of mine have been through the loss of a child […] out of the blue, [friend] called me [and] said, you know, I'm sorry, and he's actually checked in on me a couple of times […] I've been pretty fortunate to have that." (Patrick)

In contrast, participants who did not have a support network of friends and family to share their grief expressed a need for organised groups or one-on-one peer support. Ideally, these would be in an informal and male-friendly setting where common experiences and advice for coping could be openly shared. Jacob explained:

> "…if there was a small group of guys that you could get together […] um, at a social setting, like even at a pub or something, um, where it doesn't feel like a counselling session or a self-help session you know, it just feels like let's get together and just chat […] just see how you're both dealing with things and how you've both, what ways you've found to deal with the grief, as well. Um, and how to deal with your partner and help your partner out, too." (Jacob)

Some also expressed a need for more anonymous forms of help-seeking, such as being connected to peers through online chat forums or reading about others' experiences through social media pages, blog posts or websites. In recent years, these forms of support have been increasing, with some participants noting they had found information and social media pages hosted by national support organisations specifically for bereaved fathers. However, other participants struggled to find these forms of support, expressing a need for guidance on what is available for fathers, and where to search. Corey shared:

> "I did try to find a lot of online information and really struggled, but I think it was only that one page that I was able to find where it talked about, um, father's grief […] possibly the sort of thing that I might have considered [was] having an anonymous chat with somebody who was in the same situation, but um, I couldn't find anything" (Corey)

Finally, participants who lived outside of major cities noted that the standard support options provided by hospitals often were not beneficial to them, as services were not always close to home. A general lack of mental health services in these areas was perceived as a real barrier to seeking and accessing support. James described:

> “We got a, um, like a take-home bag thing [from the hospital], but that didn’t contain any follow-up help really. And it was all – well there was, but it was all [city]-based. But there’s nothing really in the country. Um, I didn’t want to drive two hours to go see someone for 40 minutes and then just drive back [again].” (James)

While GPs could be a good starting point for accessing mental health services for those in rural areas, not everyone had a regular healthcare professional whom they felt they could speak to about their concerns:

> “…when we lost our baby, um, we were living in a very small town and it was very hard to have help nearby. Um, and so I didn’t, I didn’t sort of actively seek help. I didn’t have a good GP to speak to and, um, to find a psychologist, just seemed like a bridge too far” (Corey)

Oliver noted that although mental health services are lacking in rural areas, options are available for men to seek support through various community-based organisations. However, he was not provided with information on these options and had to locate them himself:

> “Out here in [rural town], the mental health side of things is really lacking […] I had no information given to me about things like the Black Dog group, or the fact that the Royal Flying Doctor’s Service have specific […] men’s mental health awareness groups. The local men’s shed, which helps to support men going through tough times. The – all of this information that I have found *myself*.” (Oliver)

Overall, participants described using varied coping styles and strategies which each had benefits. However, many participants expressed a need for guidance or advice from others to find what works for them.

Discussion

Consistent with previous research on parents’ experiences of TOPFA (Hodgson et al., 2016; Pitt et al., 2016), men in this study described experiencing substantial shock, ill-preparedness and grief. Although commonalities in the grief experience exist across pregnancy loss types, these findings support the view that TOPFA presents specific challenges; particularly the complex process of decision-making and potential stigma associated with the decision to terminate (France et al., 2013; Hanschmidt et al., 2018; Hunt et al., 2009). Findings from this study demonstrate that men are equally impacted by these difficulties, with participants describing considerable emotional distress despite ultimately feeling as though they made the right, or only, decision for their baby in the context of the diagnosed anomalies.

While previous research has highlighted inconsistencies or inadequate care following TOPFA (Hodgson et al., 2016; Hunt et al., 2009), most men in this study reported receiving sensitive care both during the decision-making process and the birth of their baby, consistent with recommendations from international bereavement care guidelines (Boyle et al., 2020; Health Service Executive, 2016; NBCP, 2020). However, hospital support was not universal and in a smaller number of cases seemed to be reliant on gestational age when parents' grief is not necessarily governed by this (Brier, 2008; Obst et al., 2020b). Similar experiences have been identified in miscarriage research; compared to later-gestation stillbirth, parents have reported lower levels of care and a lack of recognition for their baby (Emond et al., 2019; Smith et al., 2020). Regardless of the baby's gestational age, the birthing experience and care should be consistent and prioritise respect for the baby. Although in Australia a 20-week gestation period is used to distinguish between miscarriage and stillbirth, this cut-off is arbitrary and does not determine the attachment that expecting parents form with their baby.

The emotional impact of loss and grief men described in response to TOPFA was not dissimilar to women's descriptions in previous studies (Asplin et al., 2014; Atienza-Carrasco et al., 2019). However, men face specific challenges, particularly regarding healthcare, support and follow-up. Echoing the experiences of men in the broader pregnancy loss literature (Bonnette & Broom, 2012; Cacciatore et al., 2013), as well as the small body of research on men's experiences of TOPFA (Carlsson & Mattsson, 2018; Kecir et al., 2020;

Robson, 2016; Sun et al., 2018), men in this study generally reported taking on a supporter role and setting their emotions aside to focus primarily on the wellbeing of their partner. This role was driven not only by an internal desire to be a good support for their partner, but also reinforced by the hospital environment and (for some men) societal expectations and norms surrounding men's roles. While men in this study did not feel explicitly excluded from healthcare, they felt on the periphery both in the hospital and follow-up, which resulted in little attention or recognition to their grief both during the termination/birth and in the weeks/months following. While men are not admitted to hospitals as patients to deliver their baby, they are also not merely visitors nor passive bystanders or support people in the TOPFA process – they are fathers grieving the death of their baby.

Nursing and midwifery staff are well situated to provide men with tailored information and to promote genuine inclusion, acknowledgement of their grief and facilitate referrals to community supports. However, the responsibility for men's needs should not only be on individual staff, but also on healthcare systems which need to recognise an equal partnership between mothers and fathers throughout pregnancy and childbirth. In line with recommendations for male-inclusive healthcare literature (Fletcher et al., 2014; Healthy Male, 2020), systems and policies should promote genuine inclusion of fathers at all stages of pregnancy and childbirth. For example, strategies could include adopting inclusive language which is family-centred rather than exclusively mother-infant centred; reviewing training materials and informational resources to ensure they are inclusive of father's experiences and needs; routinely assessing fathers' mental health and wellbeing before discharge from hospital and in targeted follow-up (particularly following loss and when men have a history of mental health concerns); and establishing connections with a wide range of male-friendly community (and TOPFA-specific) support services to facilitate referral from hospital to community. Regarding TOPFA specifically, healthcare professionals should consider the timing of offering support to men, given presentations of grief may be delayed. Assessments of men's needs should also be sensitive to experiences of guilt, shame or blame which can complicate grief. Given the complex interactions between the depths of men's pain, male role expectations from society and a lack of male-specific support options (especially those specific to TOPFA), it is unrealistic to expect men to seek support themselves. Rather, men in this study expressed a need for direct guidance to recognise their grief, as well as active follow-up from healthcare professionals and/or counsellors in the weeks and months following.

Limitations and future research

While participants' losses occurred at a range of gestational ages, approval and support to terminate from healthcare professionals was unanimous in all cases due to the seriousness and rarity of the diagnosed anomalies. Given the importance of stigma surrounding TOPFA in shaping some men's experiences of grief, future research should explore the experiences of men and women who did not receive a unanimous decision, as their grief may be hidden to a further extent. Similarly, although the sample for this study included representation of men from varied educational backgrounds and geographic regions of Australia, all of the participants shared similar cultural backgrounds and remained in a relationship with the partner who experienced TOPFA, which may indicate a potential bias toward the type of men who chose to participate in the study. While qualitative research does not strive for generalisability (Braun & Clarke, 2013), it is important to note that the experiences of this small group of men may not be representative of all men who experience TOPFA. There is a need for future research to focus particularly on under-represented populations including rural and remote men, culturally and linguistically diverse men, men who experience relationship breakdown following infant loss, men from low and middle-income countries, and gay, trans/masculine and non-binary people (McNeil et al., 2020; Riggs et al., 2020).

It is possible that bias also arose within the data analysis process, given the authors are a team of women researchers without direct individual experiences of TOPFA. However, self-reflexivity was engaged throughout the analysis process to promote an awareness of the researchers' roles in analysis and minimise potential bias. In addition, all participants who engaged in member reflections reported that the themes and sub-themes were an accurate representation of their experiences.

Finally, since men in this study described a lack of male-specific resources and support for TOPFA, research is needed to develop, trial and evaluate tailored support programs that target men employing a variety of modalities including face-to-face, online, written and visual materials. Both this study and others (Bonnette & Broom, 2012; Miller et al., 2019; Obst et al. 2019) have demonstrated that men's grief following the death of a baby is a highly individualised experience, and no one approach will meet the needs of all.

Conclusion

This study contributes to the limited body of international research on men's experiences of TOPFA. Findings indicated that TOPFA is an extremely difficult experience for men, characterised by emotional reactions of shock and grief, challenges in decision-making, and perceived stigma surrounding termination of pregnancy. Because men were not admitted to the hospital as a patient in the same way as their partner, they described feeling overlooked by current services, particularly in relation to the provision of support and assessment of men's needs. They described a need for specific support services which are tailored for men, as well as follow-up services directed to men following a termination of pregnancy.

Relevance to clinical practice

The study's findings provide further support for a need to broaden the focus of healthcare systems toward family-centred and father-inclusive views of pregnancy and childbirth. Nursing/midwifery professionals are well-positioned to assist in this regard and can play a crucial role in supporting men to cope with the substantial challenges associated with TOPFA and the lasting impact of grief. It is important to acknowledge the central role of fathers and support them in addressing their grief following TOPFA. Nursing/midwifery professionals can provide men and their families with tailored information, promote genuine inclusion of fathers, acknowledge men's grief, and facilitate referrals to community supports which may suit a variety of coping styles and needs.

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CHAPTER 7. GENERAL DISCUSSION AND CONCLUSIONS

7.1 Summary of findings

In light of a lack of previous research and available psychological theories, this thesis sought to explore men's experiences of grief after pregnancy loss and neonatal death. Specifically, the program of research was guided by four overarching research questions: (1) how do men experience grief following pregnancy loss and neonatal death; (2) what factors influence men's grief following pregnancy loss and neonatal death; (3) how does type of loss (i.e., miscarriage, stillbirth, TOPFA, or neonatal death) impact men's grief experiences; and (4) how can future services and bereavement care guidelines best support men following pregnancy loss and neonatal death? The publications forming this thesis built upon a small body of previous research (e.g., Miller et al., 2019; Obst & Due, 2019a; Riggs et al., 2018) by comprehensively exploring factors contributing to grief at individual, interpersonal, community and system/policy levels, and experiences of grief according to style of coping and type of loss. In this Chapter, I briefly outline the key findings from each of the studies in the thesis, then discuss a cross-study synthesis detailing the broad significance of the findings, contributions to knowledge, practical implications, and recommendations for future research.

Study 1 (reported in the first publication, Chapter 3) was a systematic review that identified, appraised and summarised the existing literature on men's experiences of grief and factors contributing to grief after pregnancy loss and neonatal death. This study found that men have highly varied grief experiences and may face unique challenges compared to women including a perceived expectation to support their partner, and a lack of recognition for their grief and emotional needs. In also examining factors related to grief, Study 1 resulted in the development of a Socio-Ecological Model of Men's Grief to illustrate the relationships between individual, interpersonal, community and system/policy-level factors and the experience of grief. In doing so, this study highlighted the need for multi-level strategies to assist men with their grief, including tailored individual bereavement support services, community support/campaigns, family-centred healthcare systems that are father-inclusive, and supportive workplace policies.

Study 2 (reported in the second publication, Chapter 4) employed a quantitative approach using multiple linear regression analyses to test the Socio-Ecological Model of Men's Grief in a sample of Australian men who had experienced a pregnancy loss or neonatal death. Results indicated that men can experience significant grief across loss types regardless of gestational age, and factors associated with grief vary according to grief style. These findings pointed to a need to develop supportive interventions for men tailored to men's specific needs, and designed with consideration for emotion-focused and activity-focused grief styles.

The third study in this thesis (reported in the third publication, Chapter 5) explored a subset of data from the nationwide survey relating to men's experiences of leave provisions and support from the workplace after a pregnancy loss or neonatal death. The results showed that while most men in the sample were offered some form of workplace leave following their loss, returning to work too soon could take an emotional toll. In addition, while not all men desired extended (or any) workplace leave after the death of their baby, flexibility to support their partner and receiving recognition and understanding from their employers was perceived as important. Overall, results from this study supported calls in Australia for a national and standardised approach to leave provision and support from men's workplaces to facilitate returning to work after pregnancy loss and neonatal death.

Finally, Study 4 (reported in the fourth publication, Chapter 6) employed qualitative methods to explore men's experiences of grief and support after TOPFA. This study found that TOPFA is an extremely difficult experience for men, particularly in the context of challenging decision-making after an unexpected diagnosis of a life-limiting foetal anomaly, and persisting societal stigma surrounding termination. In addition, men struggled to identify where they ‘fit’ in the hospital environment, and perceived a lack of supports directed toward them in the hospital and the community.

In line with the overarching aims of this thesis, each of the four studies was designed to explore and develop a comprehensive understanding of men’s experiences of grief and identify important contributors to grief to inform future support services. Across the studies, consistent themes included a need to examine the experience of grief from a holistic (socio-ecological) perspective and the importance of validating and recognising men’s unique experiences as grieving fathers. Overall, findings highlighted a need for increased awareness and recognition of men’s role as grieving fathers after pregnancy loss and neonatal death, and for healthcare services and supportive interventions to be tailored according to various grief styles and men’s unique needs.

7.2 Significance of the findings and contributions to knowledge

7.2.1 Men’s experience of grief and contributing factors

This thesis contributes to the literature on models of grief, specifically addressing the knowledge gap on men’s grief after pregnancy loss and neonatal death. While current understandings of grief acknowledge the various biopsychosocial impacts (McCoyd & Walter, 2015), and previous research has explored disenfranchised grief after pregnancy loss (Doka, 1999; Lang et al., 2011) and gendered challenges for grief (Doka & Martin, 2011; Martin & Doka, 2000), these explorations have generally existed separately and had seldom been applied together to pregnancy loss and neonatal death experiences. Drawing upon the Biopsychosocial Model (Engel, 1977, 1997) and the Public Health Model of Bereavement Support (Aoun et al., 2012) as theoretical frameworks, Study 1, in comprehensively exploring men’s experiences and biopsychosocial factors relating to grief, integrated these multiple perspectives into a single model. The resulting Socio-Ecological Model of Men’s Grief has important implications for the development of multi-level supportive interventions for men, as well as healthcare and workplace policies to recognise men as grieving fathers, which will be discussed further in Section 7.2.

Contrary to early studies comparing women and men’s grief after pregnancy loss and neonatal death that suggested men generally display lower levels of grief than women (and are therefore less affected by loss; e.g., Alderman et al., 1998; Conway & Russell, 2000; Cope et al., 2015), this thesis found substantial levels of grief in men across the program of research. Qualitative data from Studies 1, 3 and 4 also indicated that men can be, and often are, deeply affected by pregnancy loss and the death of their babies in the neonatal period. While grief experiences also varied substantially between men, the individual factor most strongly associated with grief appeared to be the quality and degree of men’s attachment to their babies during the pregnancy, which both this study and previous literature (e.g., Brandon et al., 2009; Doan & Zimerman, 2003; Vreeswijk et al., 2014) suggest is built through everyday interactions such as talking to their baby and developing a strong emotional bond.

Importantly, findings from Study 1 also suggested that some grief measures (including the PGS) may be biased toward intuitive expressions of grief, and less sensitive to identifying instrumental expressions. Early research on men’s grief after the death of a child indicated a trend toward instrumental grief styles, as well as the challenge of a ‘double bind’ in experiencing an expectation to both suppress and (appropriately) express emotional grief responses (Cook, 1988; Doka & Martin, 1998). The expectation to suppress outward grief responses when assuming the primary role of a ‘supporter’ to their partner was also consistent in early research on men’s experiences of pregnancy loss (McCreight, 2004; Miron & Chapman, 1994; Murphy & Hunt, 1997). However, in line with previous research on styles of grief existing on a continuum from instrumental to intuitive regardless of gender (Doka & Martin, 2011), participants in Studies 2 and 3 demonstrated varied expressions of grief, including higher average intuitive grief scores in the overall sample. In contrast to early potential ‘deficit’ views of the instrumental grief style, benefits of both intuitive and instrumental styles of grieving were detailed by participants in Study 3, along with the importance of finding a balance in oscillation between styles. These findings are in line with the Dual Process Model (Stroebe & Schut, 1999), and may also be reflective of the growing emergence of ‘multiple masculinities’ for men (Anderson & McCormack, 2018; Creighton & Oliffe, 2010), indicating there is no ‘one size fits all’ style of grief expression or help-seeking. In addition, while the ‘supporter role’ appeared to remain an important aspect of men’s grief experiences, Study 2 highlighted that the impact on grief was significant only where this role was perceived to take precedence over men’s own needs. In contrast to previous research positioning this role as detrimental to men adequately processing their grief (McCreight, 2004; Miron & Chapman, 1994), this thesis identified potential benefits of the supporter role, including providing a clear focus and purpose for men in the initial days/weeks following the death of their baby.

Despite considerable variability in men’s grief responses, consistent challenges concerning acknowledgement and recognition of grief were also identified across the program of research. While grief following pregnancy loss has long been recognised in previous research as disenfranchised (Doka, 1999; Lang et al., 2011), results from Study 1 suggested that men may face added or ‘double’ disenfranchisement, given a lack of social/community recognition for their position as grieving fathers. Studies 2 and 3 also suggested that the theme of added disenfranchisement may be exacerbated at the policy/system level if men do not feel acknowledged and included in the hospital, or the impact of their loss is not recognised by their employer and/or workplace more generally.

Study 4 also identified a major continuing challenge for men in relation to transitioning from support between the hospital and the community; this challenge appeared relevant for all loss types, however particularly so for TOPFA, given the potential for added stigma surrounding the decision to terminate (France et al., 2013; Hanschmidt et al., 2018; Irani et al., 2019). Therefore, referrals and access to both TOPFA- and men-specific community supports was important.

7.2.2 Grief and type of loss

In the context of inconsistent findings regarding the impact of gestational age on parents' grief scores from previous research, this thesis contributes further knowledge on grief for men according to the type of pregnancy loss or neonatal death. As two of the few published papers comparing grief for men after multiple loss types in a single study, Studies 1 and 2 found that men's average grief scores on the PGS were above the cut-off for what is considered to be a high degree of grief for all included loss types. Specifically, findings suggested that men's quality of attachment to their unborn/newborn baby is a stronger predictor of the intensity of their grief, regardless of time spent developing attachment and/or the increasing gestational age of the baby. While it could be expected that increasing gestational age might lead to higher levels of grief simply because men have likely had more time with their baby and/or their baby may seem to become more 'real' to them, the finding that quality of attachment is the stronger predictor is not entirely unsurprising given broader literature concerning attachment, loss and grief. For example, while early attachment theories focused specifically on the bond between mothers and their infants post-birth and in the early years of life, developments in theory exploring prenatal attachment have also recognised the potential for both mothers and fathers to develop strong bonds with their baby throughout pregnancy (Brandon et al., 2009; Condon, 1985; Vreeswijk et al., 2014). In pregnancy loss more specifically, research has also identified the complex physical, emotional and social losses represented in parents' grief, including shock and yearning that is typically relating to what could have been (i.e., hopes and dreams for the future life with the baby; Lang et al., 2011), rather than what has been.

While these findings support the view that men can experience significant grief regardless of loss type/gestational age, it was also clear from the program of research that different loss types may involve unique considerations, with important implications for the type of support required. For example, the highest average grief scores following later-gestation stillbirth and TOPFA found in Study 2 may be related to factors including the unexpected nature of these losses, having to navigate the process of late-term birth, and the high levels of stigma and disenfranchisement that are associated with these types of loss more than neonatal death in particular (Brierley-Jones et al., 2015; Burden et al., 2016; Hodgson et al., 2016; Lang et al., 2011; Pitt et al., 2016; Pollock, Ziaian, et al., 2020). In exploring the experience of TOPFA for men in more depth, Study 4 found that TOPFA was associated with unique pressures including the challenges of decision-making and ongoing societal stigma surrounding the decision to terminate; pointing to a need for TOPFA-specific information support services to assist men and families with these challenges.

In Study 3, different considerations were also found in terms of workplace support, especially in the case of miscarriage, where men received less support from the workplace and returned to work sooner than men who had experienced a stillbirth, TOPFA or neonatal death. While early-term miscarriage may not require as intensive medical intervention or support as later-term losses, the research suggested that a lack of recognition for grief and/or returning to work too soon may have long-term detrimental impacts on men's emotional wellbeing.

Overall, the findings of this thesis align with grief theories and current conceptualisations of grief (e.g., Buglass, 2010; Hall, 2014; McCoyd & Walter, 2015; Smit,

2015) in that grief was a highly individualised experience for participants across all studies. However, while grief intensity and style are also clearly not determined by gender, it is clear from the findings that men can face specific challenges regarding grief. This is particularly so following pregnancy loss and neonatal death, given complex interactions between societal expectations of men and current woman-centred systems and policies regarding pregnancy and perinatal health. Importantly, this research supported previous research which suggested that current grief measures may not fully capture instrumental styles of grief (Barr, 2006; Conway & Russell, 2000; Franche & Bulow, 1999; Huffman et al., 2015), which may lead to underestimation of the intensity of some men's grief. It is important for future measurement and assessment of grief to expand considerations to the potential influence of multiple biopsychosocial and socio-ecological factors to ensure the development of a more comprehensive understanding of individual experiences.

7.2.3 Men's bereavement support needs

Informed by the Socio-Ecological Model of Men's Grief, this thesis highlighted the importance of not only developing supportive interventions for men at the individual level, but also developing interventions at the community and system/policy levels to support men in managing their grief long-term; adding important considerations for researchers and health professionals developing supports for men after pregnancy loss and neonatal death. Contributing to growing calls from researchers to "enhanc[e] support for men" (Nguyen et al., 2019, p. 1) after pregnancy loss and neonatal death (Jones et al., 2019; Miller et al., 2019; Williams et al., 2020), exploration of factors related to different styles of grief in this thesis provide a solid theoretical foundation from which to develop supportive interventions. For example, given findings to suggest that intuitive grievers may benefit from increased hospital/healthcare professional support, a potential intervention could include developing a fathers/partners' consultation service to provide formal brief assessments of men's grief and mental health in the hospital, including brief counselling and referral to external community mental health services if required. For instrumental grievers, couples-based grief information and/or joint psychoeducation sessions following the loss could be beneficial to enhance mutual understanding and recognition of each partner's needs and foster helpful communication styles. In addition, providing men-specific information and support on managing return to work through grief could be beneficial, particularly for instrumental grievers who are more likely to return to work sooner following their loss. Overall, findings from across the program of research indicated that while men's perceived needs for support varied depending on the intensity of their grief and their grieving styles, targeted men-specific supports were desired by many participants, both immediately after the pregnancy loss or neonatal death, and/or in the weeks and months following. Therefore, regardless of grief style, a follow-up telephone call service directly to men in the weeks/months following pregnancy loss and neonatal death to monitor mental health and ongoing support needs could also be beneficial.

Findings also highlighted that there is a gap between the support men desire compared to the support men receive. This deficit is particularly the case regarding the support men received when transitioning from the hospital back to the community; many participants expressed that they struggled to identify support options due to a lack of guidance and follow-up from healthcare professionals and scarcity of support services that appeal to men. Participants in this program of research did not generally report feeling marginalised in the hospital as has been reported in previous qualitative studies (Bonnette & Broom, 2012; McCreight, 2004; Murphy & Hunt, 1997; Pabón et al., 2019; Puddifoot & Johnson, 1997). This finding may reflect changes over time in adopting family-centred care models, or differences in care across countries (e.g., feelings of neglect and marginalisation in the hospital were a salient issue for Colombian men in Pabón et al.'s [2019] study). However, findings regarding a lack of follow-up from the hospital or referral to community supports for men are not dissimilar to findings of other more recent studies (Cacciatore et al., 2013; Chavez et al., 2019; Miller et al., 2019; Obst & Due, 2019a; Wagner et al., 2018), indicating an important area for future intervention. Importantly, Study 4 further indicated that support for men residing in regional communities was a particular challenge, with a perceived lack of accessible pregnancy loss and neonatal death services available in face-to-face or online/telehealth formats.

Finally, findings from Studies 2, 3 and 4 also supported previous literature on discrepancies in bereavement care that men and families receive at the margins of loss types (i.e., losses occurring close to the 20-week gestation cut-off for miscarriage or stillbirth; Smith et al., 2020) and for earlier-gestation losses, as compared to later-gestation pregnancy losses (Franche, 2001; McCreight, 2008; Obst & Due, 2019a). In Study 4 particularly, participants who had experienced TOPFA just before 20 weeks' gestation perceived a lower level of acknowledgement for their babies, and had birth experiences that differed substantially to TOPFA which occurred later in gestation. Given findings that grief for men was *not* dependent on the baby's gestational age, these discrepancies in care appear to have substantial and deleterious impacts on the grief experience for men (and their partners). Implications of these findings for future updates of bereavement care guidelines and the development of supportive interventions for men are outlined below.

7.3 Implications of the findings for practice

7.3.1 Bereavement support specifically for men

Similar to findings regarding grief, men's experiences of bereavement support across the studies in this thesis were also highly varied. In Studies 2, 3 and 4, some participants reported satisfaction with the support they received, while others experienced difficulty locating bereavement support services. In general, participants perceived a lack of grief information and bereavement supports dedicated to men. Participants provided various suggestions for desired men-specific supports, including online informational resources, peer support networks (face-to-face and anonymous options), direct follow-up provided by healthcare professionals, and proactive referrals for emotional support services. These suggestions are not dissimilar to those made by participants in previous qualitative research exploring men's experiences of support after pregnancy loss (e.g., McCreight, 2004; Miller et al., 2019; Obst & Due, 2019a; Wagner et al., 2018; Williams et al., 2020).

Additionally, however, when other participants could locate available services, they were not always perceived as appealing, accessible, or helpful regarding men's specific needs. Some participants, particularly those who lived in rural or remote areas of Australia, felt simply that the physical location of services served as a major barrier to access. However, in line with previous qualitative research among men after pregnancy loss (e.g., McCreight, 2004; Obst & Due, 2019a), many men also reported feeling uncomfortable with the concept of peer support services or participating in group support programs. Aligning with the gender and masculinity theories discussed in Section 2.1.6, some participants in Study 4 described their hesitations to access available peer and group services in the context of wider social expectations to 'be a man' and remain 'strong' for their partner and family. A lack of awareness regarding their own need for support also seemed to be exacerbated by men's uncertainty surrounding their 'fit' in the maternity/perinatal environment. Therefore, alongside an expressed need for tailored information from healthcare professionals about what support was locally available in participants' areas of residence, a key finding expressed by participants was a need for a "push" to normalise and provide access to available services in the form of direct and proactive follow-up from healthcare professionals.

In Australia, community support services aimed at men after pregnancy loss and neonatal death have increased substantially during the time the research for this thesis was undertaken and published. For example, Bears of Hope provide ‘Sport and Support’ groups for bereaved fathers based in New South Wales (NSW), and have a nationally-available *WhatsApp* peer support group for bereaved fathers. Sands Australia and Red Nose (now merged) also deliver dedicated ‘Father’s Support Services’, which includes national peer support/telephone counselling for men. Recently, Sands and Red Nose have partnered with SMS4Dads, a research program that provides expectant/new fathers with information and connections to online services via text messages sent to their mobile phones throughout pregnancy and early parenting (Fletcher et al., 2017, 2019, 2020). The partnership with Sands and Red Nose aims to expand the SMS4Dads service to include messages to prevent stillbirth, and has proposed ongoing program development to provide supportive messages to fathers whose babies die during or shortly after pregnancy (Sands Australia, 2021). As an additional intervention at the community level, ‘Beards of Hope’ is a national public awareness campaign dedicated to raising awareness of men’s grief, and money for Bears of Hope’s fathers’ support services. In 2021, Red Nose also published a Fathers of Loss Support Series, including ten online short videos with fathers speaking on different aspects of their loss and advice for other fathers. Finally, Miracle Babies Foundation has also established a ‘Just for Dads’ online portal, including a dedicated Fathers and Grief informational page, which was authored by our research team and informed by the wider program of research forming this thesis.

Along with being developed specifically for bereaved fathers, collectively, these services are suited to various styles of grieving, including intuitive and instrumental styles. Availability of a variety of support options from informational grief psychoeducation through to formal peer support and counselling also aligns with the Public Health Model of Bereavement Support (discussed previously in Chapter 2; Aoun et al., 2012), allowing individuals to access the type of support that aligns with their perceived level of need.

Particularly for men who expressed a desire for anonymous forms of support, the *WhatsApp* group, SMS4Dads program, Fathers of Loss Support Series and 'Just for Dads' portal represent easily accessible approaches to accessing information and may serve as a gateway to accessing more formal support services, including online or telephone counselling, if this is required. Given that some of the services mentioned above were introduced after the research for this thesis was undertaken, men's experiences regarding the availability of men-specific grief information and support are likely to improve in the near future.

While the provision of services targeted directly to men is an essential first step in addressing gaps in men's care, the findings from this thesis also demonstrate a need to improve men's perceived – and real – access to support services, which requires multi-level strategies to increase men's engagement in available services. For example, participants discussed a need for active follow-up and direct referral to services, facilitated by dedicated healthcare professionals in the weeks/months following their loss – regardless of loss type. In addition, increasing communication, collaboration and referral systems between hospitals and community support services – including those discussed above – would be beneficial to provide greater continuity of care from the hospital to the community for men. Furthermore, interventions at a health service level, such as providing a formal program of longer-term follow-up telephone calls or appointments specifically to men, could be particularly beneficial to ensure men are aware of the support options available to them, and encouraged to access services in the weeks/months following loss.

Research has also highlighted that it is important for services targeted at men to take into account a 'masculinities model' to enhance perceived efficacy and reduce attrition (Kivari et al., 2018; Seidler et al., 2017, 2021). Both in Australia and internationally, there remains a lack of mental health services specifically for men, and training available for therapists on delivering therapy focused on men. Positively, in 2021, the Movember

Foundation launched a trial of 'Men in Mind', an online professional training program informed by research (Seidler et al., 2017, 2018, 2020) aiming to increase therapists' skills and confidence to engage, connect with, and respond more effectively to men seeking mental health support. The findings of this program of research support wider calls for individual interventions with men to be delivered by qualified therapists trained in men's mental health (Courtenay, 2005; Kivari et al., 2018; Pederson & Vogel, 2007; Seidler et al., 2020), as well as in grief and bereavement specifically following pregnancy loss and neonatal death (Obst & Due, 2019a). Interventions informed by this knowledge would aid the provision of structured advice on managing the unique challenges that bereaved fathers can face following pregnancy loss and neonatal death, including finding a balance between supporting a partner *and* processing their own grief, potential for delayed grief responses, exploring support strategies that suit instrumental grieving styles, and navigating potential differences in grief styles between members of a couple relationship.

7.3.2 Father-inclusive systems and policies

7.3.2.1 *Hospital and healthcare systems*

Uncertainty surrounding men's 'fit' within the hospital setting was reported by participants as a barrier to engagement and access to desired supportive services in Studies 2 and 4. As such, participants' accounts suggested there is a need for systems to implement strategies to include formal and systematic engagement of fathers throughout pregnancy and childbirth, and in the event of a pregnancy loss or neonatal death. These findings support implementing existing father-inclusive practice recommendations (e.g., Commonwealth of Australia, 2009; Fletcher, 2008; Healthy Male, 2020) across all perinatal and maternity hospital/healthcare settings. Specifically in regard to men's experiences of pregnancy loss and neonatal death, findings highlighted the importance of actively referring to, and including fathers in all birth, labour and bereavement care processes, as well as follow-up appointments. A central part of this process would include adopting family-centred language that is father-inclusive, providing opportunities for individual discussion with fathers and tailored information regarding both their own and their partner's grief and support needs.

Another priority at the hospital system level is to consider introducing formal assessment of, and data collection regarding, fathers' mental health into routine maternity/health services data protocols; particularly following cases of pregnancy loss or neonatal death. In 2021, the iCOPE Digital Screening Tool was launched to screen for symptoms of depression and anxiety in new mothers and assess psychosocial risk factors which may flag a need for increased support. Given that not all men will require formal intervention for grief, versions of screening tools like iCOPE, after validation in samples of bereaved fathers, could be a useful way to facilitate the identification of men in need of further support and follow-up after a pregnancy loss or neonatal death.

In line with calls from recent research in the broader men's health space (e.g., Bateson et al., 2017; Darwin et al., 2021; Seidler et al., 2019), enhancing family-centred practices that are family-inclusive in healthcare systems and policies may also be aided by providing education on men's grief, grieving styles and support needs as a standard part of all perinatal and maternity health professionals' training. Additionally, targeted continuing professional development opportunities for health practitioners in the community (such as GPs) would also be beneficial, as increased awareness and confidence in addressing men's grief and support needs may assist in contributing to improving continuity of care from the hospital to the community.

While suggestions for healthcare system improvement from participants in this thesis were clear, the ongoing challenges surrounding the implementation of family-centred practices that are father-inclusive (outlined previously in Chapter 2) are also acknowledged. Particularly in the context of limited funding and resources, staffing structures, gendered perspectives on fatherhood and mental health, and cases including family violence, there is no doubt that implementing changes for formal inclusion of men into the existing healthcare system is no small, nor simple, task (Bateson et al., 2017; Darwin et al., 2021; Panter-Brick et al., 2014; Rominov et al., 2017). However, several strategies to address these challenges have also been suggested. For example, Bateson et al. (2017) acknowledge that while fear of assault from men is a widely held worry among female perinatal health professionals, most fathers do not pose a risk, and effective strategies can be put into place where necessary. For example, risks can be managed with multi-level strategies including engagement with family and domestic violence or child protection services. This will ensure the health of women and children while also engaging men as fathers in the majority of cases where family and domestic violence is not a concern.

In addition, there are also substantial potential benefits of working safely with families where family and domestic violence is a risk, with programs aimed at working with fathers who have previously perpetrated family and domestic violence demonstrating reduced incidents of violence and improved family relationships (Bateson et al., 2017; McConnell et al., 2016). Importantly, a lack of helpful education and/or encouragement of reflective supervision among health professionals regarding fatherhood has been identified as a perpetuating factor in fuelling unhelpful stereotypes (e.g., that men are disinterested, or less capable than women in parenting) and systemic biases toward father-inclusive practice issues. Bateson et al. and others (e.g., Darwin et al., 2021; Fletcher et al., 2014; Panter-Brick et al., 2014) argued that it is essential for formal clinical training to help raise awareness of the importance of father engagement, especially since evaluations of emerging training programs have identified improved knowledge and attitudes toward fathers among health professionals, and positive impacts on family-centred practice (e.g., see: Burgess et al., 2014; de Montigny et al., 2020; Humphries & Nolan, 2015).

Overall, it is important that woman-centred and father-inclusive practices need not be viewed as dichotomous or opposing approaches. Rather, an ideal maternity and perinatal healthcare system would integrate family-centred strategies that are father-inclusive in the adoption of holistic, family-centred care to address the needs of all individuals directly involved in the experience of pregnancy and childbirth – regardless of family structure. While the pregnant person and their infant should rightly remain the centre of a childbirth experience, research has shown that genuine and formal engagement of fathers (and non-birthing partners more generally), where appropriate and possible, is an essential part of supporting the overall health and wellbeing of a family unit (Alio et al., 2011; Darwin et al., 2021; Fletcher et al., 2014, 2015; Plantin et al., 2011).

7.3.2.2 *Workplace bereavement policies*

In addition to healthcare system policies, previous research has also noted that feeling supported by the workplace to seek help is a positive predictor in men's tendencies to engage in mental health services and/or take parental leave (Brandth & Kvande, 2019; Haas & Hwang, 2019; McKenzie et al., 2018; Seidler et al., 2020). The findings of this thesis highlighted that there remains a need for inclusive workplace policies across industries to drive recognition and active encouragement of men to access available leave and additional support if/when needed. As discussed in Study 3 (Chapter 5), government recognition for bereavement leave following pregnancy loss and neonatal death in Australia has increased substantially since the National Stillbirth Senate Inquiry (McCarthy et al., 2018). Following ongoing advocacy by national pregnancy loss and neonatal death support organisations, legislation now exists to allow parental and bereavement leave for parents following stillbirth and miscarriage (Borys, 2021; Curtis, 2020; Ireland, 2020). After a miscarriage in Australia, parents can now access two days' paid compassionate/bereavement leave; after a stillbirth, parents can access up to 12 months of unpaid leave in addition to compassionate/bereavement leave and potentially, a period of paid parental leave (Borys, 2021; Fair Work Ombudsman, 2022; Imrie, 2021a). These changes have occurred in conjunction with wider social recognition of the need for flexibility in the workplace for all parents and families, with numerous large corporations and small businesses in Australia now certified with the national 'Family Friendly Workplaces' initiative (UNICEF Australia, 2021).

In addition to increased government recognition, in 2021, the findings from Study 3 were invited for inclusion in the Baby Loss Project; a nationally-available training program for workplaces that aims to upskill employers to respond proactively when an employee experiences pregnancy loss, stillbirth or infant death (Imrie, 2021b). The program aims to provide support to employers on understanding grief, managing sensitive conversations, and developing inclusive human resource policy to allow bereaved employees access to bereavement/parental leave and emotional support. Inclusion of this research in the training program advocated the need for employers to specifically recognise the needs of fathers after baby loss, including the following key recommendations:

- Be proactive in asking men how they are feeling and coping after their loss, and continue to check in with them in the weeks/months following, as support needs may change.
- Be proactive in offering men leave and additional support, rather than waiting for them to request it; an active approach from employers will be instrumental in assisting to create cultural change regarding the acceptability of men seeking support.
- If the workplace cannot offer standard types of leave or support, consider other supports such as referral to an Employee Assistance Program, allowing for a stepped progression back into a normal workload, or short-term flexibility in work hours or location.

While this thesis highlighted that men grieve and cope with their loss in different ways and require varying levels of support, it is vital that employers strive to recognise and understand the impact of pregnancy loss and neonatal death on men. Even where workplace leave was not available to men in this program of research, participants described deep appreciation for employers who could express genuine care and compassion, pointing to the need for sensitive interpersonal interaction as well as systemic policies that are inclusive and supportive.

7.3.3 Potential recommendations for future bereavement care guidelines

The findings of this thesis suggest there is a need to extend or amend current bereavement care recommendations – such as those in Australia from PSANZ/Stillbirth CRE and NBCP guidelines from the UK – to be more father-specific. Recommendations should accompany efforts outlined above to extend the focus of healthcare systems to be family-centred and father-inclusive, and develop supportive interventions specifically for men. While all additions to future guidelines should be developed with extensive consultation with bereaved parents and healthcare professionals, suggestions for potential recommendations from the findings of this research include:

- Ideally, all fathers/partners should leave hospital with information about grief, contact details for 24-hour follow-up support and ways to access care. If possible, support details should be appropriate to geographic location.
    - While current guidelines note the importance of 24-hour support and information about grief, there is no direct discussion of ensuring fathers also have access to tailored care or support.
- Fathers/partners should receive at least one individual follow-up call or visit from an appropriately skilled health care professional after their partner is discharged from hospital. In recognition of the potential delayed grief responses in fathers, an additional follow-up telephone call would ideally also be made in the weeks/months following initial follow-up to conduct brief screening for mental health concerns, re-offer information on coping with grief, and offer referrals to local community support services.

    - While a follow-up telephone call or visit is currently recommended in guidelines for mothers, follow-up directly to fathers is not included.

In any follow-up review meetings held at the hospital after the baby's death, ensure:

- All members of the couple/family unit attend together to receive important information and results. Such an approach may require flexibility regarding appointment time and/or place to accommodate parents who may have returned to work.
- Provide psychoeducation on common grief reactions and discuss the potential for discordant grief styles between couples, including practical tips on how to support one another.
- Practical and emotional support needs unique to fathers, including tips for supporting their partner alongside balancing the need to support and be supported, potential for delayed grief responses, and men's options/rights for accessing paid bereavement or paternity leave before returning to work, should be addressed in all written information on fathers' grief and discussed in follow-up support.
    - While current guidelines outline the importance of addressing practical support needs including sources of financial support, options for accommodation and assistance if parents are away from their local home environment, birth and death certificates, birth registration, medical certificates for employers, support needs specific to fathers identified from this research are not directly discussed.
- Conduct brief mental health screening for fathers/partners prior to discharge from hospital and in follow-up telephone calls or home visits to facilitate helpful referral pathways.
    - Establish and use referral pathways for parents who may be at risk of complicated bereavement due to factors relating to the death, medical or personal history, social circumstances or other stressors.

In addition to these recommendations specifically for hospitals, findings from this thesis also offer insight regarding education of health professionals and ideas for community services such as those provided by pregnancy loss and neonatal death support organisations, GPs and fertility clinics. Specific suggestions are provided below. I recognise that some organisations and clinics may have already enacted various initiatives aligning with these; as such, the suggestions here represent a broad list of ideas that could be helpful for services if they have not already been considered, supported by the findings of this research:

- Ensure content on men's health, including mental health and grieving styles, are included in standard tertiary education courses for all health professional trainees;
- Ensure all fertility specialists and community healthcare professionals and peer supporters are trained in family-centred care that is father-inclusive following pregnancy loss and neonatal death;
- Consider offering loss-specific peer support groups (particularly for TOPFA) for parents who may not feel comfortable attending a support group that is inclusive of all loss types;
- Offer individualised follow-up support and information on available online supports to fathers/partners when engaging in telephone support calls or home support visits with mothers;
- In assessing bereaved parents' needs, consider the wide range of socio-ecological factors that may be contributing to their experience to guide the development of an individualised program of support;
- Increase the visibility and reach of available father-specific bereavement support services through targeted community advertising;
- Ensure father-specific grief information and support resources developed by community support organisations are displayed and accessible in all GP and fertility clinics;

- Develop and pitch continuing professional development courses to GPs on engaging with fathers after pregnancy loss and neonatal death, including the appropriate provision of information on available father-specific community resources to facilitate referrals;
- Continue to strengthen partnerships between hospitals, community parent support organisations and GPs to facilitate continuity of care and smooth follow-up and referral processes.

Given findings that loss types (particularly TOPFA) may carry unique needs surrounding grief, it is also important to provide tailored information to parents that is specific to loss types, including referrals to appropriate (TOPFA-specific) online and locally-available community supports. In addition, future bereavement care guidelines could include particular recommendations regarding losses that occur at the margins of standard gestational classifications of miscarriage or stillbirth. For example, it cannot be assumed that the psychological experience of a TOPFA or miscarriage at 18 or 19 weeks' gestation will differ from a stillbirth at 20 weeks' gestation. While specific medical and birth needs may differ according to gestational age, parents presenting to a hospital for care should be adequately prepared for the experience of labour and birth. The terminology used to refer to the baby and type of loss should always be in line with parents' preferences, and wherever possible, consistency in bereavement care practices regardless of loss type is essential (Smith et al., 2020).

7.4 Strengths

The mixed methods approach employed for this thesis was appropriate for achieving the research aims and providing depth in understanding men's experiences. In the context of a lack of theory to understand men's grief, Study 1 was the first systematic review to comprehensively examine and collate previous research findings on men's grief and the factors associated with men's grief after pregnancy loss and neonatal death. Adopting frameworks from the Biopsychosocial Model, Public Health Model of Bereavement Support and gender/masculinity theories to guide exploration of potential contributors to grief resulted in a wider range of identified factors for consideration, forming the Socio-Ecological Model of Men's Grief. Similarly, Study 2 provided a comprehensive examination of multiple levels of factors that may contribute to men's grief, as well as exploring factors contributing to different styles of grief. Employing multiple stepwise linear regression analyses allowed the opportunity to explore factors existing at the levels identified in the socio-ecological model, and additional content analysis in Study 3 allowed further exploration particularly on the impact of returning to the workplace on grief. Finally, Study 4 informed a rich understanding of men's experiences of grief and support following TOPFA, for which qualitative inquiry was most appropriate. With the use of mixed methods to explore the research questions, this thesis was able to capitalise on known benefits of this methodological approach, including gathering multiple perspectives to provide a comprehensive explanation of factors contributing to grief and providing a rich exploration of men's experience of grief (Creswell & Hirose, 2019; Johnson et al., 2007). In particular, the consistency of the broad themes identified in the cross-study synthesis enhanced confidence in the overall findings and implications (Kavanaugh et al., 2011).

In the context of limited previous research among men and reported difficulties in recruiting men to pregnancy loss and neonatal death research, a further strength of this thesis was its success in recruiting over 250 participants, with representation from all Australian States and Territories, as well as urban and rural areas. To date, Study 2 resulted in the largest sample of men in an Australian context – and indeed one of the largest reported samples of men worldwide – in pregnancy loss and/or neonatal death research. The success of the recruitment approach may be due to multiple factors. Specifically, targeting the research directly for 'men/fathers' rather than 'parents' more generally, aligned with father-inclusive practice recommendations, which indicate that men tend to associate mothers more strongly with the general term ‘parent’ (Commonwealth of Australia, 2009; Fletcher, 2008; Fletcher et al., 2014). In addition, the online format of the survey distributed via social media maximised reach and accessibility, allowing participants to complete the survey from any setting, time or place that was convenient for them.

Consumer engagement in research and guideline development can lead to more meaningful and relevant outcomes (Miller et al., 2017; NHMRC, 2018). Therefore, the inclusion of a reference group in this program of research served as a further strength, particularly in integrating views from individuals with lived experience or expertise in pregnancy loss and neonatal death to guide the development of the nationwide online survey for Study 2. In line with recommendations from the research reference group, promoting the credibility of the research and team through a link to an official research webpage (hosted by the official University of Adelaide website) may have also resulted in increased trust and credibility for the research, and increased confidence that it would result in meaningful output including media articles, outreach/advocacy work, and the final Industry Report (see Appendix 13). Finally, in the context of research indicating some men’s hesitancy to engage in face-to-face mental health services (Berger et al., 2005; Galdas et al., 2005; Seidler et al., 2016; Yousaf, Popat, et al., 2015), the option to remain anonymous in the research may have increased appeal to some participants. Notably, over half of the sample in Study 2 chose to remain anonymous. In Study 3, while interviews were offered via a range of methods (video conferencing, face-to-face is possible for participants, and telephone), all participants elected for interviews over the phone, with men reporting they felt comfortable sharing their experiences in this way.

As outlined previously, this research was also conducted during a timely and transformative period for recognition of pregnancy loss and neonatal death at a national level in Australia. The establishment of the Senate's Select Committee on Stillbirth Research and Education in March of 2018, and the subsequent Inquiry which was tabled to Parliament on the 4th of December in 2019, has been instrumental in raising the public profile of stillbirth and informing policy to recognise the deep and enduring impact of parents' grief. The opportunity to contribute research findings (both from this thesis and previous work by the authors on the same topic) to the Inquiry, as well as to capitalise on public interest in the topic through media articles, helped to raise the profile and reach of this research.

7.5 Limitations and future research

While recruitment success was a strength of this research, participants self-selected to participate. As a result, their perspectives cannot be assumed to be representative of all men grieving the death of a baby in Australia. Recruitment occurred via national pregnancy loss support organisations. This approach was chosen for convenience and to increase the likelihood that participants had existing connections to, and/or knowledge of, community support organisations, should they require support after survey completion. However, advertisement through these organisations may have restricted the scope of the sample to men who had more intense or intuitive grief responses to the death of their baby and who had already sought community/peer support. Alternatively, it is also possible that those who participated may have had more success in adjusting to living with their loss, given their connection to community/peer support services. Following the publication of media articles related to the nationwide survey, I also received some emails from men who expressed that they had not been aware of the survey, but would have taken part if they had seen it advertised through wider community-based channels. These communications indicated a missed opportunity to reach a broader audience of potential research participants; as such, future research could consider recruiting through more general community groups and/or fatherhood forums to further maximise reach.

There remains a pressing and important gap in regard to exploring the experiences and needs of diverse samples of men after pregnancy loss and neonatal death. While this research was open to participation from gender and/or sexuality diverse men, none chose to participate. This outcome highlights the need for research targeted specifically to gender and/or sexuality diverse parents, who face unique challenges in regard to loss and may be less likely to self-select into research on ‘parents’ or ‘men’s’ experiences of pregnancy loss and neonatal death (Riggs et al., 2015, 2020; Ziv & Freund-Eschar, 2015). While work in this area is beginning to emerge (Riggs et al., 2020; Rose & Oxlad, 2022), continuing future research to explore the grief experiences and support needs of gender and/or sexuality diverse parents is essential to ensure bereavement care guidelines and systems/policies are inclusive and tailored to the needs all types of families.

In addition, there is a need for research among men from LMICs, as well as men in high-income countries who are from culturally and linguistically diverse (CALD) backgrounds (McNeil et al., 2020; Shakespeare et al., 2019). Similar to previous research, the cultural diversity of the samples comprising this research was limited. Limited cultural diversity was the case for Study 1 in that most articles included in the systematic review were from ‘western’ countries. Similarly, in Study 2 - and therefore Studies 3 and 4 where men were recruited via Study 2 - most men in the sample (85%) identified as ‘Australian’. Given the multicultural nature of Australian society, with 30 percent of the population born overseas (ABS, 2021), and the clear cultural impacts on grief (Klass & Chow, 2021; Rosenblatt, 2008, 2017; Stroebe & Schut, 1998), the current findings cannot be assumed to be representative of the views of all cultural groups, including those with large numbers of people in Australia. Similarly, the thesis cannot be seen as representative of the experiences of Aboriginal and Torres Strait Islander men, for whom grief also has specific cultural considerations (Raphael & Delaney, 2011; Wynne-Jones et al., 2016). These gaps are particularly important to note since, as mentioned in Chapter 1, ongoing and significant discrepancies exist in stillbirth rates among Aboriginal and Torres Strait Islander and CALD families in Australia compared to other Australians (Rumbold et al., 2020). Future research with these populations is a significant priority to ensure culturally-sensitive bereavement care guidelines, as well as tailored and appropriate community and health professional support, are provided to all families.

Finally, Studies 2, 3 and 4 relied on retrospective accounts of grief, which included losses occurring up to 20 years ago. In the process of peer review for publication, several reviewers identified that this inclusion criterion was open to potential recall bias, particularly in that social recognition for pregnancy loss and neonatal death and related healthcare and workplace policies may have changed substantially over time. Additional analyses were conducted for Studies 2 and 3 to allow for examination of grief scores (and receipt of workplace leave) by time since loss. However, only a small number of participants (9.2%) reflected on losses occurring 11+ years ago, and grief scores grouped by time since loss did not significantly differ. Despite this, it is acknowledged that relying on participants' retrospective accounts may be open to bias and that systems and supports have changed greatly over this period of time. Therefore, a need for an updated evaluation of men's grief and support experiences in Australia is needed, especially given the introduction of new men-specific support services since this program of research was conducted.

Overall, the research forming this thesis provides a solid theoretical foundation concerning men's grief following pregnancy loss and neonatal death and avenues for future research. While there has been a substantial increase in research on parents' experiences of pregnancy loss in recent years, gaps remain regarding interventions and therapies developed specifically for and targeted to men. A useful next step for research will be developing, implementing and evaluating trials of supportive interventions with men, informed by the factors contributing to grief and grief styles. Part of this research could involve longitudinal designs, following men throughout the pregnancy journey and in the event of pregnancy loss and neonatal death, to reduce reliance on retrospective accounts of grief and better determine what interventions are acceptable and beneficial to men at the time of loss and in weeks/months following. There is also a need to develop measures of grief that are more inclusive of instrumental styles of grieving that many men display to support meaningful evaluation of interventions.

Finally, given the instrumental roles of healthcare professionals in forming men's experiences of pregnancy loss and neonatal death, there is a need for future intervention research and evaluation of programs to also explore the experiences of those caring for bereaved parents. Previous research has acknowledged the impact of pregnancy loss and neonatal death on caring professionals and highlighted important barriers and facilitators to providing care (e.g., Ellis et al., 2016; Jones & Smythe, 2015; Nuzum et al., 2014; Petrites et al., 2016; Shakespeare et al., 2019; Wallbank & Robertson, 2008). Integrating the experiences of parents and healthcare professionals into the evaluation of future programs will be essential to gain a comprehensive understanding of barriers and facilitators to successfully delivering supportive care and interventions.

7.6 Self-reflexivity

At times I questioned my position in this research as an 'outsider' (Bonner & Tolhurst, 2002; Breen, 2007), specifically my right and ability to accurately and sensitively represent the experiences of the participants who had so generously shared their stories with me. However, participants in Studies 2 and 4 did not question my role; instead they expressed positive feedback about the survey/interview process, gratitude for the opportunity to share their stories, and feelings of ease in discussing their experiences, despite some initial nervousness. Nonetheless, given that men's experiences were so varied, it was a challenge to summarise results (particularly for Study 3), in a way that was both broad, and specific enough, to represent shared and contrasting viewpoints. However, I also felt my outsider position gave me a useful amount of 'space' from the data and men's experiences, allowing me to approach data analysis with a broad lens. Acknowledging my position, seeking ongoing feedback from the research reference group and engaging in member-checking (Tracy, 2010), was a further strength of the research. It was a welcome surprise, as well as a relief, to receive feedback from multiple participants and bereaved fathers in the community that the publications and media articles resulting from this research had been representative of their views. Below are some examples of reflections men shared with me:

> "…thank you for taking a special interest in this area, and the hard work you are doing to highlight what a lot of men go through silently."
>
> "…[the research] hit[s] on all the major points and problems with the current system from my own experience […] It's really disappointing that so many others seem to have suffered with the same experience as myself, but the points and themes you have put together gives me hope that the system can be improved for future dads."
>
> "I believe that you have done an outstanding job that has and will, give men more options to deal with grief and potentially lead to tools that can help us with this issue. I really appreciate the opportunity to take part in the study."

In acknowledging my position as a woman approaching the research with a broad feminist lens, I also spent a great deal of time grappling with 'getting the messaging right', surrounding improving recognition and engagement of men in perinatal healthcare services whilst also upholding the essential rights and needs of childbearing women. However, I formed a perspective from conducting the research for this thesis that support of men's mental health plays an essential part in upholding the wellbeing of whole-family units that include fathers. Participants' accounts suggested that where we can support men's mental health and improve their knowledge of their own needs and options for support during pregnancy and childbirth, this would have positive flow-on effects for their ability to engage in mutually-supportive relationships with their partners, other children and families more broadly.

There is no doubt that throughout this research, I was deeply moved and emotionally impacted by participants' stories of grief following the death of their babies. Particularly during the first two years of the combined PhD/Masters program, which was solely dedicated to the PhD research, my life felt very much 'consumed' by death, grief and loss. At times, the stories I collected felt confronting, overwhelming and deeply saddening. Given the recruitment success of the research, as well as a lack of previous research into this topic, I additionally felt a great deal of responsibility to carry men's stories and use them to do something valuable to contribute to improvement in future experiences. The emotional impact this research had on me has fuelled a deep desire to share the messaging and recommendations as widely as possible through outreach and advocacy opportunities.

7.7 Conclusion

The findings of this thesis provide a comprehensive evidence base from which to make recommendations and build future resources and interventions to improve care and support for men after pregnancy loss and neonatal death. While men do not experience the physical process of a pregnancy loss or neonatal death, they are also not 'only' support people – they are, almost always, fathers grieving the death of their baby. Working toward genuine acknowledgement and recognition of men as such will require ongoing development and evaluation of multi-level strategies informed by a Socio-Ecological Model of Men's Grief, including those approaches aimed at individuals, families, communities, and wider systems/policies.

While grief following pregnancy loss and neonatal death is clearly a highly individualised experience, this research demonstrated that men may experience significant grief and face unique challenges that require dedicated support from trained healthcare professionals. Although not all men will require formal support during their grief, there is a pressing need to reduce existing barriers to accessing care for men, particularly at the health services/system level. In recognition of a spectrum of possible grieving styles that cannot be addressed through one single intervention, it is important that several options continue to be available to men depending on individual and family needs. However, it is clear that support and recognition received in the hospital or healthcare setting where the loss takes place precipitates men's ongoing and long-term experiences of grief and access to support in the community; in this context, there is truly only "one chance to get [bereavement care] right" for men, women and families (Downe et al., 2013, p. 1). Therefore, expansion of existing in-hospital services to include specific father/partner supports – such as a consultation service staffed by health professionals trained in family-centred care that is father-inclusive – could be instrumental in shaping men's grief experience and access to future support. Finally, raising awareness of father's mental health through continuing professional development of all trainee health professionals is key to assisting the integration of family-centred care that is father-inclusive into all perinatal healthcare and community support settings. Engaging with and supporting men and fathers has the potential for far-reaching positive impacts not only for their own health, but also for the health of whole family units that include men.

To conclude, it has been an immense privilege for me to spend the last five years researching men's grief and support after pregnancy loss and neonatal death. It is my hope that the resulting publications, presentations, wider advocacy work, and discussions I have had along the way with passionate supporters have played a part in the case for positive change for men, women and all families, now and into the future.

APPENDIX 1. Nationwide Survey Study Flyer

THE UNIVERSITY of ADELAIDE
SAHMRI South Australian Health & Medical Research Institute
Healthy Mothers, Babies and Children

#DadsGrieveToo

Fathers are needed to participate in a research project aiming to improve our knowledge of Aussie dads' grief and bereavement following pregnancy loss and/or neonatal loss.

There remains a lack of understanding regarding men's grief and subsequent support needs following the loss of a baby – especially in the Australian context.

We are seeking men who have experienced the loss of a baby in Australia within the last 20 years at any stage of pregnancy, or during the neonatal period (first 28 days of life), to complete a survey on their experiences. This information may be used to inform future bereavement care guidelines, and improve support services for men.

To participate, please follow this survey link:

https://www.surveymonkey.com/r/MenPregnancyLossSurvey

For more information, please visit the research webpage at:
https://health.adelaide.edu.au/mens-grief
or contact Kate Obst at: kate.obst@adelaide.edu.au

APPENDIX 2. Participant Information Sheet for Study 4

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: Dr Clemence Due
STUDENT RESEARCHER: Ms Kate Obst
STUDENT'S DEGREE: PhD/Master of Psychology (Health)

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 Kate Obst. It will form the basis for her degree of PhD/Master of Psychology (Health) at the University of Adelaide, under the supervision of Dr Clemence Due, Dr Melissa Oxlad, and A/Professor Philippa Middleton. Ms Obst is supported by an Australian Government Research Training Program Scholarship, and a Westpac Bicentennial Foundation Future Leaders Scholarship.

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 will take place can take place at the University of

Adelaide (North Terrace Campus), over the telephone, or an alternative public area 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. Ms Obst may also present the results of the study 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 Kate (phone: (08) 8313 6972 or email: kate.obst@adelaide.edu.au) or Dr Due (phone: (08) 8313 6096 or email: clemence.due@adelaide.edu.au).

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 Kate (email: kate.obst@adelaide.edu.au) to organise a time and place for an interview.

Yours sincerely,
Ms Kate Obst
Dr Clemence Due
Dr Melissa Oxlad
A/Professor Philippa Middleton

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/male-parent-supporters
  Online live chat: available via link below
  https://www.sands.org.au/online-live-support

- **Bears of Hope Grief Support**
  Call 1300 11 HOPE, or email support@bearsofhope.org.au

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

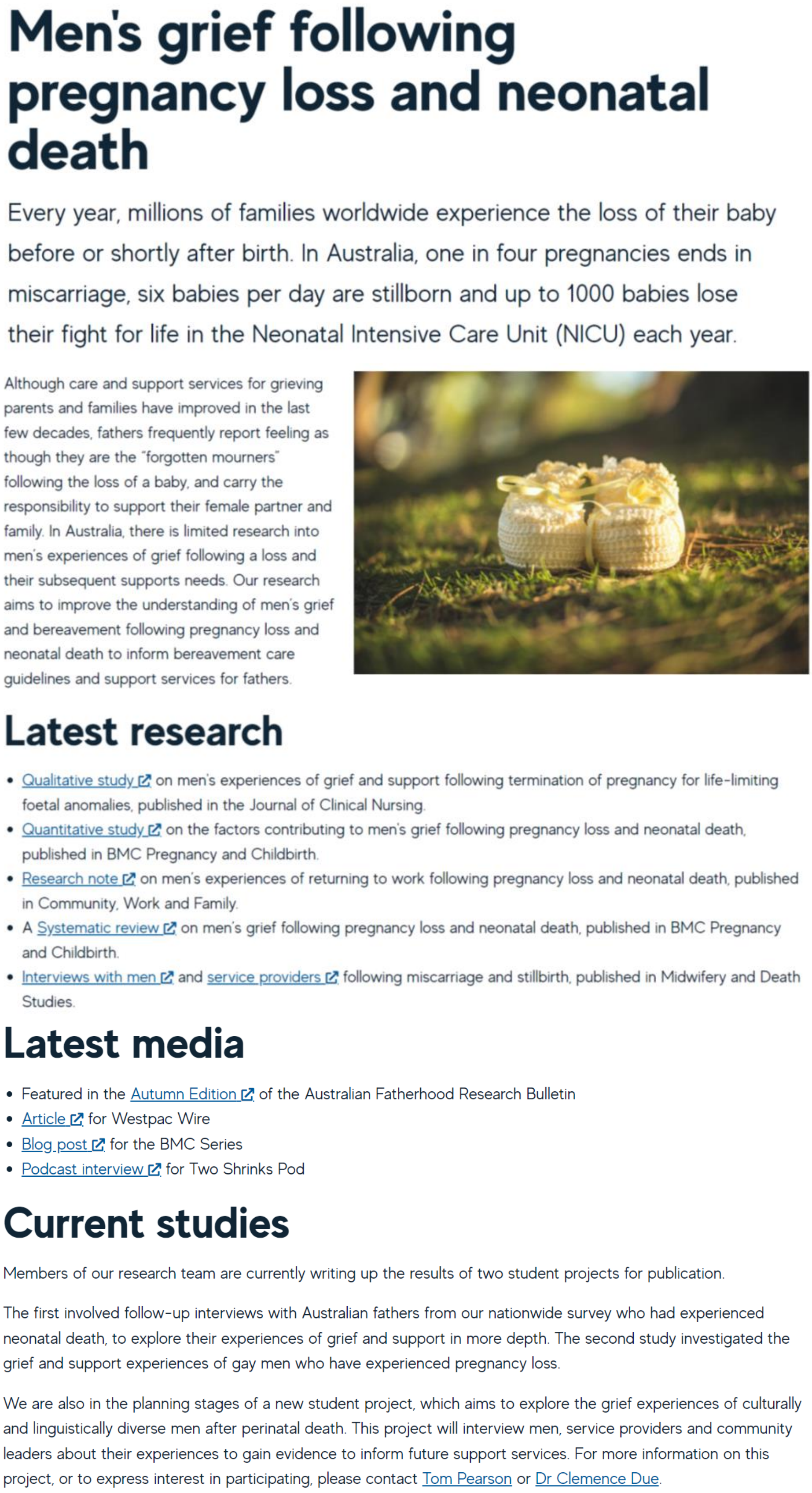
- **Pregnancy Birth & Baby Helpline**
  Free call 7 days a week: 1800 882 436

- **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 3. Research Webpage



Men's grief following pregnancy loss and neonatal death

Every year, millions of families worldwide experience the loss of their baby before or shortly after birth. In Australia, one in four pregnancies ends in miscarriage, six babies per day are stillborn and up to 1000 babies lose their fight for life in the Neonatal Intensive Care Unit (NICU) each year.

Although care and support services for grieving parents and families have improved in the last few decades, fathers frequently report feeling as though they are the "forgotten mourners" following the loss of a baby, and carry the responsibility to support their female partner and family. In Australia, there is limited research into men's experiences of grief following a loss and their subsequent supports needs. Our research aims to improve the understanding of men's grief and bereavement following pregnancy loss and neonatal death to inform bereavement care guidelines and support services for fathers.

Latest research

- Qualitative study on men's experiences of grief and support following termination of pregnancy for life-limiting foetal anomalies, published in the Journal of Clinical Nursing.
- Quantitative study on the factors contributing to men's grief following pregnancy loss and neonatal death, published in BMC Pregnancy and Childbirth.
- Research note on men's experiences of returning to work following pregnancy loss and neonatal death, published in Community, Work and Family.
- A Systematic review on men's grief following pregnancy loss and neonatal death, published in BMC Pregnancy and Childbirth.
- Interviews with men and service providers following miscarriage and stillbirth, published in Midwifery and Death Studies.

Latest media

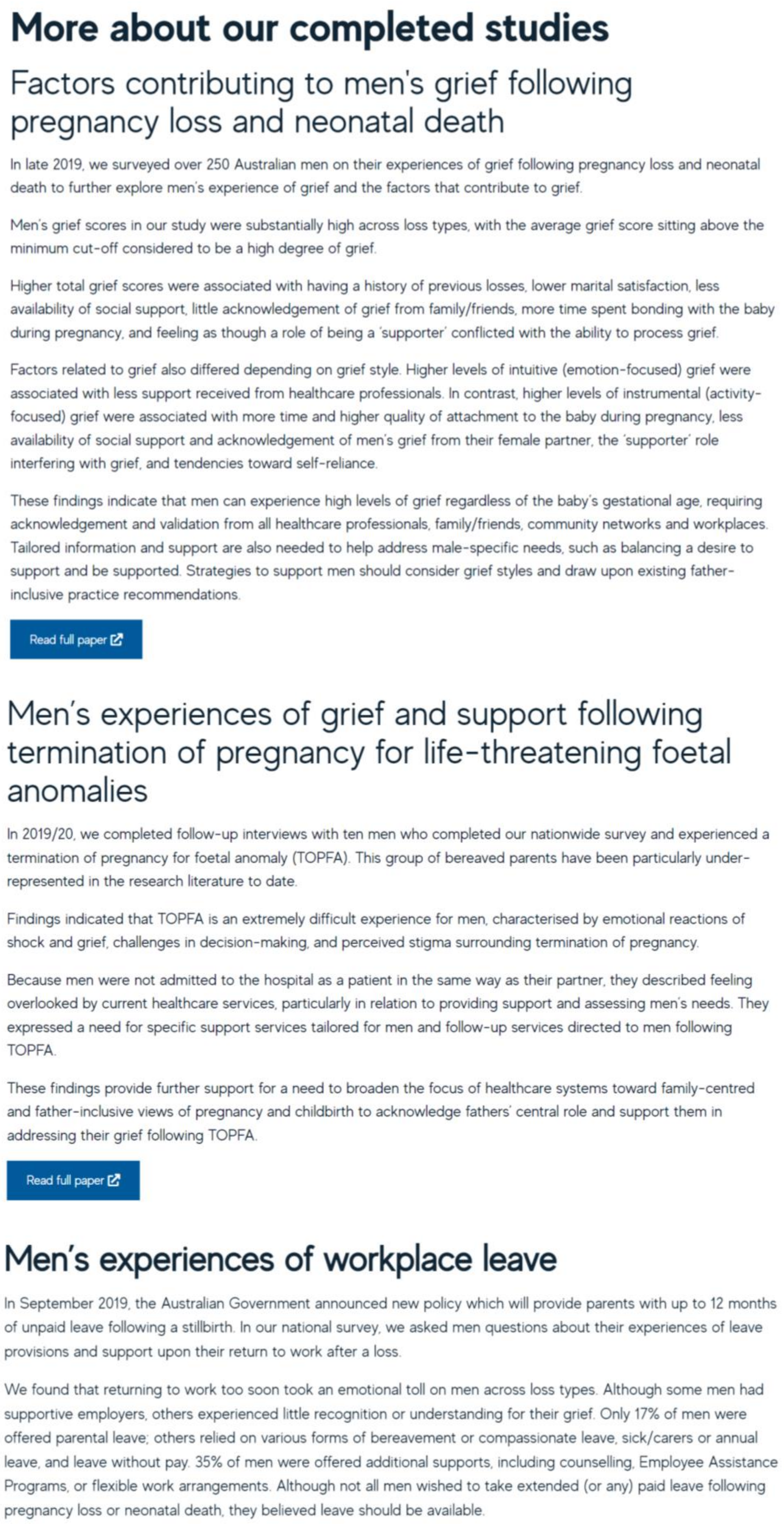
- Featured in the Autumn Edition of the Australian Fatherhood Research Bulletin
- Article for Westpac Wire
- Blog post for the BMC Series
- Podcast interview for Two Shrinks Pod

Current studies

Members of our research team are currently writing up the results of two student projects for publication.

The first involved follow-up interviews with Australian fathers from our nationwide survey who had experienced neonatal death, to explore their experiences of grief and support in more depth. The second study investigated the grief and support experiences of gay men who have experienced pregnancy loss.

We are also in the planning stages of a new student project, which aims to explore the grief experiences of culturally and linguistically diverse men after perinatal death. This project will interview men, service providers and community leaders about their experiences to gain evidence to inform future support services. For more information on this project, or to express interest in participating, please contact Tom Pearson or Dr Clemence Due.



More about our completed studies

Factors contributing to men's grief following pregnancy loss and neonatal death

In late 2019, we surveyed over 250 Australian men on their experiences of grief following pregnancy loss and neonatal death to further explore men's experience of grief and the factors that contribute to grief.

Men's grief scores in our study were substantially high across loss types, with the average grief score sitting above the minimum cut-off considered to be a high degree of grief.

Higher total grief scores were associated with having a history of previous losses, lower marital satisfaction, less availability of social support, little acknowledgement of grief from family/friends, more time spent bonding with the baby during pregnancy, and feeling as though a role of being a 'supporter' conflicted with the ability to process grief.

Factors related to grief also differed depending on grief style. Higher levels of intuitive (emotion-focused) grief were associated with less support received from healthcare professionals. In contrast, higher levels of instrumental (activity-focused) grief were associated with more time and higher quality of attachment to the baby during pregnancy, less availability of social support and acknowledgement of men's grief from their female partner, the 'supporter' role interfering with grief, and tendencies toward self-reliance.

These findings indicate that men can experience high levels of grief regardless of the baby's gestational age, requiring acknowledgement and validation from all healthcare professionals, family/friends, community networks and workplaces. Tailored information and support are also needed to help address male-specific needs, such as balancing a desire to support and be supported. Strategies to support men should consider grief styles and draw upon existing father-inclusive practice recommendations.

Men's experiences of grief and support following termination of pregnancy for life-threatening foetal anomalies

In 2019/20, we completed follow-up interviews with ten men who completed our nationwide survey and experienced a termination of pregnancy for foetal anomaly (TOPFA). This group of bereaved parents have been particularly under-represented in the research literature to date.

Findings indicated that TOPFA is an extremely difficult experience for men, characterised by emotional reactions of shock and grief, challenges in decision-making, and perceived stigma surrounding termination of pregnancy.

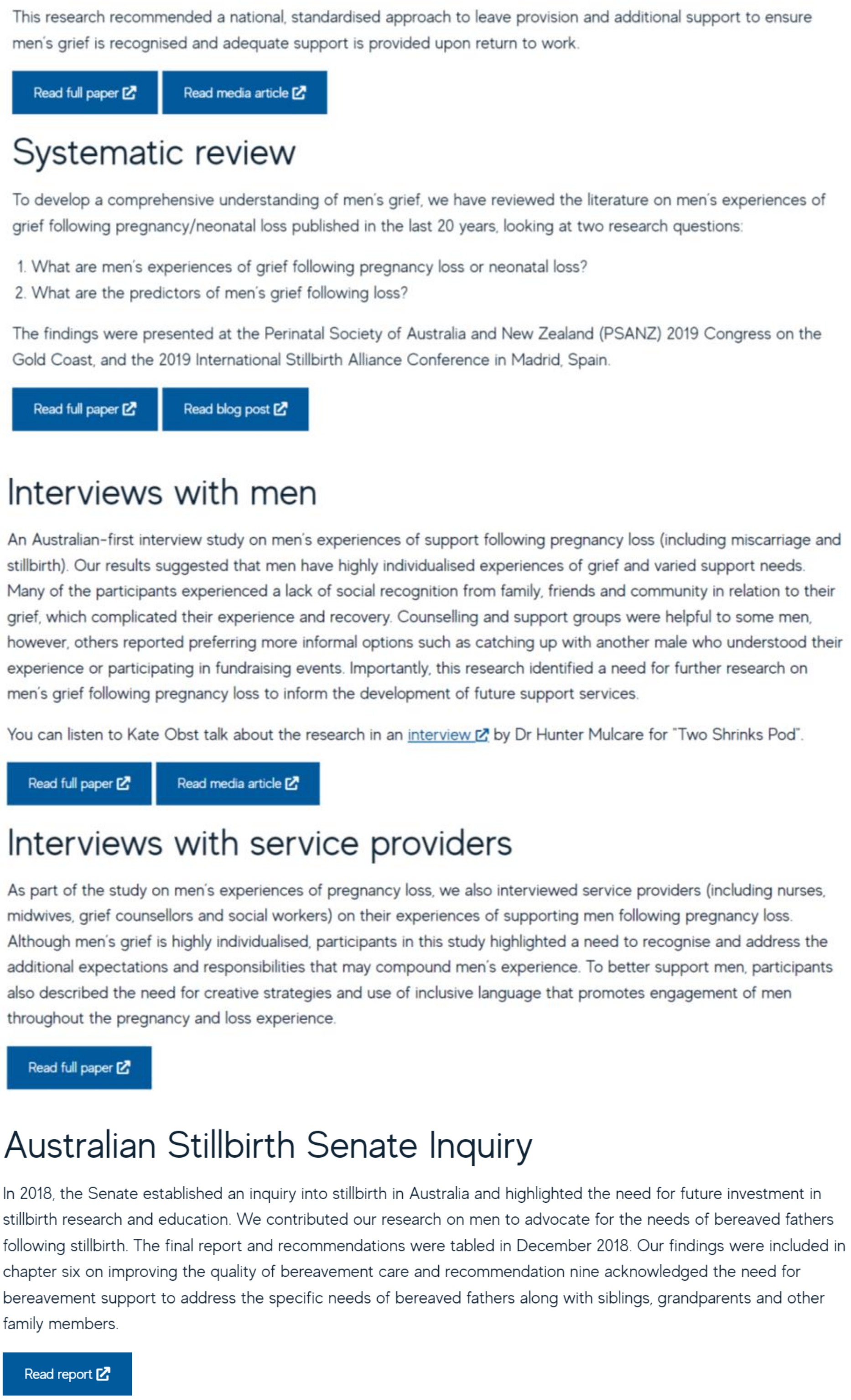
Because men were not admitted to the hospital as a patient in the same way as their partner, they described feeling overlooked by current healthcare services, particularly in relation to providing support and assessing men's needs. They expressed a need for specific support services tailored for men and follow-up services directed to men following TOPFA.

These findings provide further support for a need to broaden the focus of healthcare systems toward family-centred and father-inclusive views of pregnancy and childbirth to acknowledge fathers' central role and support them in addressing their grief following TOPFA.

Men's experiences of workplace leave

In September 2019, the Australian Government announced new policy which will provide parents with up to 12 months of unpaid leave following a stillbirth. In our national survey, we asked men questions about their experiences of leave provisions and support upon their return to work after a loss.

We found that returning to work too soon took an emotional toll on men across loss types. Although some men had supportive employers, others experienced little recognition or understanding for their grief. Only 17% of men were offered parental leave; others relied on various forms of bereavement or compassionate leave, sick/carers or annual leave, and leave without pay. 35% of men were offered additional supports, including counselling, Employee Assistance Programs, or flexible work arrangements. Although not all men wished to take extended (or any) paid leave following pregnancy loss or neonatal death, they believed leave should be available.



This research recommended a national, standardised approach to leave provision and additional support to ensure men's grief is recognised and adequate support is provided upon return to work.

Systematic review

To develop a comprehensive understanding of men's grief, we have reviewed the literature on men's experiences of grief following pregnancy/neonatal loss published in the last 20 years, looking at two research questions:

1. What are men's experiences of grief following pregnancy loss or neonatal loss?
2. What are the predictors of men's grief following loss?

The findings were presented at the Perinatal Society of Australia and New Zealand (PSANZ) 2019 Congress on the Gold Coast, and the 2019 International Stillbirth Alliance Conference in Madrid, Spain.

Interviews with men

An Australian-first interview study on men's experiences of support following pregnancy loss (including miscarriage and stillbirth). Our results suggested that men have highly individualised experiences of grief and varied support needs. Many of the participants experienced a lack of social recognition from family, friends and community in relation to their grief, which complicated their experience and recovery. Counselling and support groups were helpful to some men, however, others reported preferring more informal options such as catching up with another male who understood their experience or participating in fundraising events. Importantly, this research identified a need for further research on men's grief following pregnancy loss to inform the development of future support services.

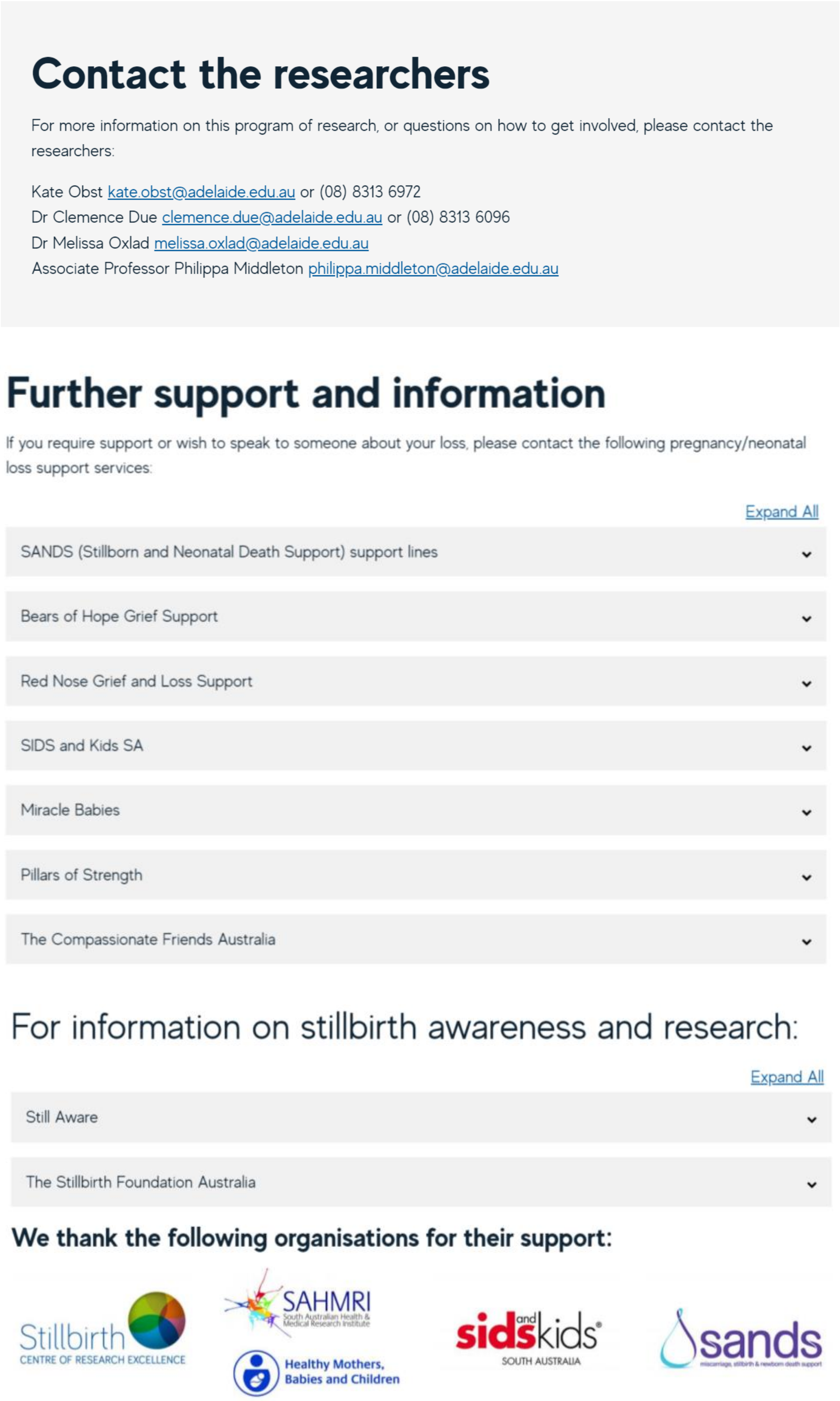
You can listen to Kate Obst talk about the research in an interview by Dr Hunter Mulcare for "Two Shrinks Pod".

Interviews with service providers

As part of the study on men's experiences of pregnancy loss, we also interviewed service providers (including nurses, midwives, grief counsellors and social workers) on their experiences of supporting men following pregnancy loss. Although men's grief is highly individualised, participants in this study highlighted a need to recognise and address the additional expectations and responsibilities that may compound men's experience. To better support men, participants also described the need for creative strategies and use of inclusive language that promotes engagement of men throughout the pregnancy and loss experience.

Australian Stillbirth Senate Inquiry

In 2018, the Senate established an inquiry into stillbirth in Australia and highlighted the need for future investment in stillbirth research and education. We contributed our research on men to advocate for the needs of bereaved fathers following stillbirth. The final report and recommendations were tabled in December 2018. Our findings were included in chapter six on improving the quality of bereavement care and recommendation nine acknowledged the need for bereavement support to address the specific needs of bereaved fathers along with siblings, grandparents and other family members.



Contact the researchers

For more information on this program of research, or questions on how to get involved, please contact the researchers:

Kate Obst kate.obst@adelaide.edu.au or (08) 8313 6972
Dr Clemence Due clemence.due@adelaide.edu.au or (08) 8313 6096
Dr Melissa Oxlad melissa.oxlad@adelaide.edu.au
Associate Professor Philippa Middleton philippa.middleton@adelaide.edu.au

Further support and information

If you require support or wish to speak to someone about your loss, please contact the following pregnancy/neonatal loss support services:

Expand All

- SANDS (Stillborn and Neonatal Death Support) support lines ⌄
- Bears of Hope Grief Support ⌄
- Red Nose Grief and Loss Support ⌄
- SIDS and Kids SA ⌄
- Miracle Babies ⌄
- Pillars of Strength ⌄
- The Compassionate Friends Australia ⌄

For information on stillbirth awareness and research:

Expand All

- Still Aware ⌄
- The Stillbirth Foundation Australia ⌄

We thank the following organisations for their support:

Stillbirth CENTRE OF RESEARCH EXCELLENCE
SAHMRI South Australian Health & Medical Research Institute
Healthy Mothers, Babies and Children
sids and kids SOUTH AUSTRALIA
sands miscarriage, stillbirth & newborn death support

Ms Obst is receiving funding for this research from an Australian Government Research Training Program Scholarship and a Westpac Scholars Trust 2018 Future Leaders Scholarship.

Research webpage link: https://health.adelaide.edu.au/mens-grief

(Current at 02 February 2022)

APPENDIX 4. PICO Outline for Systematic Review

- **P** (Population): Adult men (aged 18+ years) who have experienced a pregnancy loss (including any definition of ectopic pregnancy, miscarriage, termination of pregnancy for life-limiting foetal anomaly, stillbirth) or neonatal death (up to 28 days after a live birth).
- **I** (Intervention or exposure): Exposure will be the experience of a pregnancy loss or neonatal death, defined as the death of a baby at any gestational age in-utero or at birth, and the death of a baby up to 28 days after a life birth.
- **C** (Comparison): Any or no comparison group; e.g., potential comparators may include women who have experienced a pregnancy loss or neonatal death.
- **O** (Outcome): Quantitative measures of men's grief or predictors of grief after pregnancy loss or neonatal death; qualitative accounts of men's experiences of grief after pregnancy loss or neonatal death and perceived factors that influenced their grief; impact of loss type or gestational age on grief. Secondary outcomes may also include, but are not limited to: men's employment status and functioning in the workplace after pregnancy loss or neonatal death; effect of cultural background on grief; maintenance or break down of parental relationship after pregnancy loss or neonatal death.

APPENDIX 5. PROSPERO Protocol for Study 1

Please note: This is the latest version of the protocol published on PROSPERO as of 02 Feb 2022. Earlier versions are available via webpage at:

https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42018103981

Men's grief following pregnancy loss and neonatal loss: a systematic review

Kate Obst, Clemence Due, Melissa Oxlad, Philippa Middleton

Citation

Kate Obst, Clemence Due, Melissa Oxlad, Philippa Middleton. Men's grief following pregnancy loss and neonatal loss: a systematic review. PROSPERO 2018 CRD42018103981 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42018103981

Review question [1 change]

Two questions will guide this review: (1) what are men's experiences of grief following pregnancy loss and neonatal loss? And (2) what are the factors that contribute to men's grief following pregnancy loss and neonatal loss?

Searches [2 changes]

This review will involve a systematic search across four electronic databases: PubMed, PsycINFO, Embase and CINAHL. Initially, preliminary searches were carried out in the databases to test various search terms and combinations. The final search strategy, using relevant keywords and index terms, has been developed in collaboration with an experienced research librarian. No date restrictions will be applied to the searches, however only articles published within the last 20 years (1998 – October 2018) will be eligible for inclusion. Search results will be downloaded into the bibliographic software Endnote, where duplicates will be removed in preparation of the screening process. The search results will be screened by the first author for selection and data extraction, with screening checks completed by the other authors.

The selection of studies for inclusion will occur over two stages. Firstly, the titles and abstracts of all returned studies from the database searches will be reviewed to determine whether or not they meet the inclusion criteria. Secondly, the full-text versions of articles deemed to meet the criteria will be reviewed to make a final decision about inclusion or exclusion. At both stages, the other authors will review a random sample (10%) of the selected articles, to determine the level of agreement between the reviewers.

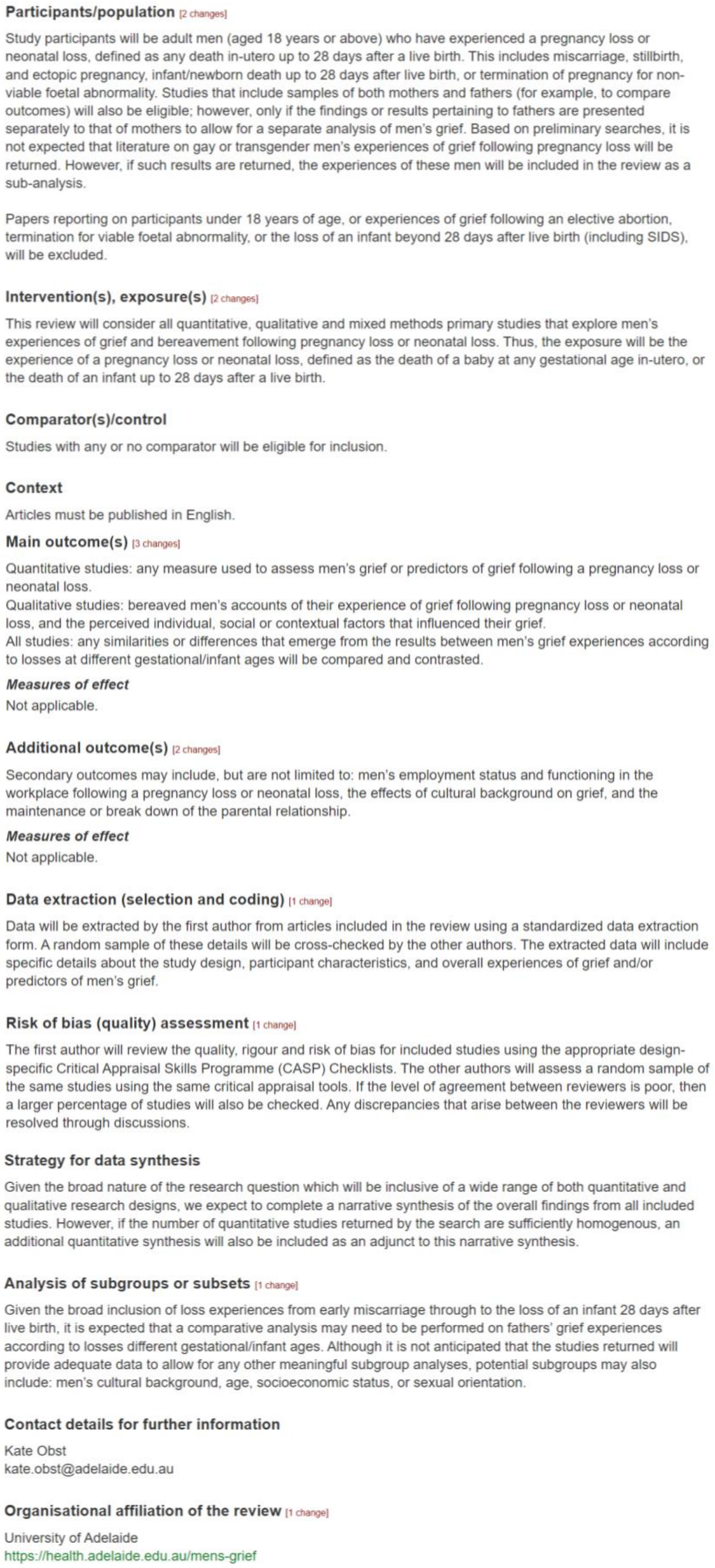
The references lists of all studies meeting the inclusion criteria will also be hand searched to identify any additional relevant articles for inclusion. Although discussion and review articles will not be included in the synthesis, the reference lists of any reviews returned by the search will also be checked for additional studies eligible for inclusion. A Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram will be created to demonstrate the number of studies remaining at each stage of the review process, and to document the reasons for study exclusion.

Types of study to be included [2 changes]

We will include all published and unpublished quantitative, qualitative and mixed methods primary data research articles that aim to explore men's experiences of grief, or the factors contributing to men's grief, following pregnancy loss or neonatal loss. Quantitative studies will report on predictors of, or factors contributing to, men's grief, using either standardised or non-standardised measures of grief. Qualitative studies can include, but are not limited to, phenomenology, narrative analysis, grounded theory, and thematic or content analysis, which focus on exploring, or generating meaning behind, men's experiences of grief following pregnancy loss or neonatal loss. Grey literature reporting on primary data, including unpublished case reports, case series, case studies, theses and dissertations, will also be eligible for inclusion. However, abstracts, letters, editorials, opinion pieces and personal accounts will be excluded, along with discussion and review papers.

Condition or domain being studied [2 changes]

This review will explore men's grief following the experience of pregnancy loss or neonatal loss. This includes any definition of a loss in-utero (i.e., miscarriage, termination for non-viable foetal abnormality, stillbirth or ectopic pregnancy), or the death of an infant up to 28 days following a live birth. Men's experiences of grief following elective abortion, termination of pregnancy for viable foetal abnormality, or the loss of an infant after 28 days (including Sudden Infant Death Syndrome [SIDS]) will not be included, as there is literature to suggest that these types of loss involve qualitatively different psychological outcomes (e.g., guilt and shame).



Participants/population [2 changes]

Study participants will be adult men (aged 18 years or above) who have experienced a pregnancy loss or neonatal loss, defined as any death in-utero up to 28 days after a live birth. This includes miscarriage, stillbirth, and ectopic pregnancy, infant/newborn death up to 28 days after live birth, or termination of pregnancy for non-viable foetal abnormality. Studies that include samples of both mothers and fathers (for example, to compare outcomes) will also be eligible; however, only if the findings or results pertaining to fathers are presented separately to that of mothers to allow for a separate analysis of men's grief. Based on preliminary searches, it is not expected that literature on gay or transgender men's experiences of grief following pregnancy loss will be returned. However, if such results are returned, the experiences of these men will be included in the review as a sub-analysis.

Papers reporting on participants under 18 years of age, or experiences of grief following an elective abortion, termination for viable foetal abnormality, or the loss of an infant beyond 28 days after live birth (including SIDS), will be excluded.

Intervention(s), exposure(s) [2 changes]

This review will consider all quantitative, qualitative and mixed methods primary studies that explore men's experiences of grief and bereavement following pregnancy loss or neonatal loss. Thus, the exposure will be the experience of a pregnancy loss or neonatal loss, defined as the death of a baby at any gestational age in-utero, or the death of an infant up to 28 days after a live birth.

Comparator(s)/control

Studies with any or no comparator will be eligible for inclusion.

Context

Articles must be published in English.

Main outcome(s) [3 changes]

Quantitative studies: any measure used to assess men's grief or predictors of grief following a pregnancy loss or neonatal loss.
Qualitative studies: bereaved men's accounts of their experience of grief following pregnancy loss or neonatal loss, and the perceived individual, social or contextual factors that influenced their grief.
All studies: any similarities or differences that emerge from the results between men's grief experiences according to losses at different gestational/infant ages will be compared and contrasted.

Measures of effect

Not applicable.

Additional outcome(s) [2 changes]

Secondary outcomes may include, but are not limited to: men's employment status and functioning in the workplace following a pregnancy loss or neonatal loss, the effects of cultural background on grief, and the maintenance or break down of the parental relationship.

Measures of effect

Not applicable.

Data extraction (selection and coding) [1 change]

Data will be extracted by the first author from articles included in the review using a standardized data extraction form. A random sample of these details will be cross-checked by the other authors. The extracted data will include specific details about the study design, participant characteristics, and overall experiences of grief and/or predictors of men's grief.

Risk of bias (quality) assessment [1 change]

The first author will review the quality, rigour and risk of bias for included studies using the appropriate design-specific Critical Appraisal Skills Programme (CASP) Checklists. The other authors will assess a random sample of the same studies using the same critical appraisal tools. If the level of agreement between reviewers is poor, then a larger percentage of studies will also be checked. Any discrepancies that arise between the reviewers will be resolved through discussions.

Strategy for data synthesis

Given the broad nature of the research question which will be inclusive of a wide range of both quantitative and qualitative research designs, we expect to complete a narrative synthesis of the overall findings from all included studies. However, if the number of quantitative studies returned by the search are sufficiently homogenous, an additional quantitative synthesis will also be included as an adjunct to this narrative synthesis.

Analysis of subgroups or subsets [1 change]

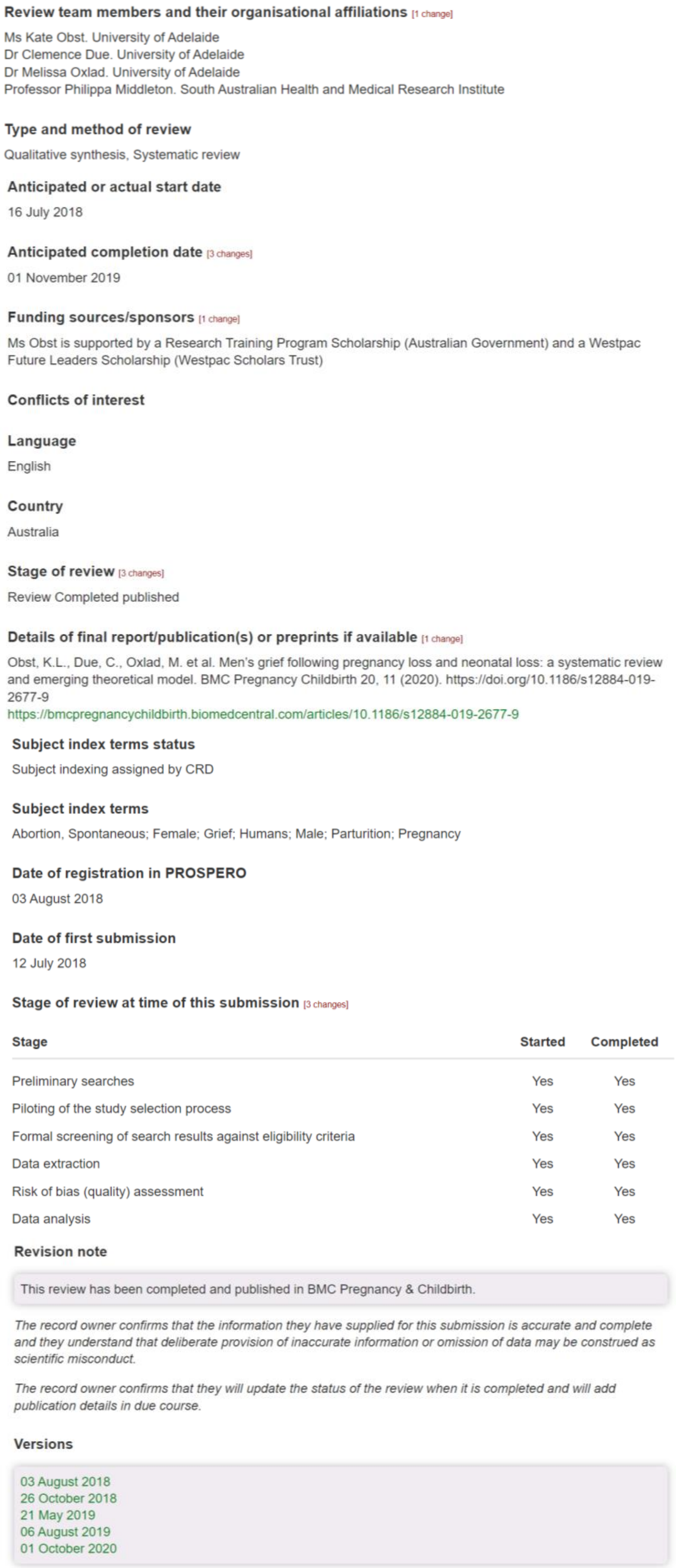
Given the broad inclusion of loss experiences from early miscarriage through to the loss of an infant 28 days after live birth, it is expected that a comparative analysis may need to be performed on fathers' grief experiences according to losses different gestational/infant ages. Although it is not anticipated that the studies returned will provide adequate data to allow for any other meaningful subgroup analyses, potential subgroups may also include: men's cultural background, age, socioeconomic status, or sexual orientation.

Contact details for further information

Kate Obst
kate.obst@adelaide.edu.au

Organisational affiliation of the review [1 change]

University of Adelaide
https://health.adelaide.edu.au/mens-grief



Review team members and their organisational affiliations [1 change]

Ms Kate Obst. University of Adelaide
Dr Clemence Due. University of Adelaide
Dr Melissa Oxlad. University of Adelaide
Professor Philippa Middleton. South Australian Health and Medical Research Institute

Type and method of review

Qualitative synthesis, Systematic review

Anticipated or actual start date

16 July 2018

Anticipated completion date [3 changes]

01 November 2019

Funding sources/sponsors [1 change]

Ms Obst is supported by a Research Training Program Scholarship (Australian Government) and a Westpac Future Leaders Scholarship (Westpac Scholars Trust)

Conflicts of interest

Language

English

Country

Australia

Stage of review [3 changes]

Review Completed published

Details of final report/publication(s) or preprints if available [1 change]

Obst, K.L., Due, C., Oxlad, M. et al. Men's grief following pregnancy loss and neonatal loss: a systematic review and emerging theoretical model. BMC Pregnancy Childbirth 20, 11 (2020). https://doi.org/10.1186/s12884-019-2677-9
https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-019-2677-9

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Abortion, Spontaneous; Female; Grief; Humans; Male; Parturition; Pregnancy

Date of registration in PROSPERO

03 August 2018

Date of first submission

12 July 2018

Stage of review at time of this submission [3 changes]

Stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	Yes
Data extraction	Yes	Yes
Risk of bias (quality) assessment	Yes	Yes
Data analysis	Yes	Yes

Revision note

This review has been completed and published in BMC Pregnancy & Childbirth.

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.

The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Versions

03 August 2018
26 October 2018
21 May 2019
06 August 2019
01 October 2020

APPENDIX 6. Qualitative Interview Protocol for Study 4

- **Can you tell me about your pregnancy history**?
  - How many pregnancies have you had?
  - Did you experience any difficulties with the pregnancy/ies?
  - Did you use IVF or assisted reproductive technologies for the pregnancy/ies?

- **Can you tell me about your relationship with your baby during pregnancy?**
  - Did you name your baby?
  - Did you interact with your baby often? If yes, how?
  - Did you view ultrasound images of your baby?
  - Did you attend obstetric appointments with your partner?
  - If yes, can you tell me what it was like attending these appointments (e.g., did you enjoy/look forward to them?)

- **Could you please share a little bit about your experiences of the pregnancy loss**?
  Example prompts to confirm details gathered from the survey:
  - How long ago was your loss?
  - Have you experienced more than one loss? If yes, how many, can what types of loss/es?
  - What was the length of gestation at the time of your loss/es?

- **Can you tell me about your reactions to the loss**?
  - Immediately, and then in the days/weeks that followed?
  - Were you outwardly emotional, or did you try to hide your emotions?
  - What were some of the thoughts that ran through your mind?
  - Did you experience any physical responses to the loss? (e.g., headaches, body aches, fatigue)

- **Has your grief experience changed over time?**
  - If yes, can you describe how?
  - Was there anything you felt made your grief experience more difficult? Or easier?

- **Did you share your grief with anyone?**
- **Did you feel as though your grief was recognised and understood by people around you?**
  - E.g., with your spouse/partner, family members, friends, or healthcare professionals?
  - If yes, what type of recognition did you receive?
  - Who was the best support to you? How?

- **Were people supportive of the termination situation** (friends, family, etc.?)
  - If yes, how?

- If no, what did they do/say that didn't feel supportive?

- **How did the loss impact the relationship with your partner/wife?**

- **Healthcare/support services**
  - What was your experience with the healthcare system/hospital?
  - How were you informed of your baby's medical difficulties (e.g., sonographer?)
  - Did healthcare staff provide adequate explanations and explain your options?
  - Was the pregnancy induced? What ward did your partner birth in (e.g., labour or general)?
  - What staff were involved?
  - What were your interactions with the staff like?
  - Did you feel included in the hospital? If yes, how? If no, why?
  - Were you offered information on men's grief/support services? If yes, what kind?
  - Has there been any follow-up from the hospital (e.g., phone calls, etc.)
  - Did you spend time with your baby in hospital? If yes, did this help you to grieve?
  - Did the termination experiences differ from [other losses]? If yes, how?
  - Did you access any support services (e.g., counselling, support groups)? If yes, what were your experiences with these?

- **Did you seek any support from others in the days, weeks or months following your loss?**
  - Who was available to you during this time?
  - Was is easy for you to reach out to others?
  - What types of supports were available to you?
  - What did [others] do to support you?
  - What supports were (or would have been) most helpful to you?
  - Did you have any particularly positive or negative experiences of support?

- **What was it like returning to work?** *(if applicable)*
  - Where/what were you employed as at the time of loss?
  - Did you inform your workplace of your loss?
  - Did you feel as though your workplace was supportive of you?
  - Were you offered/did you take leave from work?
  - Anything else your workplace could have done to support you?
  - How did you find the return to work? (E.g., was it difficult, easy, helpful, unhelpful to grief, did you struggle, etc.)

- **Generally, how do you approach stressful events that arise?**
  - What helps you get through tough times?
  - Was coping with your pregnancy loss different to how you cope in other difficult situations?

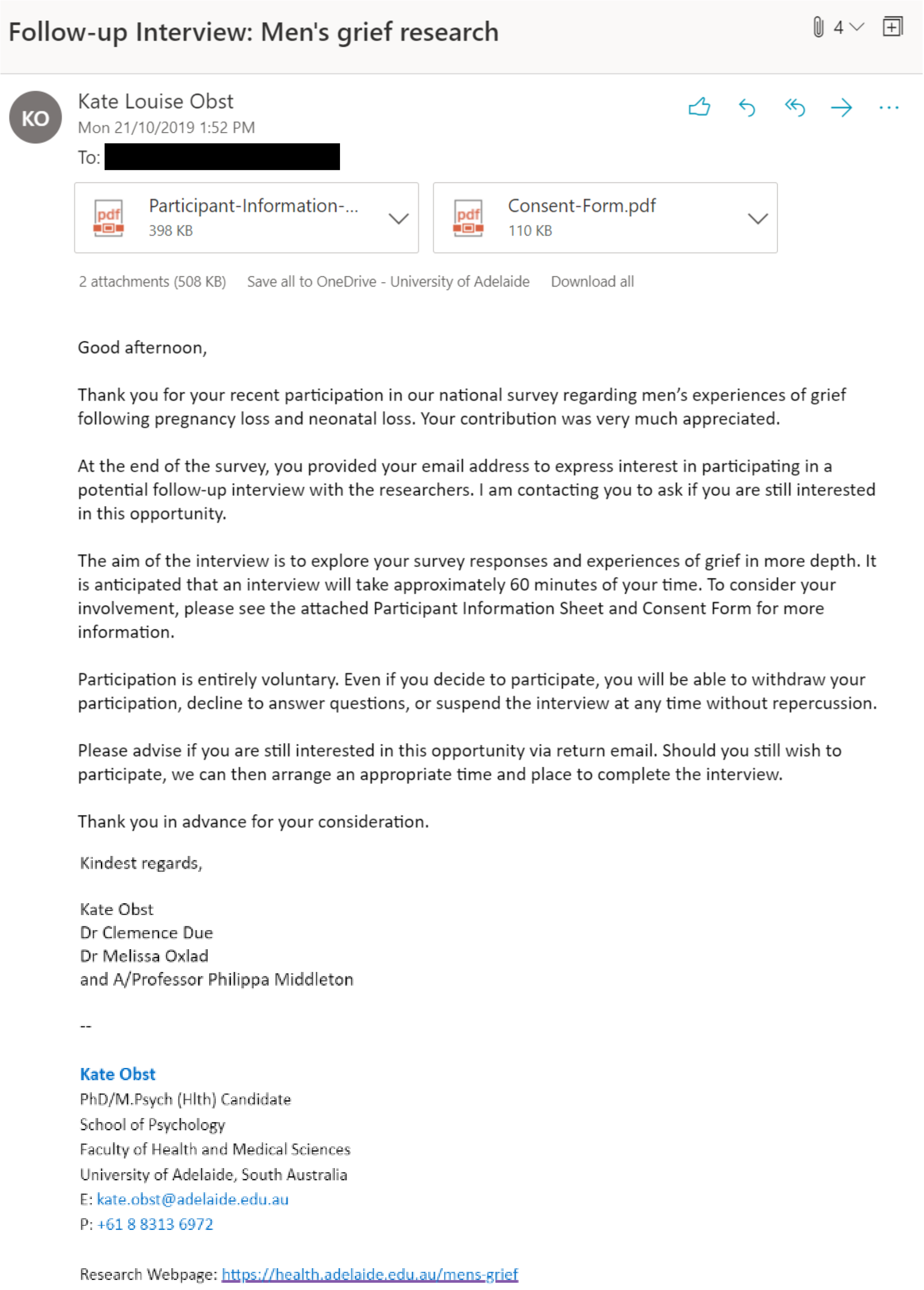
- **Subsequent pregnancies** *(if applicable)*
  - Did your grief continue into subsequent pregnancies? What was your experience like?
  - How has the process been different this time around (e.g., heightened anxiety, etc.)
  - Was the healthcare experience any different?

- **Relationship with other children** *(if applicable)*
  - How did you manage parenting your other children through your loss?
  - Did your other children make a difference to your grief?
  - How did your other children cope with the loss?

- **Wrap-up**
  - Did you feel as though the questions asked in the online survey were inclusive of all aspects of your grief?
  - Is there anything else you would like to tell us that you considered important to your experience?
  - Is there anything we haven’t covered that you think would be useful to include in future bereavement care guidelines or support services for men?

  - Confirm demographic info from participant’s survey responses
  - Would you like a copy of the interview transcript to check/provide feedback?
  - Would you like a copy of emerging results?

APPENDIX 7. Follow-Up Email to Survey Participants for Study 4 Participation



Follow-up Interview: Men's grief research

KO

Kate Louise Obst
Mon 21/10/2019 1:52 PM
To: [redacted]

Participant-Information-...
398 KB

Consent-Form.pdf
110 KB

2 attachments (508 KB) Save all to OneDrive - University of Adelaide Download all

Good afternoon,

Thank you for your recent participation in our national survey regarding men's experiences of grief following pregnancy loss and neonatal loss. Your contribution was very much appreciated.

At the end of the survey, you provided your email address to express interest in participating in a potential follow-up interview with the researchers. I am contacting you to ask if you are still interested in this opportunity.

The aim of the interview is to explore your survey responses and experiences of grief in more depth. It is anticipated that an interview will take approximately 60 minutes of your time. To consider your involvement, please see the attached Participant Information Sheet and Consent Form for more information.

Participation is entirely voluntary. Even if you decide to participate, you will be able to withdraw your participation, decline to answer questions, or suspend the interview at any time without repercussion.

Please advise if you are still interested in this opportunity via return email. Should you still wish to participate, we can then arrange an appropriate time and place to complete the interview.

Thank you in advance for your consideration.

Kindest regards,

Kate Obst
Dr Clemence Due
Dr Melissa Oxlad
and A/Professor Philippa Middleton

--

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Research Webpage: https://health.adelaide.edu.au/mens-grief

APPENDIX 8. Consent Form for Study 4

Human Research Ethics Committee (HREC)

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 9. COREQ Checklist for Paper 4

Topic	Item No.	Description	Reported on Page No.
Domain 1: Research team and reflexivity			**Note these pages are valid as per the published version of the paper, not this thesis*
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interviews?	Page 6
Credentials	2	What were the researcher’s credentials? E.G., PhD, MD	Page 6 (provided on participant info sheet)
Occupation	3	What was their occupation at the time of study?	Page 6 (provided on participant info sheet)
Gender	4	What was the researcher’s gender?	Page 7
Experience and training	5	What experience or training did the researcher have?	Page 7
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	Page 6
Participant knowledge of the interviewer	7	What did the participants know about the researcher?	Page 6
Interviewer characteristics	8	What characteristics were reported about the interviewer?	Page 7
Domain 2: Study design			
Theoretical framework			
Methodological orientation and theory	9	What methodological orientation was stated to underpin the study?	Page 5
Participant selection			
Sampling	10	How were participants selected?	Page 6
Method of approach	11	How were participants approached?	Page 6
Sample size	12	How many participants were in the study?	Page 8
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
Setting			
Setting of data collection	14	Where was the data collected?	Page 7
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	Page 7
Description of sample	16	What are the important characteristics of the sample?	Page 8 and Table 1
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors?	Page 5
Repeat interviews	18	Were repeat interviews carried out?	N/A
Audio/visual recording	19	Did the researcher use audio or visual recording to collect data?	Page 6

Field notes	20	Were field notes made during or after interviews?	Page 6 (audit trail)
Duration	21	What was the duration of interviews?	Page 6
Data saturation	22	Was data saturation discussed?	Page 7
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	Page 6
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	Page 8
Description of the coding tree	25	Did the authors provide a description of the coding tree?	Page 9 and Figure 1 (Thematic map)
Derivation of themes	26	Were themes identified in advanced or derived from the data?	Pages 7 and 8 (deductive and inductive approaches)
Software	27	What software, if applicable, was used to manage the data?	N/A
Participant checking	28	Did participants provide feedback on the findings?	Page 8
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? E.g., participant number/pseudonym	Pages 9-22
Data and findings consistent	30	Was there consistency between the data presented and findings?	Pages 9-22
Clarity of major themes	31	Were major themes clearly presented in the findings?	Page 9, 12 and 17
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Pages 9-22

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 35.

APPENDIX 10. Systematic Review Search Strategies by Database

PubMed

Men	Grief	Pregnancy/child loss
“men”[mh]	“bereavement”[mh]	“abortion, spontaneous”[mh]
men[tiab]	bereave*[tiab]	spontaneous abortion*[tiab]
“male”[mh]	grief*[tiab]	“stillbirth”[mh]
male[tiab]	griev*[tiab]	stillbirth*[tiab]
males[tiab]	mourn*[tiab]	still birth*[tiab]
“fathers”[mh]	“attitude to death”[mh]	stillborn*[tiab]
father*[tiab]		“still born*”[tiab]
“spouses”[mh]		“pregnancy, ectopic”[mh]
spouse*[tiab]		ectopic pregnanc*[tiab]
partner*[tiab]		“fetal death”[mh]
husband*[tiab]		fetal death*[tiab]
paternal*[tiab]		foetal death*[tiab]
paternity[tiab]		fetus death*[tiab]
masculinity[mh]		foetus death*[tiab]
masculin*[tiab]		pregnancy loss*[tiab]
		miscarriage*[tiab]
		“perinatal death”[mh]
		perinatal death*[tiab]
		“perinatal mortality”[mh]
		perinatal mortalit*[tiab]
		“infant mortality”[mh]
		infant mortalit*[tiab]
		“infant death”[mh]
		infant death*[tiab]
		infant loss*[tiab]
		neonatal mortal*[tiab]
		neonatal death*[tiab]
		neonatal loss*[tiab]
		baby's death*[tiab]
		baby death*[tiab]

PsycINFO

Men	Grief	Pregnancy/child loss
human males.sh	bereavement.sh	spontaneous abortion.sh
men.ti,ab	bereave$.ti,ab	spontaneous abortion$.ti,ab
male.ti,ab	grief.sh	stillbirth$.ti,ab
males.ti,ab	grief$.ti,ab	still birth$.ti,ab
fathers.sh	griev$.ti,ab	stillborn$.ti,ab
father$.ti,ab	mourn$.ti,ab	still born$.ti,ab
spouses.sh		ectopic pregnanc$.ti,ab
spouse$.ti,ab		fetal death$.ti,ab
partner$.ti,ab		foetal death$.ti,ab
husband$.ti,ab		(fetus adj4 death$).ti,ab
paternal$.ti,ab		(foetus adj4 death$).ti,ab

paternity.ti,ab		pregnancy loss$.ti,ab
masculinity.sh		miscarriage$.ti,ab
masculin$.ti,ab		perinatal death$.ti,ab
		perinatal mortalit$.ti,ab
		infant mortalit$.ti,ab
		infant death$.ti,ab
		infant loss$.ti,ab
		neonatal mortal$.ti,ab
		neonatal death$.ti,ab
		neonatal loss$.ti,ab
		baby$ death$.ti,ab

Embase

Men	**Grief**	**Pregnancy/child loss**
‘male’/de	bereavement/de	‘spontaneous abortion’/de
male:ti,ab	bereave*:ti,ab	‘spontaneous abortion*’:ti,ab
males:ti,ab	grief/exp	miscarriage*:ti,ab
men:ti,ab	grief*:ti,ab	‘ectopic pregnancy’/de
father/de	griev*:ti,ab	‘ectopic pregnanc*’:ti,ab
father*:ti,ab	mourn*:ti,ab	‘fetus death’/de
spouse/exp	‘attitude to death’/de	‘fetal death*’:ti,ab
spouse*:ti,ab		‘foetal death*’:ti,ab
partner*:ti,ab		(fetus NEXT/4 death*):ti,ab
husband*:ti,ab		(foetus NEXT/4 death*):ti,ab
‘paternal behavior’/de		stillbirth/de
paternal*:ti,ab		stillbirth*:ti,ab
paternity:ti,ab		‘still birth*’:ti,ab
‘masculinity’/de		stillborn*:ti,ab
masculin*:ti,ab		‘still born*’:ti,ab
		‘pregnancy loss*’:ti,ab
		‘perinatal death’/de
		‘perinatal death*’:ti,ab
		‘perinatal mortality’/exp
		‘perinatal mortalit*’:ti,ab
		‘infant mortalit*’:ti,ab
		‘infant death*’:ti,ab
		‘infant loss*’:ti,ab
		‘newborn mortality’/de
		‘newborn mortalit*’:ti,ab
		‘neonatal mortal*’:ti,ab
		‘neonatal death*’:ti,ab
		‘neonatal loss*’:ti,ab
		‘baby* death*’:ti,ab
		‘death of a baby’:ti,ab

CINAHL

Men	Grief	Pregnancy/child loss
MH men	MH bereavement+	MH abortion, spontaneous
TI men	TI bereave*	TI “spontaneous abortion*”
AB men	AB bereave*	AB “spontaneous abortion*”
MH male	TI grief*	TI miscarriage*
TI male*	TI griev*	AB miscarriage*
AB male*	AB grief*	MH pregnancy, ectopic
MH men’s health	AB grief*	TI “ectopic pregnanc*”
TI “men’s health”	TI mourn*	AB “ectopic pregnanc*”
AB “men’s health”	AB mourn*	MH perinatal death
MH fathers	MH attitude to death	TI “perinatal death*”
TI father*		AB “perinatal death*”
AB father*		TI stillbirth*
MH expectant fathers		AB stillbirth*
MH spouses		TI “still birth*”
TI spouse*		AB “still birth*”
AB spouse*		TI stillborn*
TI husband*		AB stillborn*
AB husband*		TI “still born*”
MH paternal behavior		AB “still born*”
TI paternal*		TI “pregnancy loss*”
AB paternal*		AB “pregnancy loss*”
TI paternity		TI “fetal death*”
AB paternity		AB “fetal death*”
MH masculinity		TI “foetal death*”
TI masculin*		AB “foetal death*”
AB masculin*		TI (fetus n4 death*)
		AB (fetus n4 death*)
		TI (foetus n4 death*)
		AB (foetus n4 death*)
		MH infant mortality
		TI “infant mortalit*”
		AB “infant mortalit*”
		TI “infant loss*”
		AB “infant loss*”
		TI “perinatal mortalit*”
		AB “perinatal mortalit*”
		TI “neonatal mortalit*”
		AB “neonatal mortalit*”
		TI “neonatal death*”
		AB “neonatal death*”
		TI “neonatal loss*”
		AB “neonatal loss*”
		TI “baby death*”
		AB “baby death*”
		TI “baby’s death*”
		AB “baby’s death*”

APPENDIX 12. Systematic Review Overview of Studies

Qualitative Studies

Author (Year)	**Study Aims** **(objectives; focus)**	**Participants/Setting** **(*N*; loss type; country; time since loss)**	**Method/Design** **(recruitment; data collection; type of analysis)**	**Grief Experience** **(key themes relating to the grief experience)**	**Key Predictors of Grief** **(factors impacting the grief experience)**
Abboud & Liamputtong (2005)	To investigate coping strategies, social support and satisfaction with health care among ethnic women and their partners following miscarriage	Six women and their male partners from Melbourne, Australia with miscarriage experience; ethnic backgrounds (Middle East); all Christian; four couples with living children	Recruited via snowball sampling; one couple through GP referral; data collected using in-depth interviews with women and men separately; used thematic analysis	Men hid their feelings to stay strong for their partners: "I kept myself strong but was hurting inside". Men tried not to make the miscarriage a big issue in their lives, instead coping by trying to return to 'normal'.	Men felt that their role during miscarriage was one of support and encouragement. Men felt that support from family and friends was helpful for female partners but not themselves. Many would have liked information from the hospital about what to expect and how to care for their partner.
Abboud & Liamputtong (2003)	To examine the experience of miscarriage for women and their partners, providing an account of what happened before, after, and during the time of their miscarriage.	Six women and their male partners from Melbourne, Australia with miscarriage experience; ethnic backgrounds (Middle East); all Christian; four couples with living children	Recruited via snowball sampling; one couple through GP referral; data collected using in-depth interviews with women and men separately; data analysed using thematic analysis	Men had to consider their partner first and hold back their emotions in order to be in control of the situation. Most men reported feeling happy now and thought little about the miscarriage.	Men's role during the time of miscarriage was to support their partner. Some did not have much discussion about the miscarriage with their partner. Subsequent children made the miscarriage easier to come to terms with.
Armstrong (2001)	To explore fathers' experiences of pregnancy after a prior perinatal loss.	Four U.S. couples experiencing pregnancy after prior perinatal loss; prior losses had occurred between 12 and 20 weeks gestation; three men were Caucasian and one was of Jamaican descent	Recruited through treating healthcare providers at clinics and medical practices; data collection using two unstructured interviews – the follow-up interview was 3-4 weeks after the first to validate and further examine emerging concepts	Men reported that the intensity of the loss was greater than anticipated. Those who were more invested in the pregnancy experienced greater grief; those who were less attached were more prepared to "move on, forget about it". Despite differing responses at the time of loss, all described similar emotions during the current pregnancy, which were attributed to the previous loss.	Death rituals (holding baby, memorial service) bought closure to fathers. Activities and "keeping busy" assisted with managing grief. All men described a need to protect their partner, however none expressed displeasure with the supporter role, as it was helpful to have a caring responsibility. All described positive experiences with support from HCPs and family/friends. Three felt belief in God was a comfort during grief.
Bonnette & Broom (2012)	To explore men's experiences of stillbirth and how they experienced fathering and grief.	12 men bereaved to stillbirth from NSW, Australia. Men were aged between 28 and 54; for two the stillbirth was their first child; one was a twin birth	A combination of purposive and snowball sampling. Data were collected using in-depth interviews (45 mins-2.5 hours); data analysed using interpretive phenomenological analysis	Masculine cultural scripts regarding emotional expression were evident; tension emerged between 'manly' considerations and men's realities of negotiating and expressing grief. There was a cultural expectation that they remain strong and stoical. Men experienced an initial inexpressiveness of emotion to 'protect' their female partners.	Each man connected or bonded with their unborn baby (especially through ultrasound attendance/viewing). Time with the baby post-birth allowed men to reconcile the stillbirth experience with their fathering identity. Tension arose between wanting recognition as a male and recognition as a grieving father. Overall, being recognized and validated as a grieving father, not merely as a supportive partner, was important.
Brierly (2018)	To explore couples' experiences grieving	Nine couples bereaved by stillbirth (26-41 weeks	Recruited via purposive sampling through online	Grief responses varied: some men were openly emotional, whereas others spoke to their role	The hospital experience played an important role in the bereavement process. Although

	late-term pregnancy loss on Facebook.	gestation) in the U.S.; all couples were Caucasian and in married heterosexual relationships; time since loss ranged from 3-12 months	pregnancy loss organisations/groups and local women's health centres; data were collected using semi-structured interviews and analysed using interpretive phenomenological analysis	as the husband/man, who needed to "be the strong one" to protect and comfort his wife. Many felt their grief navigation was more internal than their wives': they were more information-seeking and task-oriented. Many discussed their desire to grieve privately, or with one close friend or family member. Several expressed guilt or failure that they were unable to protect their wife and unborn child from harm. A few associated emotions with weakness, however more encouraged other males experiencing stillbirth to express themselves.	women were more likely than men to use Facebook for grieving, all participants talked about using Facebook to navigate grief. The "memories" function and targeted advertising were particularly harmful to the grief process, as these served as a constant reminder that they no longer needed baby supplies or parenting resources.
Cacciatore (2013)	To evaluate fathers' experiences of stillbirth and psychosocial care.	131 fathers who had experienced a stillbirth (> 22 weeks gestation) between 2000 and April 2010 in Sweden. Majority of losses occurred two years prior to assessment; 95% of fathers were present at the birth.	Recruited via purposive sampling through the Swedish National Infant Foundation website. Data collected using an online questionnaire (82 items covering demographic info and stillbirth topics); analysed qualitatively using inductive manifest content analysis.	16% of fathers felt sadness, anger or being hurt: dominantly this related to their fatherhood being unrecognised or invalidated.	86% of fathers expressed gratitude for compassionate and professional provider care. Men were thankful when HCPs legitimised their fatherhood by treating the baby as if s/he was born alive. Insensitive treatment was the primary reason fathers perceived transgressions and subsequent psychological distress/grief.
Campbell-Jackson et al. (2014)	To explore mothers' and fathers' experiences of becoming a parent to a child born after a recent stillbirth, covering the period of the second pregnancy and up to two years after the birth of the next baby.	Seven couples with British and Polish backgrounds who had experienced stillbirth (>24 weeks gestation). Subsequent children were an average of 16.6 months old (SD = 7.4 months).	Mothers who had taken part in a previous study on stillbirth were approached, along with their partners, via an invitation letter. Data were collected using semi-structured individual interviews with women and men separately, and analysed using interpretive phenomenological analysis.	Although all fathers described worry and fear throughout subsequent pregnancy, some thought that their experience was less intense than their wives'. Fathers described managing their own anxieties whilst focussing on practical tasks to provide support for their spouse.	Some fathers found it difficult to find space to grieve as they felt they needed to stay strong in order to support their spouse. Being at a different stage of grief from their spouse was also highlighted as a challenge. For fathers, work was the most reported source of distraction.
Cholette (2012)	To enhance understanding of the paternal experience of perinatal loss, to help inform future care and support to bereaved families.	Seven fathers who had experienced perinatal loss (death of a fetus in-utero or neonatal death up to the first 28 days of life) in the U.S. or Canada. Ages ranged from 34-61 years; all men were married and Christian. Time since loss ranged from 3 months to 28 years.	Purposive sampling through obstetrical health care providers. Data were collected using individual interviews, and analysed using Hermeneutic interpretive phenomenology	Regardless of the type, all reported a deep sense of lasting loss which changed their lives. Some fathers began to work diligently on home or work projects as a form of time out. All of the men expressed concern for their spouse, and this took precedence over their own grief and wellbeing. Although healing transpired with time, the loss was never forgotten.	Fathers expressed a need to be a protective father/husband/man by demonstrating strength and stoicism. As a result, the paternal grief was commonly left unacknowledged not only by society but by themselves. Communication and support from family and friends were crucial to men's ability to cope.
Colon (2009)	To explore paternal grief experiences following pregnancy loss, to gain knowledge of the grief	Nine fathers who had experienced perinatal loss (from conception until 28 days after birth) in the U.S.	Purposive sampling through medical centres, medical staff, and Church pastors. Data were collected using unstructured	All men experienced the loss as deeply significant and devastating. Men reported overwhelming emotions including sadness, crying, frustration, devastation,	Fathers used a variety of strategies to manage their emotions, including sport, returning to work, and creativity to express their grief. Validating the loss of the child and men's

	process and perceptions of fathers.	Men were aged between 41 and 78 years, time since loss ranged from 7 to 54 years. All had currently living children, and identified as Christian (5) or Protestant (4).	individual interviews, and analysed using a phenomenological approach with assistance of the NVIvo software package.	disappointment, and arguing with God. Many felt angry and helpless that their wives had to ensure pain and suffering. Many compartmentalised their feelings to take control of practical responsibilities and support their spouse.	sense of fatherhood was important. For many, their faith provided them with the strength to meet the difficulty of their loss. Sensitivity to the needs for privacy, being there, and meeting material needs was helpful and encouraging.
Ekelin et al. (2008)	To conceptualize women's and their partners' experiences and ways of handling the situation before, during, and after second trimester ultrasound examination with the diagnosis of a nonviable fetus.	Nine Swedish women and six male partners were interviewed within a year of receiving the nonviable diagnosis. For four couples, this was their first baby; one had experienced a miscarriage previously.	Participants were recruited through the ultrasound department at a Swedish regional hospital. Data were collected using in-depth interviews with the couples together; grounded theory was used to analyse the results.	The men felt their roles should be supportive, even though they felt as sad and out of control as the women. Men do not necessarily "move on" more quickly – reactions are individual, and men's grief may be delayed due to the initial supporter role.	No data pertained to predictors of men's grief specifically. However, for parents generally, they were affected positively when they were taken care of with empathy. Some discussed concentrating on the children they already had; additional grief was related to work, time of year, and other life circumstances.
Fisher (2002)	To describe and explore the lived experience and meaning of miscarriage to the father.	Nine fathers who had experienced miscarriage prior to 20 weeks gestation from the U.S. All were married and Caucasian, and aged between 32 and 49 years. Time since the loss ranged from one week to 10 years. Eight had living children, for one the miscarriage was his first baby.	Convenience sampling occurred through grief support groups, newspaper advertisements and religious newsletters. Each father participated in two semi-structured interviews, data was analysed using phenomenology.	Eight of nine fathers experienced a bereavement response. Miscarriage affected each father, although each had a unique perception: some were devastated, others less affected. The fathers' need to "do something" was often at the cost of their own feelings. Denial was a coping mechanism for three fathers. Many tried to frame the miscarriage positively to come to terms with it. Anxieties continued into subsequent pregnancies.	The need to offer comfort and support to the mother was expressed by five fathers. A reason for the loss reduced blame and helped fathers to cope. Having people available to talk to about the miscarriage helped fathers to mourn their loss. Al fathers described their relationships with their spouses as loving and supportive, which may have lessened their grief responses. Two fathers saw their baby's remains (20 weeks gestation), and felt this greatly influenced their grief response.
Hamama-Raz et al. (2010)	To examine and understand the meaning ascribed by religious couples, both together and separately, to spontaneous abortion and how this meaning was manifested in their couple relationship.	Five couples from Israel, who had experienced spontaneous abortion (miscarriage) up to the 20th week of pregnancy. Three couples identified as Haredi, and two as Dati-Leumi. All were aged between 26 and 35 years; time since loss ranged between two months and two years.	Recruitment occurred through snowballing within the Israeli religious sector. Data were collected using in-depth interviews with men and women separately, and were analysed using content analysis.	Men reported repressing their painful emotions and resorting to rationalization to create a coping partnership. The initial reaction for men was one of helplessness, however they actively worked to overcome their own sense of shock to support their wives.	The husbands did not express any relationship with the fetus. They preferred to view the fetus as tissue and therefore felt no pain or meaningful loss. Men coped with the loss through logical explanation and rationalization (i.e., "it must mean something was wrong with the fetus"). Religion helped the couple to cope. Men reported a consistent role as comforter throughout the entire process, focussing on strengthening the couple relationship and sense of togetherness.
Jones-Peeples (2014)	To understand male partners' perceptions regarding their experience of perinatal loss as well as the range of psychological and emotional consequences of perinatal loss on men.	Five committed, heterosexual couples from the U.S. participated. All were married and identified as Christian. Males ranged in age from 31 to 41 years, all identified as Caucasian. Couples has experienced	Recruitment occurred through internet and social media advertisements, and snowball sampling. Data were collected using in-depth semi-structured interviews with the male partner. The type of analysis used was grounded theory	Regardless of the length of pregnancy, all men experienced the loss as a significant life event. Initial reactions to the loss included intense shock, disbelief, overwhelming emotions and reactions including crying, confusion and disappointment. All expressed feelings of fear, anxiety, helplessness and anger that their wives had to ensure great amounts of physical	All of the men described supporting their wives throughout the process, and many expressed feeling like they "needed to be strong" and even suppress their own feelings to support their wives. While men described reviewing less support from medical personnel, family and friends, many wanted their wives to be more supported due to their

		two miscarriages (nine and 11 weeks gestation), and four stillbirths (one loss of twins; 20 through to 27 weeks gestation).	(assisted with the use of NVivo).	pain. The men noticed changes in their behaviours, including increased sadness and crying, decrease in social and physical activities, difficulty sleeping and physical exhaustion.	physical and emotional trauma. Men used a variety of strategies to manage their own grief, including work, exercise, and staying busy, and their faith/church. Finding ways to remember and validate the life of their child helped men to grieve and move forward.
Kavanaugh & Hershberger (2005)	To examine the experience of low-income, African American parents surrounding perinatal loss and to describe how other life stressors influenced the parents' responses and caring needs.	17 mothers and six of their male partners who had experienced perinatal loss participated. 11 couples had experienced stillbirth between 17 and 37 weeks gestation, and six had experienced neonatal death between one and 28 days after birth. Six couples had experienced prior perinatal loss. Fathers ranged in age from 20-34 years.	Participants were recruited through a newspaper advertisement, along with referrals from hospital staff. Data were collected using two individual interviews with each parent; follow-ups occurred between two and five weeks following the first. Data were analysed using a descriptive phenomenological approach.	Parents experienced intense feelings; fathers emphasised that they also hurt and experienced a loss of control. Men reported keeping their emotions under control for fear of further upsetting the mother. Although they wanted to support their partners, they were unsure how to do so.	All but one father saw their baby; most fathers were very reluctant to hold their baby but did so with encouragement from nurses or family members. This time with the baby was cherished by parents. Fathers, more so than mothers, found it helpful to keep busy, to "move forward," and to think positively about the future.
Kelley & Trinidad (2012)	To examine parents' and physicians' experiences and beliefs surrounding stillbirth within the context of the clinical encounter.	22 U.S. bereaved parents to stillbirth and obstetric/gynaecologic health professionals participated: two of which were fathers. No further demographic data was collected.	Participants were identified and initially recruited through parent hospital guild groups, followed by snowball sampling within these groups. Data were collected using three semi-structured focus groups, and analysed using thematic discourse analysis.	The grief experience following stillbirth was ambiguous; one father described his grieving process as uncertain and changing over time. Both fathers described feeling sadness or depression, but supporting their wives was their primary focus.	A sense of constrained grieving was caused by social discomfort and taboo which extended to husbands and grandparents, who were not expected to grieve the loss of a stillborn baby beyond feeling some transient disappointment or sadness for their wife or daughter.
Lukas (1999)	To reveal the characteristics and dimensions of the process of experiencing paternal grief, mourning, and adaptation following perinatal loss.	15 U.S. men who had experienced perinatal loss, ranging in age from 28-52 years. Gestational age of their babies at time of loss was 20-42 weeks, and time since loss ranged from 5-98 months. All men were married and employed in full-time work.	Recruitment occurred through perinatal loss support groups. Data were collected using semi-structured individual interviews and administration of the Perinatal Grief Scale.	Each of the fathers recognised and acknowledged their loss as one of a baby. Common grief responses included alienation, life change, frustration, sadness, shock and helplessness. Unique elements of grief included disappointment, ritual, disenfranchisement, attachment and masculinity. Fathers experienced disenfranchised grief in the sense that the attention and focus was on their female partner, both in the healthcare system and in relation to family/friends/community.	The most common expressions positively affecting or facilitating grief were reported to be support group participation, rituals, positive healthcare experiences, returning to work, social support, and family. Most fathers expressed gratitude for support groups, however some felt they impeded grief adaptation due to the "female-centred" nature. Positive experiences with the hospital led to both increased support group participation and improved grief outcome. Returning to work gave fathers a break from grief. Only five felt that family members were a positive support; others were disappointed with the support they received from them.
McCreight (2004)	To examine the impact of miscarriage and stillbirth on male partners in Northern Ireland.	14 men who attended self-help groups for pregnancy loss. Three men had experienced a miscarriage, six a stillbirth, and five both	Participants were recruited through local pregnancy loss support groups. Data were collected using semi-structured, in-depth	Men in this study grieved deeply following their loss. Irrespective of time lapse since the bereavement, all appeared to have suffered. Many questioned their identities as fathers. All of the fathers in the study expressed a need to	Most of the men saw an ultrasound scan of their unborn baby; these fathers reported developing an awareness of the baby as a real living person. Not all men had access to a birth certificate for their babies; this prevented them

		miscarriage and stillbirth. Gestational ages at the time of loss ranged from seven to 41 weeks; two men had no living children. Men's ages ranged from 21 to 43; time since loss ranged from two months – 20 years.	interviews. A narrative approach to analysis was taken using content analysis, assisted by the use of NVivo.	put their own grief and emotional needs aside in order to support and comfort their partner.	from having their experience of death validated. Several men reported being marginalised by hospital staff, despite the fact that they had onerous responsibilities at the time. All fathers indicated that they frequently felt their loss had been devalued by the wider community. Self-help groups also afforded to the men an opportunity to grieve through rituals and remembrance services.
Meaney et al. (2017)	To explore the experiences of those who have experienced miscarriage, focusing on men's and women's accounts of miscarriage.	16 Irish parents bereaved by miscarriage, six of which were men. Gestational age at the time of loss ranged between six and 16 weeks, and time since loss ranged from 18-96 months. The men had a history of two to seven previous miscarriages, and the number of living children ranged from three to none.	Participants were initially recruited through women's previous participation in a prospective cohort study on miscarriage, then through snowballing techniques. Data were collected using semi-structured individual interviews, and analysed using interpretive phenomenological analysis.	Men reiterated that although they did not experience the miscarriage physically, they were affected emotionally and did go through a grieving process. Men felt that their primary role was to support their partners through the loss and, at times reluctantly, while planning subsequent pregnancies.	Rituals to acknowledge the loss were extremely important to all participants. Keeping busy helped participants cope with their loss; this was particularly evident in the participants who already had children. Men in this study indicated that they were less likely to openly discuss the miscarriage unless prompted by another person with a similar experience.
Murphy (1998)	To describe the experience of early miscarriage from a male perspective using a phenomenological approach.	Participants were five men who had experienced a miscarriage prior to 24 weeks gestation. All losses had occurred more than two years prior to the interview.	Purposive, snowball sampling was used to recruit participants. Data were collected using unstructured individual interviews, and analysed using a phenomenological approach.	Miscarriage was a sudden, unexpected event. Initial feelings included shock, disbelief, upset and helplessness. All men felt concern for their female partners. There was a perception that early miscarriage provoked a more intense reaction for their partners than for themselves. Men described an expectation that they should be stronger and tougher in order to support their partner and have no need to grieve or share their feelings.	Participants indicated that the intensity of men's grieving may be related to the extent to which the foetus seemed 'real' to them. A common coping strategy the men used was to ignore things, try to forget the miscarriage and carry on with life as normal. All participants also commented that they felt very alone in trying to cope. Most support came from friends, family and their partner, but not from health professionals.
Obst (2017)	To explore Australian men's experiences of support following a female partner's pregnancy loss.	Participants were eight Australian men who had experienced a pregnancy loss between six months and five years ago, and seven pregnancy loss service providers. Men were aged between 33 and 45 years, all we in a de facto or married relationship. Losses occurred between 20 and 31 weeks of gestation, and included several "early miscarriages" prior to 20 weeks.	Recruitment occurred through local pregnancy loss support organisations and social media advertisements. Data were collected using semi-structured individual interviews and analysed using thematic analysis.	Men described varied experiences with grief and subsequent support needs. Grief was not related to gestational age, but rather an individual experience. Many men described how a lack of recognition for their grief made the grieving process even harder, as they felt as though they had to suppress their feelings. Participants downplayed their grief experiences in relation to that experienced by women, given that their female partners had endured the physical component of the pregnancy and loss.	Many men described practical responsibilities as impacting their grief experience, including: caring for other children, work, and "trying to keep everything normal at home". The most helpful health professionals were those who were patient with men and gave them space to process their loss and grief. The majority of men recounted positive experiences with helpful family members or friends, especially in the earliest stages following the loss. All of the men mentioned a feeling of being a 'supporter' to their female partner and children. Stigma around men's help-seeking and societal expectations for how men should behave in relation to grief and loss served as a barrier to accessing support for grief.

O'Leary & Thorwick (2006)	To present information about the father's perspective during the experience of a pregnancy following perinatal loss.	Participants were 10 U.S. fathers whose female partners were currently pregnant subsequent to a perinatal loss. Ages ranged between 28 and 59 years. Five fathers had one living child each, one father had two. All losses occurred within one year prior to participation.	Recruitment occurred through friends of former parents who had been involved in a pregnancy loss support group, advertisement in a bereavement newsletter, and staff referrals at a perinatal centre. Data were collected using individual interviews, and analysed using descriptive phenomenology.	Pregnancy (and loss) was regarded as a women's experience, and fathers felt ignored. Fathers described how "life goes on" in spite of the need to grieve. They were exhausted, physically and emotionally, but when asked how they managed, a common response was "I keep myself busy". Fathers made an effort to appear strong, but their overt behaviour contradicted their inner state of stress and vulnerability. Protecting their partner can impede fathers from dealing with their own feelings.	Lack of recognition was identified as a societal issue by six fathers; they described feeling overlooked and wanted to be seen as more than a "support person". Many had Some had obligations of older children and manifold household tasks if their partner was on bed rest. They were not given time off from work like their female partners/wives. Societal pressure for men to be "the strong one" created a tremendous burden and was a barrier for securing much needed support.
Samuelsson et al. (2001)	To describe how fathers experienced losing a child as a result of intrauterine death.	Participants were 11 Swedish fathers who had experienced stillbirth between 32 and 42 weeks gestation. Fathers' ages ranged between 31 and 46 years, and time since loss ranged between five and 27 months. Eight were married to, and three cohabiting with, the mother of their stillborn child. For five fathers the stillborn child was their first child.	Participants were recruited through a Swedish hospital (not specified). All fathers whose offspring died during weeks 29 to 42 between 1997 and 1998 were invited to participate. Data were collected using individual interviews, and analysed using phenomenology.	Following the loss, fathers wept and felt severe grief, meaninglessness, abandonment, emptiness, guilt, and fear of the abnormal. They didn't think so much about themselves but tried first of all to protect their partner. They tried to take care of practical matters themselves, however grief was exhausting and made it difficult to cope with these tasks. At times, they felt left behind, outside of it all, confused, and submerged in a totally female-dominated world. There was a need to be left alone, but at the same time they needed help and support.	The primary elements in fathers coming to grips with their grief were tokens of remembrance and support from the obstetric staff and hospital chaplains. Having had children previously was thought of as source of strength and an asset that facilitated their everyday lives. The most valuable help in everyday life was the good relationship with their partner. Most also received good support from relatives, friends, and fellow workers, although they felt that their partner received more. They sought recognition as mourning fathers from caregivers and significant others.
Tennenbaum (2008)	To gain insight and a more comprehensive portrayal of the range of psychological and emotional consequences of recurrent miscarriage on couples.	15 U.S. couples who had experienced the loss of three or more consecutive pregnancies prior to the 20th week of gestation. Age of the couples ranged from 23 to 49 years; 11 identified as White/Caucasian, three as Hispanic/Latino and one as Black. Couples had experienced between three and 10 miscarriages, and time since the last ranged from one to 18 months.	Recruitment occurred through internet advertisements on miscarriage-related websites, invitations to couples known by the researchers, and snowball sampling. Data were collected using in-depth, semi-structured interviews over the phone, and were analysed using grounded theory.	All men expressed grief, although specific manifestations differed. All men expressed sorrow and/or deep disappointment during the miscarriages. Most of the men reported a real sense of loss and great difficulty coping – they cried both alone and with their wives. With each miscarriage, men lost more and more hope that they would ever have a biological child. Several husbands reported difficulty meeting expectations of their roles as husband, support, caretaker, as well as family and medical liaison. They reported a need to protect their wives, even if it was at their own expense.	For most of the men, attending the ultrasound or seeing images was a significant experience that often compounded their grief – it made the pregnancy more of a reality and increased attachment. A lack of answers significantly affected all the husbands. Men became angry when they felt that their grief was ignored; they felt that they needed to be strong and not show emotion. Sharing their loss with family, friends or their church community was helpful. A few men reported friction in their marriage due to different coping strategies, however all believed the loss brought them closer together.
Wagner et al. (2018)	To examine the lived experiences of fathers who have experienced miscarriage.	11 U.S. fathers who had experienced a miscarriage before 24 weeks gestation. Each was currently married to the mother of the lost pregnancy. Several had experienced multiple miscarriages, nine had since	Participants were recruited using convenience sampling of personal contacts and social media, followed by snowball sampling. Data were collected using face-to-face semi-structured interviews, and	Participants perceived themselves as fathers, and reported taking their responsibilities as one "very seriously". An expressed need to provide, protect and nurture led the fathers to question whether they could have done more to prevent the loss. Fathers recalled being focused on the health and wellbeing of their partner and care of their families; these	Belief that the miscarriage was the loss of a person, rather than the loss of a pregnancy, seemed to make processing more difficult. Support from others (family and friends) who had also experienced miscarriage was particularly meaningful. Practical support was helpful (e.g., cooking meals, time off from work and extensions on projects, gift baskets).

		experienced a successful pregnancy. Nine identified as Caucasian, two as Black.	analysed using phenomenology.	responsibilities needed to be balanced with their own grief. Fathers described the need to be strong for the mother, which impacted their ability to experience grief.	Fathers often experienced disenfranchisement indirectly by not being recognized as a part of the process: although they believed the mother should be the primary focus, they often felt ignored by others.
Wagner et al. (1998)	To explore with fathers their perinatal death experiences.	11 fathers who had experienced perinatal death (conception to 28 days after birth) in the U.S. Fathers ranged in age from 28 to 38 years, all identified as non-Hispanic White. Seven losses occurred before birth, and four experienced a neonatal death. Time since loss ranged from six months to five years.	Participants were recruited through a community support group called "Hoping". The facilitator of the group referred 11 participants from the group to participate. Data were collected using structured telephone interviews, including numerically rated responses and open-ended questions.	Fathers were asked to rate their grief at the time of perinatal death from 1 (no grief) to 10 (severe grief). The mean response was 8.5, however higher scores were reported for second trimester and neonatal losses. Those who had experienced first trimester loss had a mean score of zero (no grief) at the time of interview. Only one father denied having cried in response to his loss (first trimester).	Only half of the fathers felt they were supported during the experience; nine fathers reported their partner as their main source of support in grief. 72% felt there was a difference between support for them and their partner from family, friends and community; with the wife receiving more support and the majority of fathers feeling "overlooked". In general, grief decreased with time since death. However, the majority of fathers expected to grieve throughout their lifetime.
Weaver-Hightower (2012)	To consider the experience of the author's own daughter's stillbirth, exploring grief, tactile contact with death, and how these demonstrate the strictures and ruptures of masculinity in Western cultures.	Autoethnography of one father's experience with the stillbirth of his daughter at 38 weeks' gestation.	Autoethnographic methods were used, including interviewing others, using self-artefact and photo elicitation, reflective memoing, participant observation in bereavement support groups, and creating art and scrapbooks.	Grief came in "flickers and fragments", the author felt that the loss ruined everything, and challenged his religious faith. He felt helpless for his wife's suffering, and wished to fix it. Additional roles (such as informing people of the loss) fell to the father. He felt as though he had to hide his grief and work to suppress any form of emotional expression.	The author developed a strong attachment to his daughter throughout pregnancy. He recognised that his grief was highly social, and regulated according to gender and other social and cultural inequalities. Mementoes performed a "critical role", along with instrumental coping strategies (e.g., woodworking), which served as a form of therapy which was not talking. Returning to work was difficult, and he felt that he could not take off the time to mourn.

Quantitative Studies

Authors (Year)	**Study Aims (objectives; focus)**	**Participants/Setting (*N* of men; loss type; country; time since loss)**	**Method/Design (recruitment; data collection; analysis)**	**Measure of Grief (grief measure used)**	**Predictors/Outcomes (key predictors and/or grief outcomes)**
Alderman et al. (1998)	To explore the psychological impact of grief and stress in couples who experienced a miscarriage. Investigated differences between the couple in how they grieve and experience the stress of miscarriage	19 Caucasian, married couples; 10 experienced a miscarriage in their first pregnancy; loss occurred within two years of study; fathers were an average of 37 years; undertaken in the U.S.	Recruitment strategy not specified; data collected via a questionnaire using validated psychological instruments.	The Grief Experience Inventory-Loss Version Impact of Event Scale (IES)	Men's overall responses differed significantly to that of women's; men had elevated scores on the avoidance subscale of the IES.
Barr (2004)	To explore the relationship of guilt- and shame-proneness to grief in bereaved parents 1 month ('early') and 13	86 mothers and 72 fathers bereaved by stillbirth (≥20 weeks gestation) or neonatal death (≤28 days after birth) in Australia; mean age of men	Parents who had experienced a stillbirth in four (of six) high-risk obstetric hospitals in Sydney were sent an invitation letter 2-3 weeks	Perinatal Grief Scale-33 **Other measures:** Test of Self-Conscious	At one month, women reported more intense grief, but at 13 months there were no sex differences in grief. Shame and guilt together explained 27% of the variance of early grief

	months ('late') after a stillbirth or neonatal death.	was 34.4 years; ethnicity was primarily English-Australian (75%); majority of parents were married (70%) or cohabiting (23%).	after the loss; semi-structured interviews and a questionnaire were completed in parents' homes or over the phone.	Affect-2 (TOSCA-2) Personal Feelings Questionnaire (PFQ) Interpersonal Guilt Questionnaire (IGQ-67)	(one month after the loss) in men. For late grief (13 months after the loss), shame and guilt together accounted for 63% of the variance in men.
Barr (2006)	To explore the relationship between parental grief following perinatal bereavement and subsequent pregnancy, according to the particular facets of grief and pregnancy state being considered.	Participants were 63 heterosexual Australian couples who had been bereaved by stillbirth (prior to 20 weeks gestation; n = 31) or neonatal death (death within 28 days of birth; n = 32). Participants were aged between 19 and 50 years of age. The majority identified as English-Australian (76%), European-Australian (10%), or Asian-Australian (8%).	Recruitment method is not specified; 44% of eligible parents from participating hospitals agreed to participate. Data was collected using two semi-structured interviews with parents, approximately one month and 13 months after the loss. Parents also completed a psychometric measure of grief. Results were analysed using repeated-measures ANOVAs.	Perinatal Grief Scale-33	The presence of living children before loss was not significantly correlated with Perinatal Grief scores at one or 13 months. A significant main effect for the Active Grief subscale of the PGS was found in men. The pregnancy status interaction was not significant for men, indicating that subsequent pregnancy status did not have an effect on grief.
Barr (2012)	To examine the intrapersonal (actor) and interpersonal (partner) relationships of personality proneness to negative self-conscious emotion (shame and guilt) to grief in couples 13 months after a perinatal death.	Participants were 63 heterosexual Australian couples who had been bereaved by stillbirth (prior to 20 weeks gestation; n = 31) or neonatal death (death within 28 days of birth; n = 32). The majority identified as English-Australian (76%), European-Australian (10%), or Asian-Australian (8%).	A letter was posted to eligible parents 2–3 weeks after the perinatal death, and 1 week later they were contacted by telephone to ascertain their willingness to participate in the study. Data was collected using self-reported questionnaires containing validated psychometric measures, and analysed using regressions and paired samples t-tests	Perinatal Grief Scale-33 **Other measures:** Test of Self-Conscious Affect-2 (TOSCA-2) Personal Feelings Questionnaire (PFQ) Interpersonal Guilt Questionnaire (IGQ-67)	Personality proneness to shame and proneness to guilt were shown to predict grief intensity in parents bereaved by stillbirth or neonatal death, and the predictions were invariably stronger in men compared with women. Analysis showed that negative self-conscious emotion had an intrapersonal (actor) relationship with grief in men.
Conway & Russell (2000)	To investigate the grief response of both the woman and her partner to miscarriage and to ascertain if support received was adequate and appropriate to their needs	39 women and 32 male partners who had experienced miscarriage in Australia. Losses occurred between 5 and 16 weeks gestation, 12 males had surviving children prior to the loss.	Purposive sampling through four major Sydney obstetric hospitals and one district hospital. Data were collected using two round of questionnaires, the follow-up 2-4 months later.	Perinatal Grief Scale	Age, length of relationship with partner, education, previous children and socio-economic status were not related to grief scores. Initial reactions were very sad (53%) and sad (34%); 75% of men said their partner's reaction affected them. Feelings of loss remained 2-4 months later for 63%; 32% still thought about it daily. Partners scored significantly higher than the women on the three PGS subscales and overall. 94% reported they were able to talk to their partner about the loss; 73% of partners rated support from relatives and 71% from friends as helpful. Only 18% of men were asked by hospital personnel how they were coping with the miscarriage – 46% said they would have liked to have been.
Cope et al. (2015)	To examine the psychological impact, specifically symptoms of grief, post-traumatic stress	158 women and 109 men who had lost a pregnancy or baby due to anencephaly. Study was based in the U.S. but also included 15	Participants were purposively sampled through their participation in a prior study on Neural Tube Defects, and through social media	Perinatal Grief Scale-33 Impact of Events Scale – Revised	Men's scores on the PGS ranged from 37 to 120 with 11% scoring in the pathogenic range for grief. Time since pregnancy was significantly associated with scores on the PGS

	and depression, in women and men who either terminated or continued a pregnancy following prenatal diagnosis of a lethal fetal defect.	participants from UK, Canada and Australia. Ethnic backgrounds were primarily non-Hispanic Caucasians (90%), with men aged between 20 and 42 years at the time of loss. Time since loss varied between one month and 32 years.	advertisements for the present study. Data collection occurred through survey questionnaires using validated measures and project-specific questions.		and IES; those with more recent losses scoring higher. Pregnancy continuation was associated with higher scores on the difficulty coping subscale, whereas termination in the second trimester was associated with higher active grief. For participants who continued the pregnancy, there were no significant differences in psychological outcome between those who had a stillborn or live-born baby (neonatal death).
Franche (2001)	To determine if the psychologic constructs of self-criticism and marital adjustment, considered jointly with obstetric and demographic factors, are significant predictors of grief during a pregnancy after a miscarriage or perinatal death	60 Canadian women between the 10th and 19th week of gestation, and 50 of their partners. Men were aged between 24 and 46 years. Gestational age at the time of prior loss ranged between four and 42 weeks; three had neonatal losses within four days after birth. Time since the loss ranged from four to 48 months.	Purposive sampling through obstetric clinics and hospital staff in a large Canadian University Hospital. Participants completed a battery of self-report questionnaires containing validating psychometric scales.	Perinatal Grief Sale–Short Form **Other measures:** Depressive Experiences Questionnaire—Self-criticism subscale Abbreviated Dyadic Adjustment Scale	In men, only gestational age at time of loss and time between loss and conception were significant predictors of grief levels. Age, number of previous losses, and number of living children, when considered in conjunction with psychologic variables, were not significantly associated with grief levels. Gestational age at time of loss was a significant predictor of active grief for men.
Franche & Bulow (1999)	To examine the impact of a subsequent pregnancy on emotional adjustment associated with a previous perinatal loss and on components of parental grief.	25 Canadian women and 24 partners expecting a baby for the first time since a prior perinatal loss, and 25 women and 18 partners who were not expecting or had a child since a prior loss. Fathers were aged between 26 and 51 years; losses occurred between 10 and 42 weeks gestation. Time since loss varied from 1 month to 31.5 months.	Purposive sampling through obstetric clinics in a large Canadian University Hospital. Participants completed a battery of questionnaires containing validated psychometric scales.	Perinatal Grief Scale–Short Form **Other measures:** Beck Depression Inventory State-Trait Anxiety Inventory Abbreviated Dyadic Adjustment Scale	For the fathers, two MANCOVAS were performed examining group differences in levels of grief and emotional adjustment. No significant group effects in emotional adjustment or intensity of grief were found between the “pregnant loss” and “loss” groups, indicating that subsequent pregnancy status did not impact upon men’s emotional and grief outcomes.
Huffman et al. (2015)	To understand the effect of gender, age, mental health history, and reproductive factors on the appraisal of miscarriage in couples.	341 couples who had experienced a miscarriage in the U.S. participated. 85% of participants were White; 4.7% black; 5.6% Asian/pacific Islander; 3.2% Hispanic; and 0.6% Native American.	Participants were part of a larger study called the Couples Miscarriage Healing Project, a randomised controlled clinical trial. Data for this study were responses to a validated psychometric scale collected at baseline.	Revised Impact of Miscarriage Scale	Women scored significantly higher than men on all measures. Younger age and more advanced gestational age at time of loss were associated with higher scores on the isolation/guilt and loss of baby subscales. Men who had living children had higher scores on the devastating event and loss of baby subscales. Mental health treatment, infertility, and miscarriage history did not affect the impact of miscarriage in men.
Jansson et al. (2017)	To compare Swedish and American couples’ experience of miscarriage by use of the Revised Impact of Miscarriage Scale.	Participants were Swedish (*n* = 70) and American (*n* = 70) couples who had experienced miscarriage up to 21 weeks gestation. The median week of miscarriage was 10.2 and 10.0 weeks for the Swedish and American couples, respectively.	Swedish couples were recruited through a gynaecology emergency clinic at Uppsala University Hospital. American participants were part of a larger miscarriage project. Data were responses to a	Revised Impact of Miscarriage Scale	The American men scored significantly higher on the factor ‘Loss of baby’ than the Swedish men. There was no difference between the scores on Isolation/Guilt or Devastating Event.

		Couples were matched according to age, number of miscarriages and previous children.	validated self-report psychometric scale.		
Johnson & Puddifoot (1998)	To explore the role of visual imagery in mediating the male grief reaction to a partner's miscarriage.	Participants were 158 British men who had experienced a miscarriage prior to the 24th week of gestation. Miscarriages occurred between the 6th and 24th week of pregnancy. Time since miscarriage was within 11 weeks. All participants were in 'stable' relationships. 38% of couples had no previous children; 29.7% had one and 32.3% had two or more. Half of the couples has experienced miscarriage previously.	Participants were purposively sampled through gynaecological wards of general hospitals and several large GP surgeries. Data were collected via a self-report questionnaire using validated psychometrics scales.	Perinatal Grief Scale **Other measures:** A modified form of the Vividness of Visual Imagery Questionnaire (baby focus)	Vivid imagers exceeded the scores on all elements of the PGS in comparison to mid-range and non-vivid imagers. Scores on the difficulty and despair subscales specifically were exceedingly high, comparable to those found for women who have experienced miscarriage. Vividness of imagery had a highly significant effect on PGS score overall. Low scores on the active grief subscale suggest that men are likely to be less demonstrative in their expression of grief.
Khan et al. (2004)	Aims were: (1) to assess the emotional responses of men to early pregnancy loss; (2) to establish if sufficient support services are provided to these men; (3) to make recommendations to improve the quality of these support services, if necessary.	Nine men who were attending an early pregnancy loss clinic in Dublin with their female partners participated. Men were aged between 20 and 39 years. All were Caucasian, and had experienced a miscarriage at less than 20 weeks gestation.	Data were collected using a study-specific questionnaire comprising of open and closed questions. Data were presented in the form of percentages of responses to questions.	No validated measure of grief.	Men described a range of feelings in response to the miscarriage, including uncertainty, sadness, blank, confusion, and anger. None were satisfied with the level of support and information received at the time of the miscarriage; they felt all support services for their partner were satisfactory but they were excluded. Some found comfort by crying, support from family/friends, or discussion with their partner.
Michon et al. (2003)	To evaluate the intensity of grief experienced by parents who have lost a child in the perinatal period (stillbirth, premature baby, term baby less than one month) and parents who have lost a child after the perinatal period (one month to 18 years).	All parents who had lost a child in Estrie, Quebec between Jan 1997 and Dec 1999 were contacted to participate in the study. The questionnaire was sent to 85 families and 71 parents returned them completed (32 of which were perinatal loss parents). Gestational age for the losses ranged between 24 and 41 weeks, and time since loss ranged between 36±9 months. 79% of parents identified as Catholic.	Data were collected using a self-reported questionnaire containing	Texas Revised Inventory of Grief [TRIG-F]	Fathers' grief was less than that of mothers. No correlations between the TRIG-F scores and gestational age were observed. Early in their grief, fathers reported finding it hard to work after the loss. Long-term, fathers still felt the need to cry for their baby, and felt anxious and upset at anniversaries and events. Long-term grief scores averaged higher than early grief scores (31±12 versus 17±9, respectively).
Puddifoot & Johnson (1999)	To investigate male's grief responses to miscarriage (as measured by the Perinatal Grief Scale), and contributing characteristics.	323 men from the UK who had experienced a miscarriage prior to the 24th week of pregnancy. Participants' ages ranged between 17 and 56 years, and approximately half had suffered a miscarriage previous to the last. Time since the last miscarriage was within 2-8 weeks prior to data collection.	Recruitment strategy is not specified – results were from two separate but methodologically identical studies. Data were collected using self-report questionnaires.	Perinatal Grief Scale	Analysis revealed high levels of grief on the PGS, but with considerable variation. Taken together, the high mean scores and the relatively large dispersion of scores indicate both a diversity of response and a generally raised level of grief. Grief increased gradually with duration of pregnancy before miscarriage. The level of grief of those who had seen an ultrasound scan was also considerably higher.

Rich (2000)	To determine the impact of post-pregnancy loss services on grief outcome in both bereaved mothers and their male partners.	249 bereaved mothers and 114 male partners from the United States and Canada returned eligible completed research packs. Couples experienced between one and 12 previous losses, between three and 42 weeks gestation. Time since loss ranged from two to 60 months. 95% of participants identified as Caucasian; 68% as Christian, Catholic or Protestant, and 33 as Jewish.	Recruitment occurred through a variety of means, including: online and in-person support groups, parent newsletters, nurse/social work referrals, and church bulletins. Data were collected using self-reported questionnaires which were mailed to parents. Data were analysed using a stepwise multiple regression analysis.	Perinatal Grief Scale – Short Form	Following the loss, 96.4% of fathers reported talking with family, and 91.2% with friends. The majority of fathers reported meeting with a doctor to review reasons for the loss (82.5%), or plan for a future pregnancy (75%). In the final regression model for fathers, length of pregnancy, talking with friends, and timing of talking with family were significant predictors of grief; accounting for 15.5% of the total variance in PGS scores.
Serrano & Lima (2006)	To describe the consequences of recurrent pregnancy loss for the couple's relationship and explore gender differences in attitudes and grief intensity.	30 couples from Lisbon who had experienced recurrent miscarriage up to 24 weeks of gestation. Men were aged between 24 and 51 years; 76.7% identified as Catholic and 16.7% as atheist. 28 couples were Caucasian and two were Black. The majority of couples (76.7%) had experienced three miscarriages, 20% had experienced four, and one couple had six. Time since the most recent loss ranged from three months to one year.	Participants were recruited at the Recurrent Miscarriage Clinic at Maternity Dr Alfredo da Costa in Lisbon. Data were collected using self-reported questionnaires which couples completed in separate areas of the waiting room prior to their appointment at the clinic.	Perinatal Grief Scale Impact of Events Scale **Other measures:** Intimate Relationships Scale Partnership Questionnaire	Both the PGS and IES revealed high levels of grief and stress associated with recurrent miscarriage for men. Duration of relationship, ethnic background, number and duration of gestations, and time since last miscarriage were not significantly associated with PGS or IES scores. Grief was related to the perceived change in sexual relationship only for men; the higher the suffering, the lower the perceived quality.
Swanson et al. (2009)	To examine the effects of three couples-focused interventions and a control condition on women and men's resolution of depression and grief during the first year after miscarriage.	The final sample for analysis consisted of 636 U.S. participants (315 men) who had experienced miscarriage prior to 20 weeks gestation. Gestational age at loss ranged from 2.7 to 20 weeks, however 95% miscarried prior to 16 weeks. The majority of men identified as White (86%), and were an average of 34 years of age.	Participants were recruited from the Washington area via posters, print and media advertisements, and pamphlets in healthcare facilities. A randomised control trial, couples were randomly assigned to nurse care (NC), self-care (SC), combined care (CC) or a control (no treatment) intervention. Data were collected using mailed surveys at approximately one (baseline), three, give and 13 months after miscarriage.	Two subscales from the Miscarriage Grief Inventory were used: Pure Grief and Grief-Related Emotions.	Men and women responded differently to miscarriage. Both CC (a combination of nurse and self-care interventions) and NC (nurse care intervention only) offered strong evidence of hastening men's resolution of Pure Grief and Grief-Related Emotions above SC (self-care intervention). Men randomised to no treatment also resolved their Grief-Related Emotions faster than men in SC. This study concluded that one nurse counselling session followed up with videos and workbooks may have provided sufficient coaching to help men come to terms with their own transitional responses to miscarriage.
Volgsten et al. (2018)	To study the emotional experience, grief and depressive symptoms in women and men, one week and four months after miscarriage.	103 women and 78 men who had experienced a miscarriage in Sweden prior to 22 weeks of gestation. Men were aged between 25 and 51 years, 96% were married to, or living with, their partner. Just over half (57.7%) had previous children, and 7.7% had experienced infertility issues.	Participants were recruited through a gynaecological clinic after miscarriage. Data were collected using self-reported questionnaires containing validated psychometric measures.	Revised Impact of Miscarriage Scale and the Perinatal Grief Scale	The relative emotional experience of miscarriage did not change significantly from one week to four months in women and men. For the men, all three subscales of the Perinatal Grief Scale were reduced after four months compared to one week.

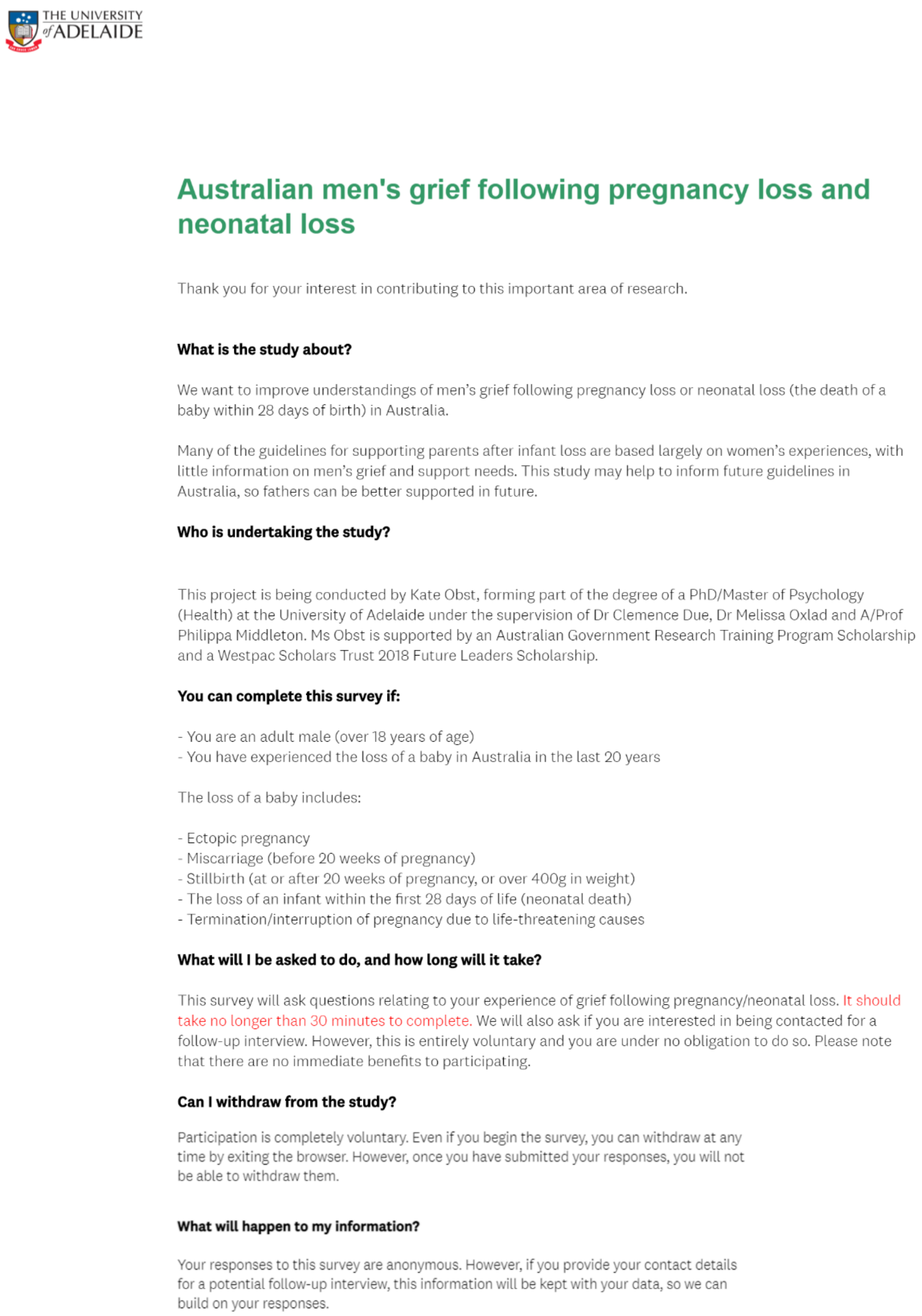
Wilson et al. (2015)	To document parents' experiences and outcomes in relation to seeing and holding a stillborn baby at a hospital with a specialist perinatal bereavement service.	26 mothers and 11 male partners who had experienced a stillbirth after 20 weeks gestation in Brisbane, Australia. Median gestational age for all losses was 27 completed weeks. 18 births were singletons, seven were twin births. The majority of participants were Caucasian.	Participants who experienced a stillbirth at the Mater Mother's Hospital in Brisbane between Sept 2007 and Dec 2008 were invited to participate in the study. Data were collected using mailed self-report questionnaires, and analysed using mixed-effects linear regression models.	Perinatal Grief Scale **Other measures:** Decisional Regret Scale and Mental Health Inventory	Nine fathers chose to see and hold their baby. One agreed or somewhat agreed that their choice did them 'a lot of harm'. Fathers who did not see and hold had significantly better mental health in all three post-loss surveys than those who did. There was a significant difference between participants who held and did not hold on the active grief subscale; however due to the small number of fathers, the estimates are imprecise.

Mixed Methods Study

Authors (Year)	**Study Aims** **(objectives; focus)**	**Participants/Setting** **(*N* of men; loss type; country; time since loss)**	**Method/Design** **(recruitment; data collection; analysis)**	**Measure of Grief** **(grief measure used)**	**Results/Outcomes** **(key predictors and/or outcomes of grief)**
Avelin et al. (2013)	To describe the grief of mothers and fathers and its influence on their relationships after the loss of a stillborn baby.	55 parents (22 fathers) bereaved by stillbirth (> 22 week' gestation) from the Stockholm region in Sweden; loss was the first child for 50% of fathers; mean age of men was 33; all parents were married or cohabiting.	All parents who experienced a stillbirth over a one year period at a hospital (86 babies) were given details of the study by a midwife after the stillbirth, before they left hospital (twin deliveries excluded). Data were collected through a mixed methods postal questionnaire at 3 months, 1 year and 2 years after the loss.	The researcher-developed questionnaire comprised multiple choice questions with space for comments, and some open-ended questions covering: demographic data, time before and during pregnancy, the delivery, contact with the stillborn baby, grief reaction, situation for any siblings, partner relationships and intimacy.	**Quantitative findings:** 82% of fathers did not feel they were grieving for their baby in the same way as their partner; however, at one year all had been able to talk to their partner 'to a great extent' about the loss. **Qualitative findings:** Men more often expressed their grief through frustration, activities or withdrawal. Others just quickly wanted to work through their grief and move forward with their lives. Relationship difficulties arose due to the expectation for the father to be the supporter and not show his feelings.

APPENDIX 12. Copy of Nationwide Survey

Copy of the nationwide survey for Study 2, as it appeared in the online SurveyMonkey platform. Please note that wording was customised according to the type of loss chosen to focus on for the survey; this copy displays wording chosen for selection of stillbirth.



THE UNIVERSITY of ADELAIDE

Australian men's grief following pregnancy loss and neonatal loss

Thank you for your interest in contributing to this important area of research.

What is the study about?

We want to improve understandings of men's grief following pregnancy loss or neonatal loss (the death of a baby within 28 days of birth) in Australia.

Many of the guidelines for supporting parents after infant loss are based largely on women's experiences, with little information on men's grief and support needs. This study may help to inform future guidelines in Australia, so fathers can be better supported in future.

Who is undertaking the study?

This project is being conducted by Kate Obst, forming part of the degree of a PhD/Master of Psychology (Health) at the University of Adelaide under the supervision of Dr Clemence Due, Dr Melissa Oxlad and A/Prof Philippa Middleton. Ms Obst is supported by an Australian Government Research Training Program Scholarship and a Westpac Scholars Trust 2018 Future Leaders Scholarship.

You can complete this survey if:

- You are an adult male (over 18 years of age)
- You have experienced the loss of a baby in Australia in the last 20 years

The loss of a baby includes:

- Ectopic pregnancy
- Miscarriage (before 20 weeks of pregnancy)
- Stillbirth (at or after 20 weeks of pregnancy, or over 400g in weight)
- The loss of an infant within the first 28 days of life (neonatal death)
- Termination/interruption of pregnancy due to life-threatening causes

What will I be asked to do, and how long will it take?

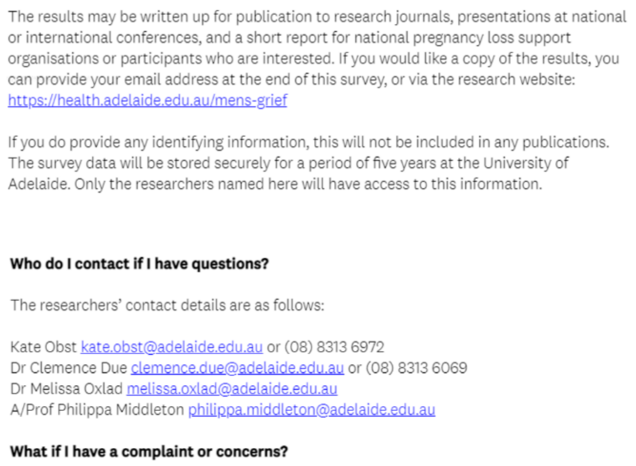
This survey will ask questions relating to your experience of grief following pregnancy/neonatal loss. It should take no longer than 30 minutes to complete. We will also ask if you are interested in being contacted for a follow-up interview. However, this is entirely voluntary and you are under no obligation to do so. Please note that there are no immediate benefits to participating.

Can I withdraw from the study?

Participation is completely voluntary. Even if you begin the survey, you can withdraw at any time by exiting the browser. However, once you have submitted your responses, you will not be able to withdraw them.

What will happen to my information?

Your responses to this survey are anonymous. However, if you provide your contact details for a potential follow-up interview, this information will be kept with your data, so we can build on your responses.



The results may be written up for publication to research journals, presentations at national or international conferences, and a short report for national pregnancy loss support organisations or participants who are interested. If you would like a copy of the results, you can provide your email address at the end of this survey, or via the research website: https://health.adelaide.edu.au/mens-grief

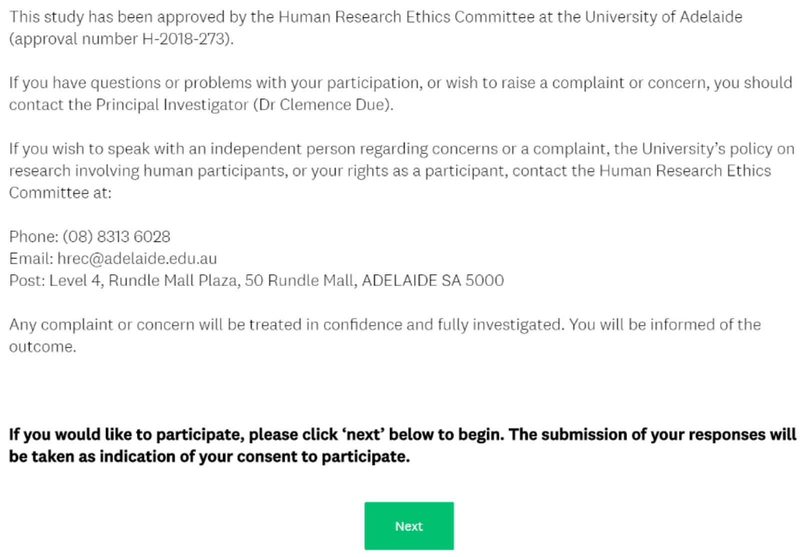
If you do provide any identifying information, this will not be included in any publications. The survey data will be stored securely for a period of five years at the University of Adelaide. Only the researchers named here will have access to this information.

Who do I contact if I have questions?

The researchers' contact details are as follows:

Kate Obst kate.obst@adelaide.edu.au or (08) 8313 6972
Dr Clemence Due clemence.due@adelaide.edu.au or (08) 8313 6069
Dr Melissa Oxlad melissa.oxlad@adelaide.edu.au
A/Prof Philippa Middleton philippa.middleton@adelaide.edu.au

What if I have a complaint or concerns?



This study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2018-273).

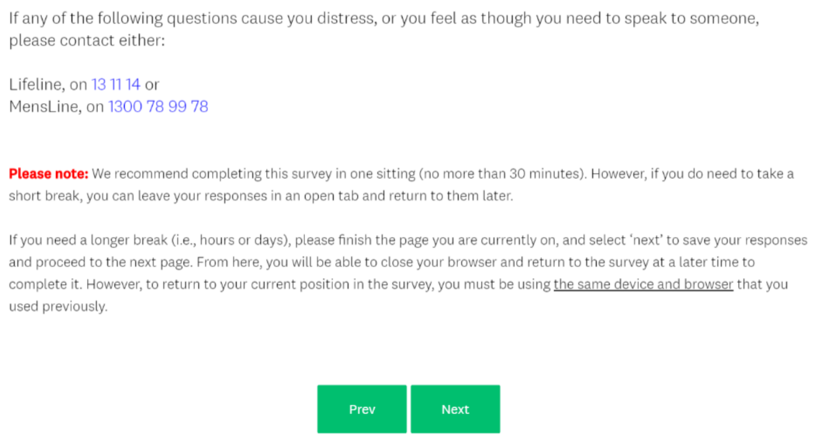
If you have questions or problems with your participation, or wish to raise a complaint or concern, you should contact the Principal Investigator (Dr Clemence Due).

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, contact the Human Research Ethics Committee at:

Phone: (08) 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 you would like to participate, please click 'next' below to begin. The submission of your responses will be taken as indication of your consent to participate.

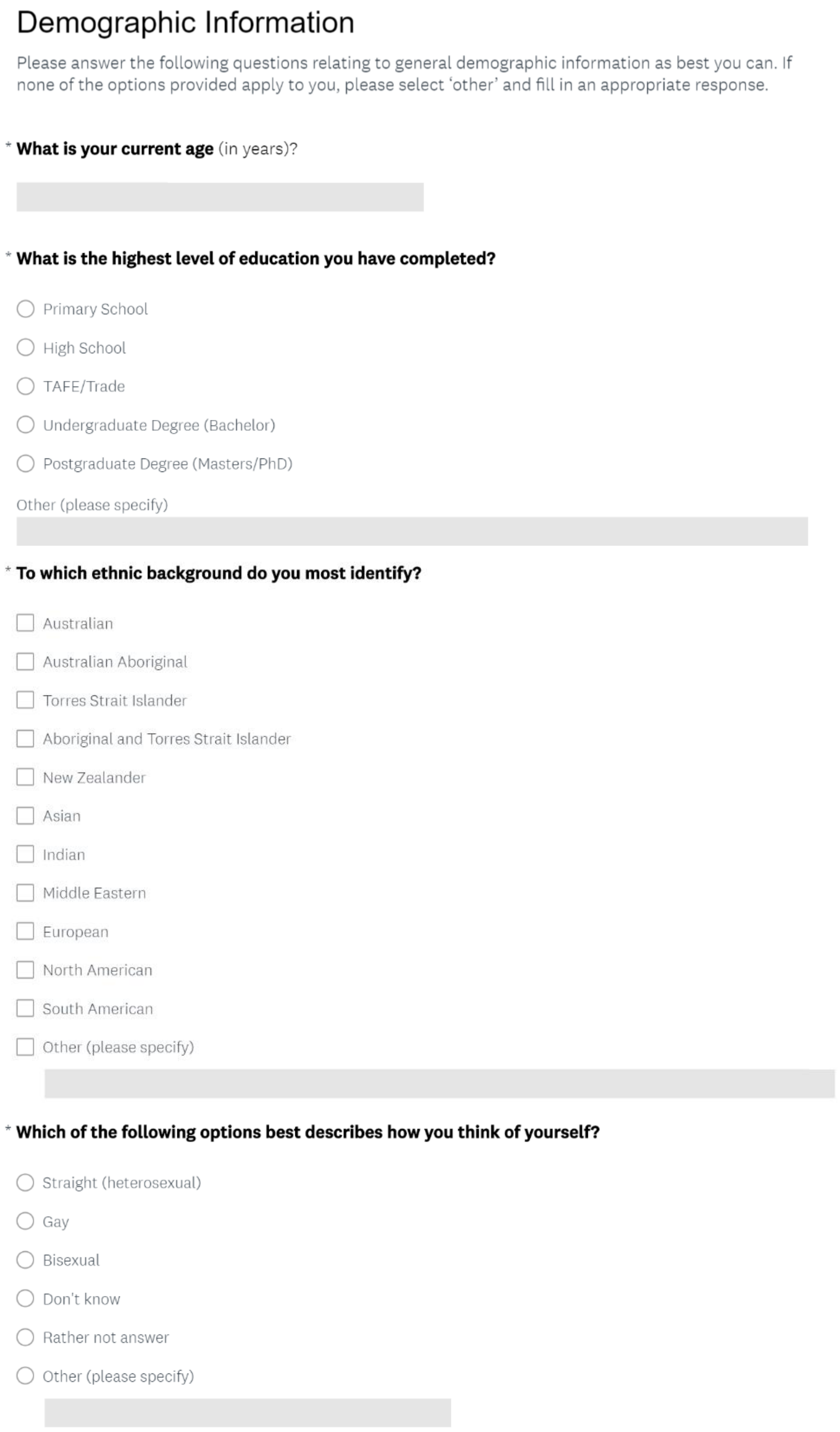


If any of the following questions cause you distress, or you feel as though you need to speak to someone, please contact either:

Lifeline, on 13 11 14 or
MensLine, on 1300 78 99 78

Please note: We recommend completing this survey in one sitting (no more than 30 minutes). However, if you do need to take a short break, you can leave your responses in an open tab and return to them later.

If you need a longer break (i.e., hours or days), please finish the page you are currently on, and select 'next' to save your responses and proceed to the next page. From here, you will be able to close your browser and return to the survey at a later time to complete it. However, to return to your current position in the survey, you must be using the same device and browser that you used previously.



Demographic Information

Please answer the following questions relating to general demographic information as best you can. If none of the options provided apply to you, please select 'other' and fill in an appropriate response.

* **What is your current age** (in years)?

* **What is the highest level of education you have completed?**

○ Primary School
○ High School
○ TAFE/Trade
○ Undergraduate Degree (Bachelor)
○ Postgraduate Degree (Masters/PhD)

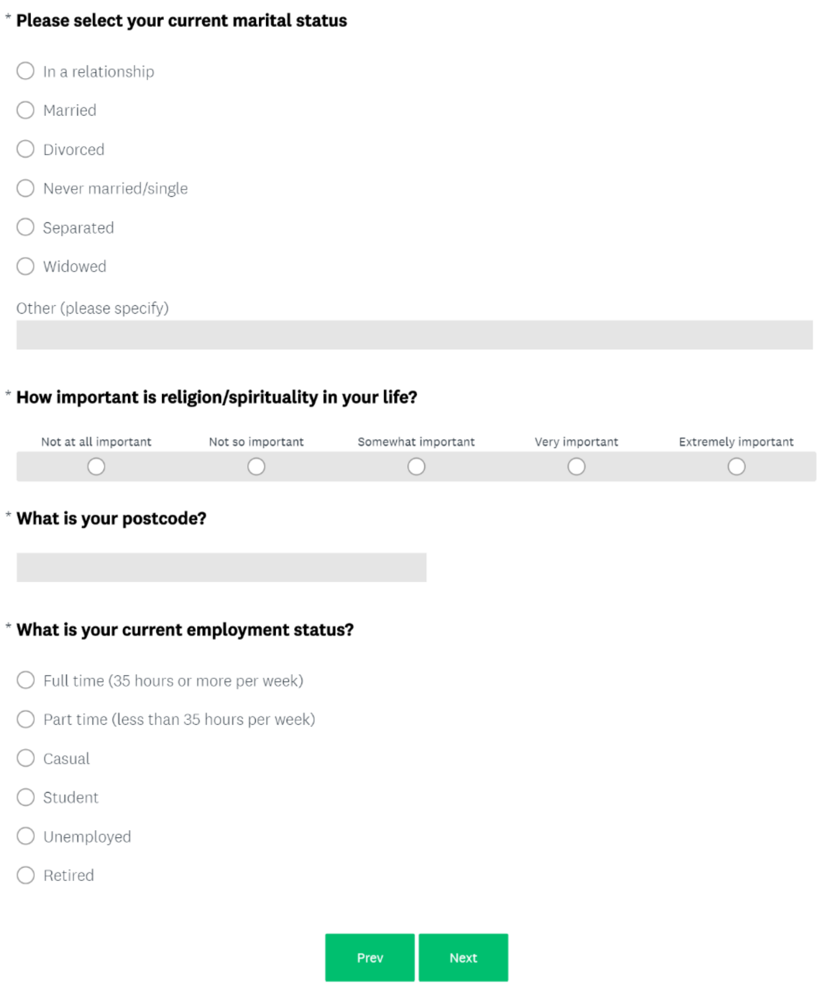
Other (please specify)

* **To which ethnic background do you most identify?**

☐ Australian
☐ Australian Aboriginal
☐ Torres Strait Islander
☐ Aboriginal and Torres Strait Islander
☐ New Zealander
☐ Asian
☐ Indian
☐ Middle Eastern
☐ European
☐ North American
☐ South American
☐ Other (please specify)

* **Which of the following options best describes how you think of yourself?**

○ Straight (heterosexual)
○ Gay
○ Bisexual
○ Don't know
○ Rather not answer
○ Other (please specify)



* **Please select your current marital status**

○ In a relationship
○ Married
○ Divorced
○ Never married/single
○ Separated
○ Widowed

Other (please specify)

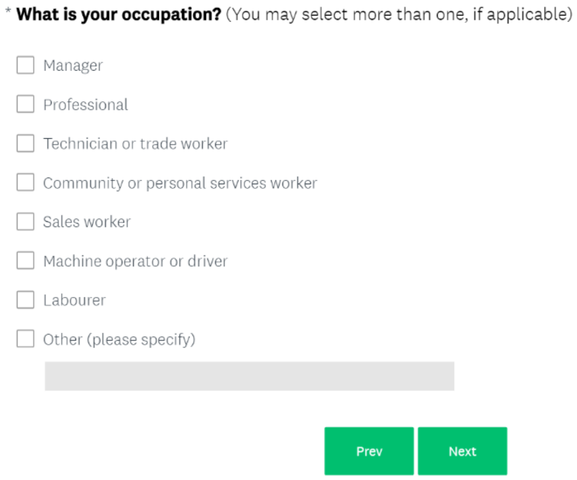
* **How important is religion/spirituality in your life?**

Not at all important	Not so important	Somewhat important	Very important	Extremely important
○	○	○	○	○

* **What is your postcode?**

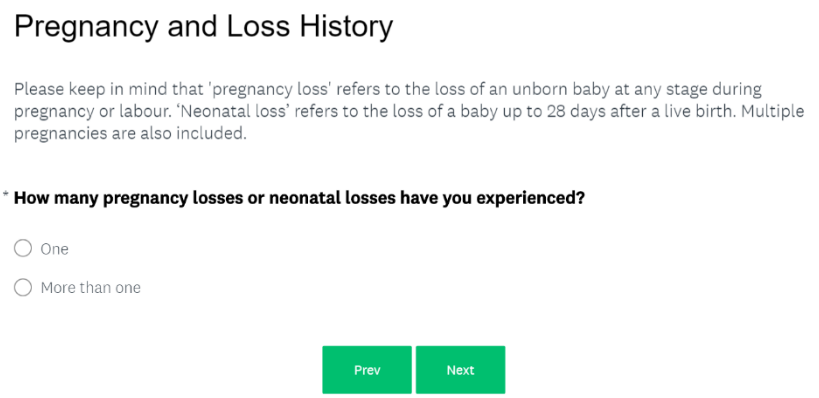
* **What is your current employment status?**

○ Full time (35 hours or more per week)
○ Part time (less than 35 hours per week)
○ Casual
○ Student
○ Unemployed
○ Retired



* **What is your occupation?** (You may select more than one, if applicable)

☐ Manager
☐ Professional
☐ Technician or trade worker
☐ Community or personal services worker
☐ Sales worker
☐ Machine operator or driver
☐ Labourer
☐ Other (please specify)



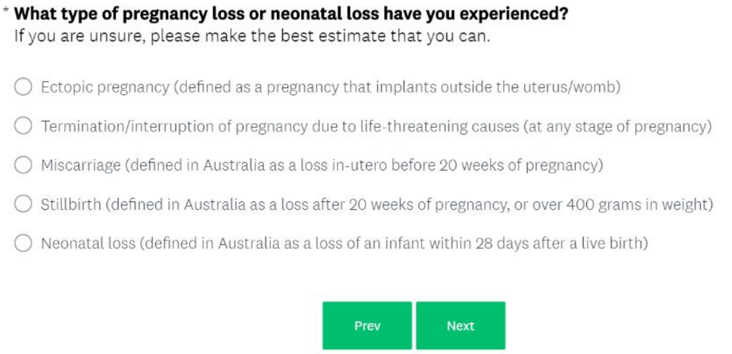
Pregnancy and Loss History

Please keep in mind that 'pregnancy loss' refers to the loss of an unborn baby at any stage during pregnancy or labour. 'Neonatal loss' refers to the loss of a baby up to 28 days after a live birth. Multiple pregnancies are also included.

* **How many pregnancy losses or neonatal losses have you experienced?**

○ One

○ More than one



* **What type of pregnancy loss or neonatal loss have you experienced?**
If you are unsure, please make the best estimate that you can.

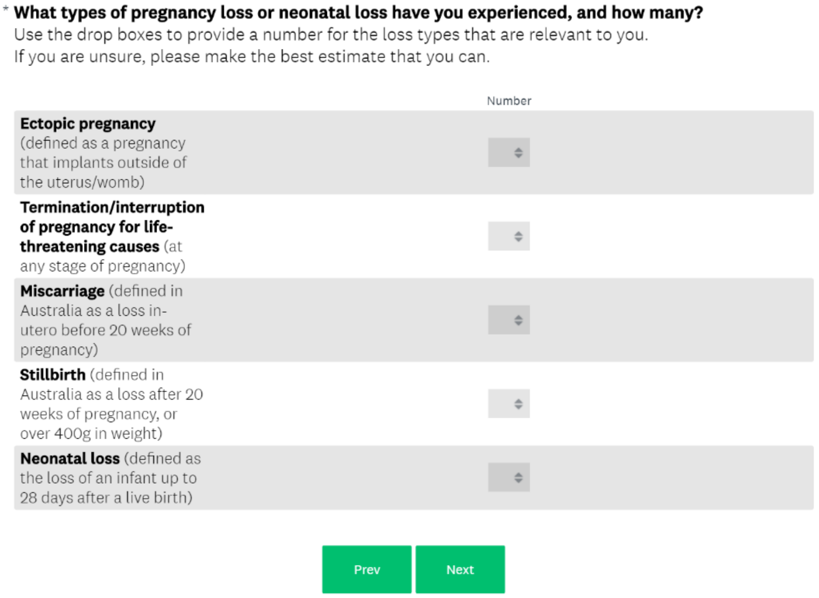
○ Ectopic pregnancy (defined as a pregnancy that implants outside the uterus/womb)

○ Termination/interruption of pregnancy due to life-threatening causes (at any stage of pregnancy)

○ Miscarriage (defined in Australia as a loss in-utero before 20 weeks of pregnancy)

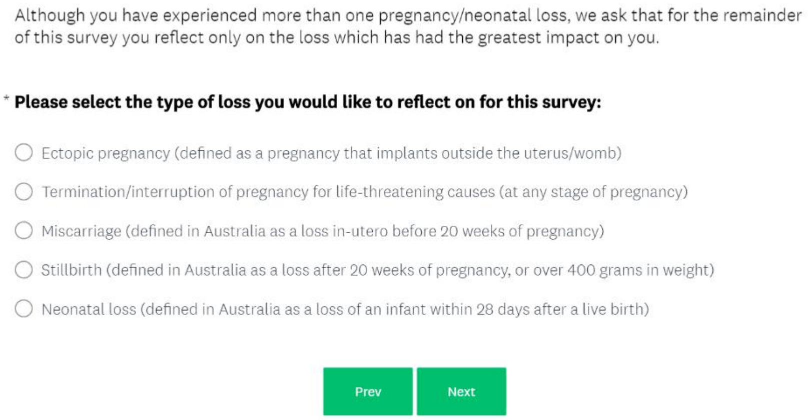
○ Stillbirth (defined in Australia as a loss after 20 weeks of pregnancy, or over 400 grams in weight)

○ Neonatal loss (defined in Australia as a loss of an infant within 28 days after a live birth)



* **What types of pregnancy loss or neonatal loss have you experienced, and how many?**
Use the drop boxes to provide a number for the loss types that are relevant to you.
If you are unsure, please make the best estimate that you can.

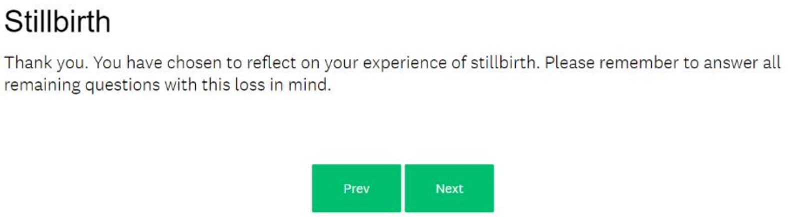
	Number
Ectopic pregnancy (defined as a pregnancy that implants outside of the uterus/womb)	⬍
Termination/interruption of pregnancy for life-threatening causes (at any stage of pregnancy)	⬍
Miscarriage (defined in Australia as a loss in-utero before 20 weeks of pregnancy)	⬍
Stillbirth (defined in Australia as a loss after 20 weeks of pregnancy, or over 400g in weight)	⬍
Neonatal loss (defined as the loss of an infant up to 28 days after a live birth)	⬍



Although you have experienced more than one pregnancy/neonatal loss, we ask that for the remainder of this survey you reflect only on the loss which has had the greatest impact on you.

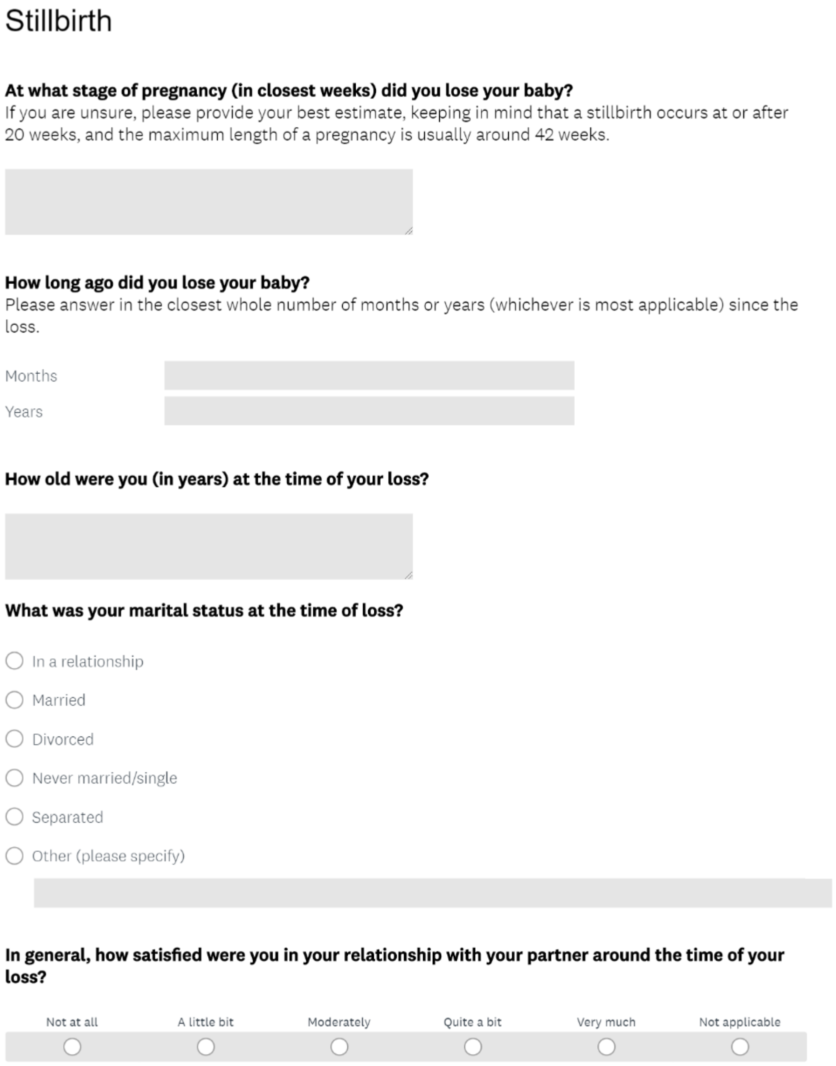
* **Please select the type of loss you would like to reflect on for this survey:**

- ○ Ectopic pregnancy (defined as a pregnancy that implants outside the uterus/womb)
- ○ Termination/interruption of pregnancy for life-threatening causes (at any stage of pregnancy)
- ○ Miscarriage (defined in Australia as a loss in-utero before 20 weeks of pregnancy)
- ○ Stillbirth (defined in Australia as a loss after 20 weeks of pregnancy, or over 400 grams in weight)
- ○ Neonatal loss (defined in Australia as a loss of an infant within 28 days after a live birth)



Stillbirth

Thank you. You have chosen to reflect on your experience of stillbirth. Please remember to answer all remaining questions with this loss in mind.



Stillbirth

At what stage of pregnancy (in closest weeks) did you lose your baby?
If you are unsure, please provide your best estimate, keeping in mind that a stillbirth occurs at or after 20 weeks, and the maximum length of a pregnancy is usually around 42 weeks.

How long ago did you lose your baby?
Please answer in the closest whole number of months or years (whichever is most applicable) since the loss.

Months

Years

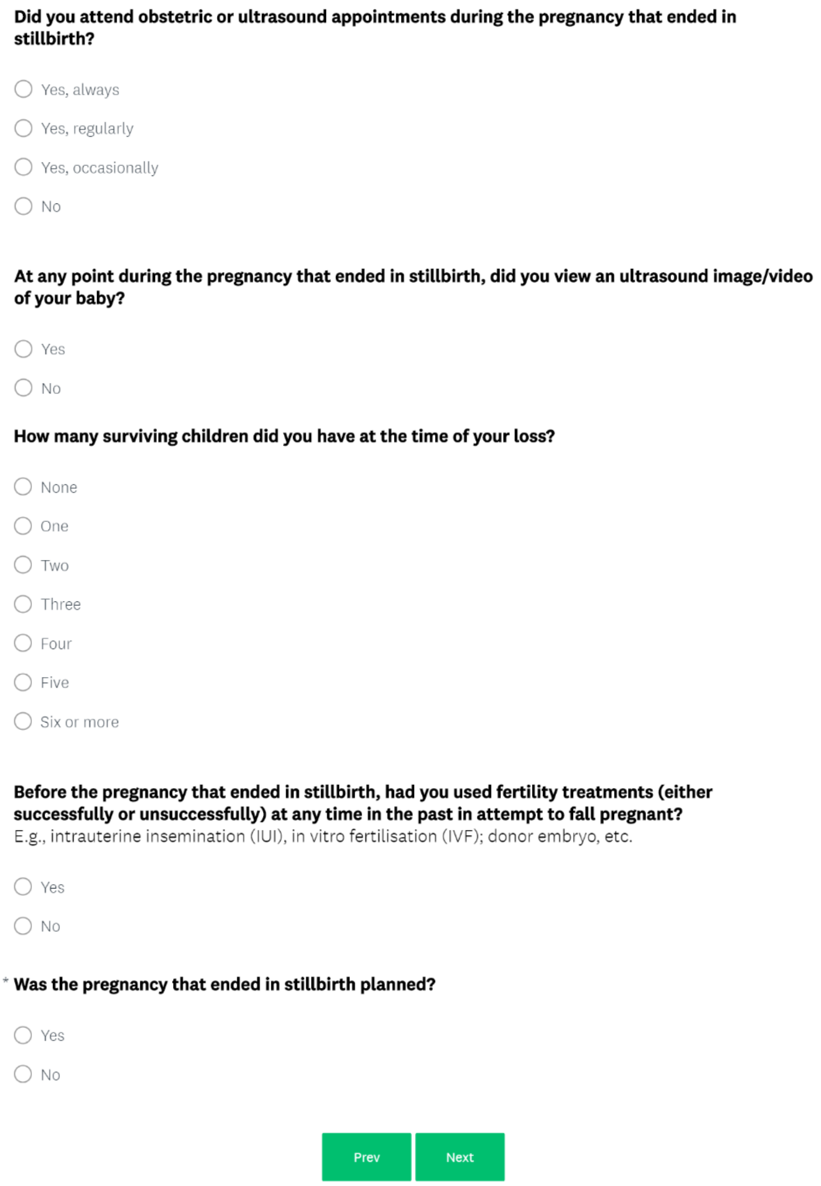
How old were you (in years) at the time of your loss?

What was your marital status at the time of loss?

- ○ In a relationship
- ○ Married
- ○ Divorced
- ○ Never married/single
- ○ Separated
- ○ Other (please specify)

In general, how satisfied were you in your relationship with your partner around the time of your loss?

Not at all	A little bit	Moderately	Quite a bit	Very much	Not applicable
○	○	○	○	○	○



Did you attend obstetric or ultrasound appointments during the pregnancy that ended in stillbirth?

○ Yes, always
○ Yes, regularly
○ Yes, occasionally
○ No

At any point during the pregnancy that ended in stillbirth, did you view an ultrasound image/video of your baby?

○ Yes
○ No

How many surviving children did you have at the time of your loss?

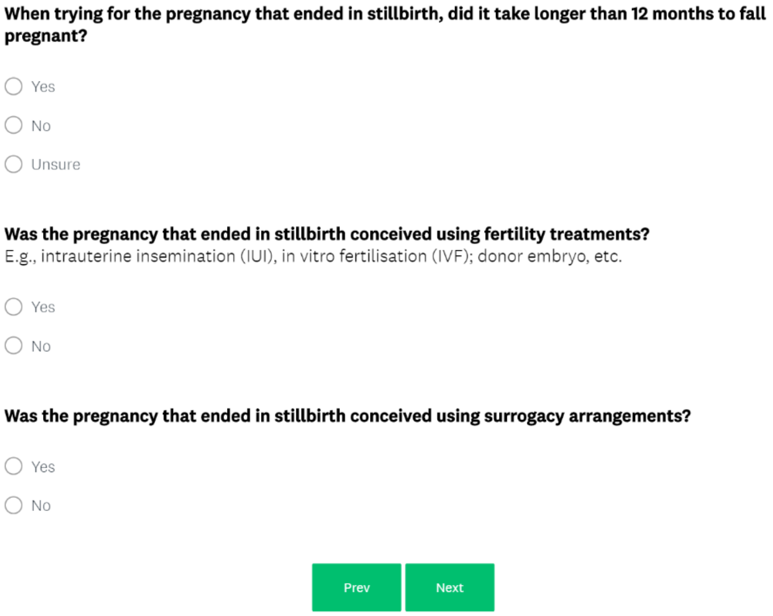
○ None
○ One
○ Two
○ Three
○ Four
○ Five
○ Six or more

Before the pregnancy that ended in stillbirth, had you used fertility treatments (either successfully or unsuccessfully) at any time in the past in attempt to fall pregnant?
E.g., intrauterine insemination (IUI), in vitro fertilisation (IVF); donor embryo, etc.

○ Yes
○ No

* **Was the pregnancy that ended in stillbirth planned?**

○ Yes
○ No



When trying for the pregnancy that ended in stillbirth, did it take longer than 12 months to fall pregnant?

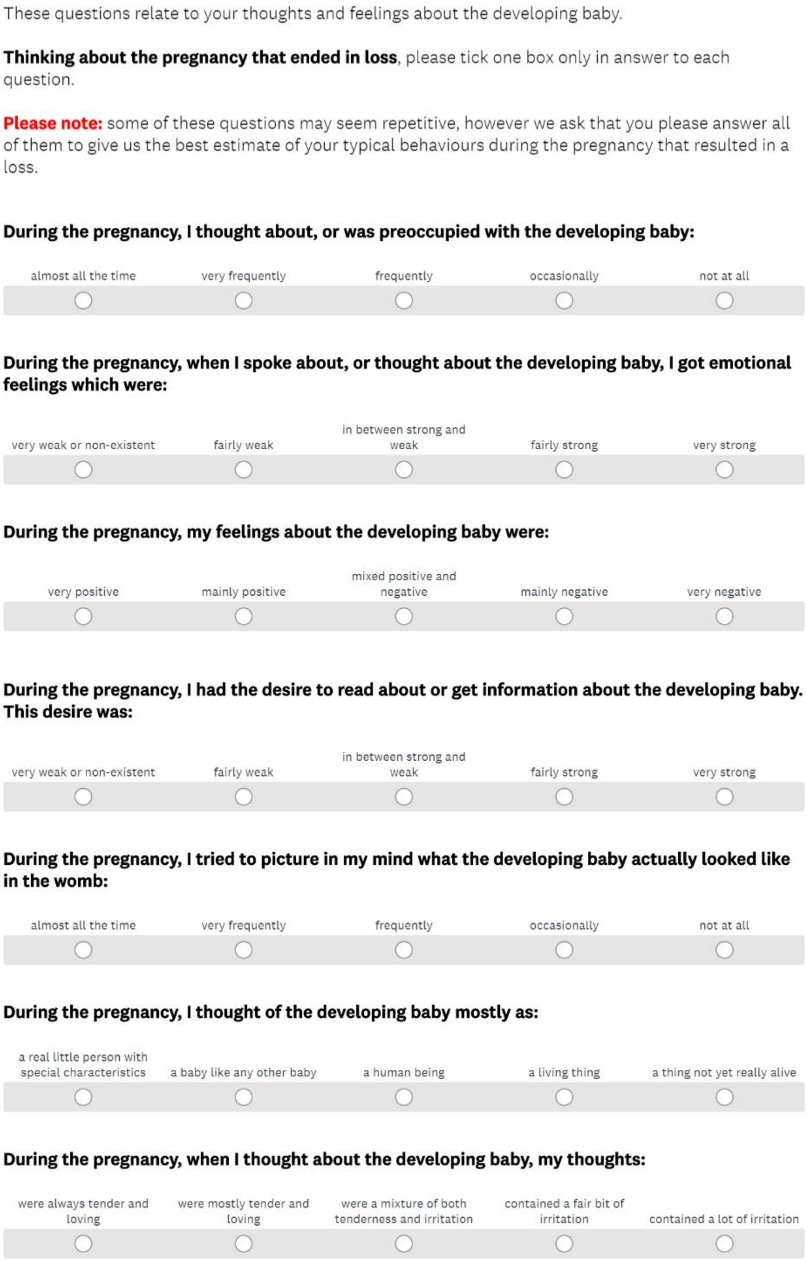
○ Yes
○ No
○ Unsure

Was the pregnancy that ended in stillbirth conceived using fertility treatments?
E.g., intrauterine insemination (IUI), in vitro fertilisation (IVF); donor embryo, etc.

○ Yes
○ No

Was the pregnancy that ended in stillbirth conceived using surrogacy arrangements?

○ Yes
○ No



These questions relate to your thoughts and feelings about the developing baby.

Thinking about the pregnancy that ended in loss, please tick one box only in answer to each question.

Please note: some of these questions may seem repetitive, however we ask that you please answer all of them to give us the best estimate of your typical behaviours during the pregnancy that resulted in a loss.

During the pregnancy, I thought about, or was preoccupied with the developing baby:

almost all the time	very frequently	frequently	occasionally	not at all
○	○	○	○	○

During the pregnancy, when I spoke about, or thought about the developing baby, I got emotional feelings which were:

very weak or non-existent	fairly weak	in between strong and weak	fairly strong	very strong
○	○	○	○	○

During the pregnancy, my feelings about the developing baby were:

very positive	mainly positive	mixed positive and negative	mainly negative	very negative
○	○	○	○	○

During the pregnancy, I had the desire to read about or get information about the developing baby. This desire was:

very weak or non-existent	fairly weak	in between strong and weak	fairly strong	very strong
○	○	○	○	○

During the pregnancy, I tried to picture in my mind what the developing baby actually looked like in the womb:

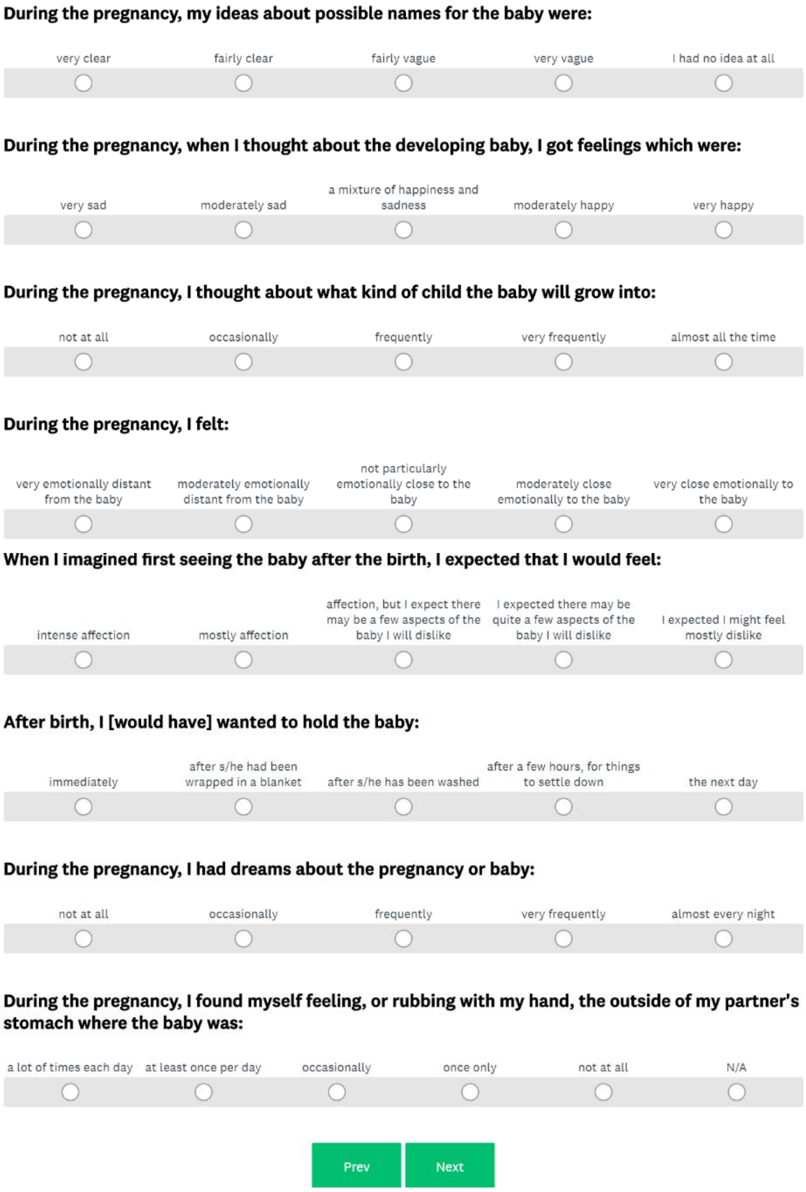
almost all the time	very frequently	frequently	occasionally	not at all
○	○	○	○	○

During the pregnancy, I thought of the developing baby mostly as:

a real little person with special characteristics	a baby like any other baby	a human being	a living thing	a thing not yet really alive
○	○	○	○	○

During the pregnancy, when I thought about the developing baby, my thoughts:

were always tender and loving	were mostly tender and loving	were a mixture of both tenderness and irritation	contained a fair bit of irritation	contained a lot of irritation
○	○	○	○	○



During the pregnancy, my ideas about possible names for the baby were:

very clear	fairly clear	fairly vague	very vague	I had no idea at all
○	○	○	○	○

During the pregnancy, when I thought about the developing baby, I got feelings which were:

very sad	moderately sad	a mixture of happiness and sadness	moderately happy	very happy
○	○	○	○	○

During the pregnancy, I thought about what kind of child the baby will grow into:

not at all	occasionally	frequently	very frequently	almost all the time
○	○	○	○	○

During the pregnancy, I felt:

very emotionally distant from the baby	moderately emotionally distant from the baby	not particularly emotionally close to the baby	moderately close emotionally to the baby	very close emotionally to the baby
○	○	○	○	○

When I imagined first seeing the baby after the birth, I expected that I would feel:

intense affection	mostly affection	affection, but I expect there may be a few aspects of the baby I will dislike	I expected there may be quite a few aspects of the baby I will dislike	I expected I might feel mostly dislike
○	○	○	○	○

After birth, I [would have] wanted to hold the baby:

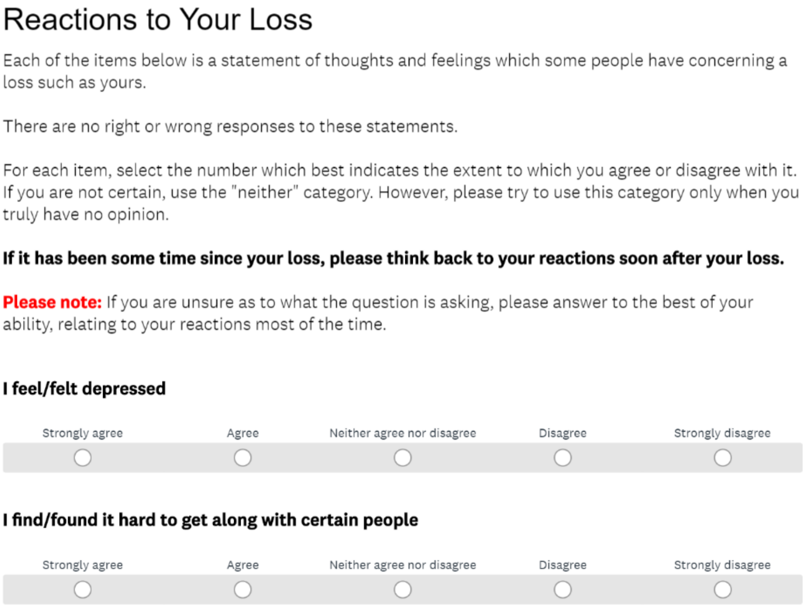
immediately	after s/he had been wrapped in a blanket	after s/he has been washed	after a few hours, for things to settle down	the next day
○	○	○	○	○

During the pregnancy, I had dreams about the pregnancy or baby:

not at all	occasionally	frequently	very frequently	almost every night
○	○	○	○	○

During the pregnancy, I found myself feeling, or rubbing with my hand, the outside of my partner's stomach where the baby was:

a lot of times each day	at least once per day	occasionally	once only	not at all	N/A
○	○	○	○	○	○



Reactions to Your Loss

Each of the items below is a statement of thoughts and feelings which some people have concerning a loss such as yours.

There are no right or wrong responses to these statements.

For each item, select the number which best indicates the extent to which you agree or disagree with it. If you are not certain, use the "neither" category. However, please try to use this category only when you truly have no opinion.

If it has been some time since your loss, please think back to your reactions soon after your loss.

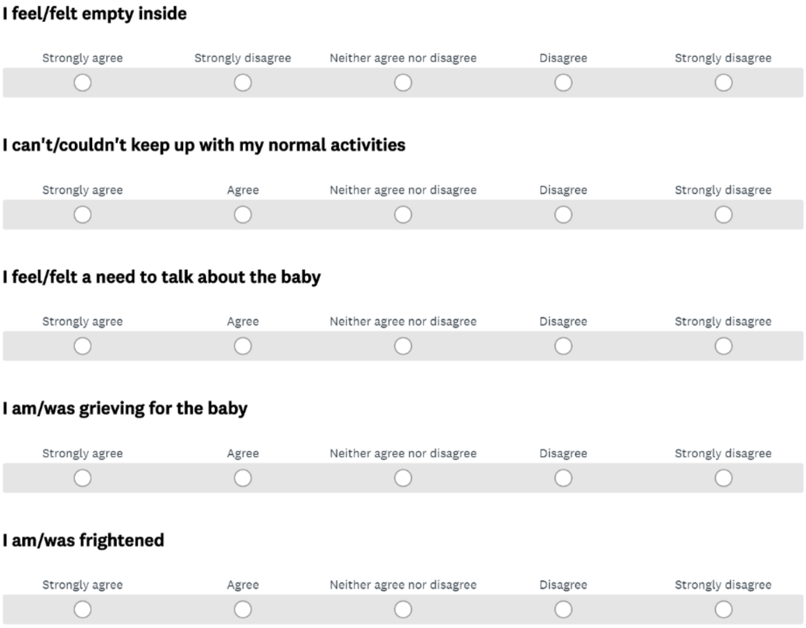
Please note: If you are unsure as to what the question is asking, please answer to the best of your ability, relating to your reactions most of the time.

I feel/felt depressed

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I find/found it hard to get along with certain people

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○



I feel/felt empty inside

Strongly agree	Strongly disagree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I can't/couldn't keep up with my normal activities

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I feel/felt a need to talk about the baby

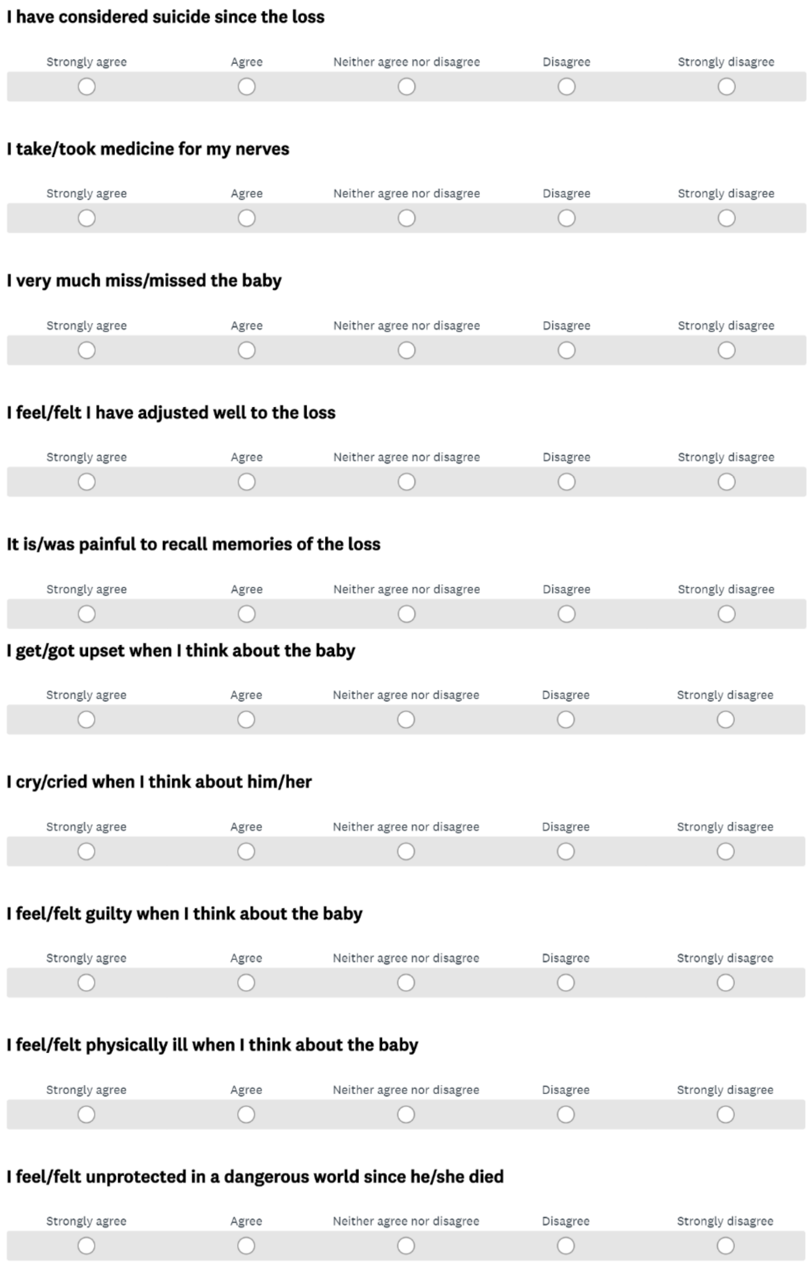
Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I am/was grieving for the baby

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I am/was frightened

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○



I have considered suicide since the loss

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I take/took medicine for my nerves

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I very much miss/missed the baby

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I feel/felt I have adjusted well to the loss

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

It is/was painful to recall memories of the loss

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I get/got upset when I think about the baby

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I cry/cried when I think about him/her

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I feel/felt guilty when I think about the baby

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I feel/felt physically ill when I think about the baby

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I feel/felt unprotected in a dangerous world since he/she died

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I try/tried to laugh, but nothing seems/seemed funny anymore

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

Time passes/passed slowly since the baby died

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

The best part of me died with the baby

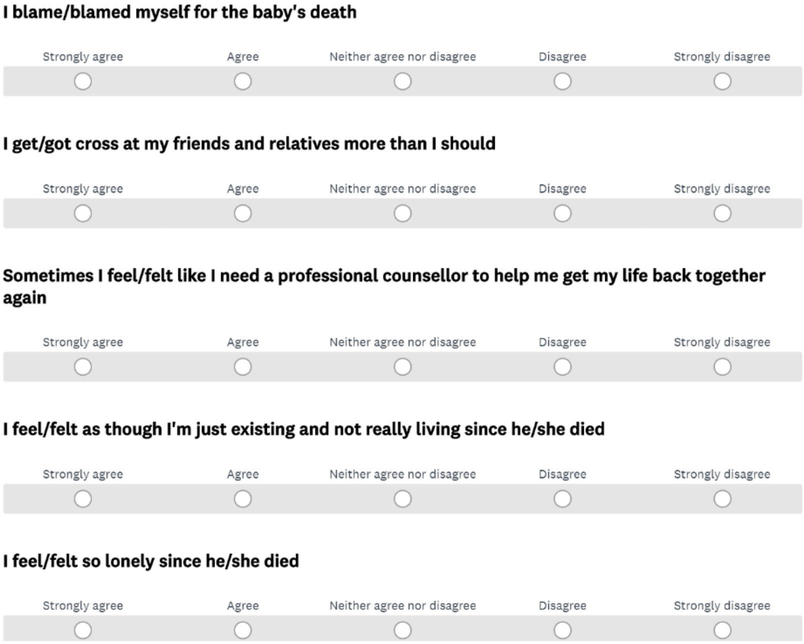
Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I have let people down since the baby died

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I feel/felt worthless since he/she died

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○



I blame/blamed myself for the baby's death

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I get/got cross at my friends and relatives more than I should

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

Sometimes I feel/felt like I need a professional counsellor to help me get my life back together again

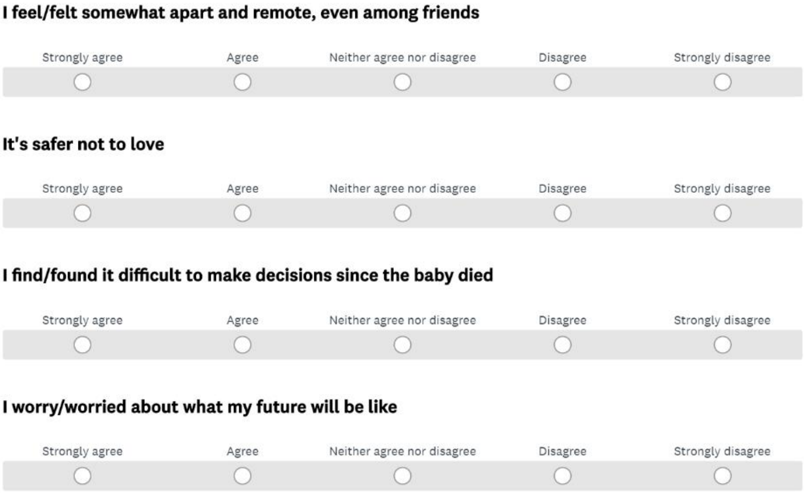
Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I feel/felt as though I'm just existing and not really living since he/she died

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I feel/felt so lonely since he/she died

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○



I feel/felt somewhat apart and remote, even among friends

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

It's safer not to love

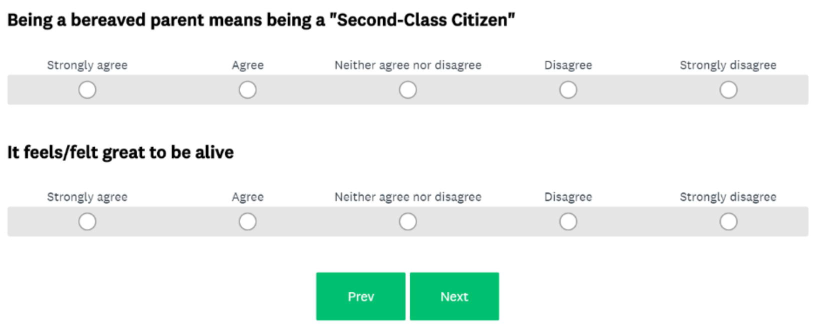
Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I find/found it difficult to make decisions since the baby died

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

I worry/worried about what my future will be like

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

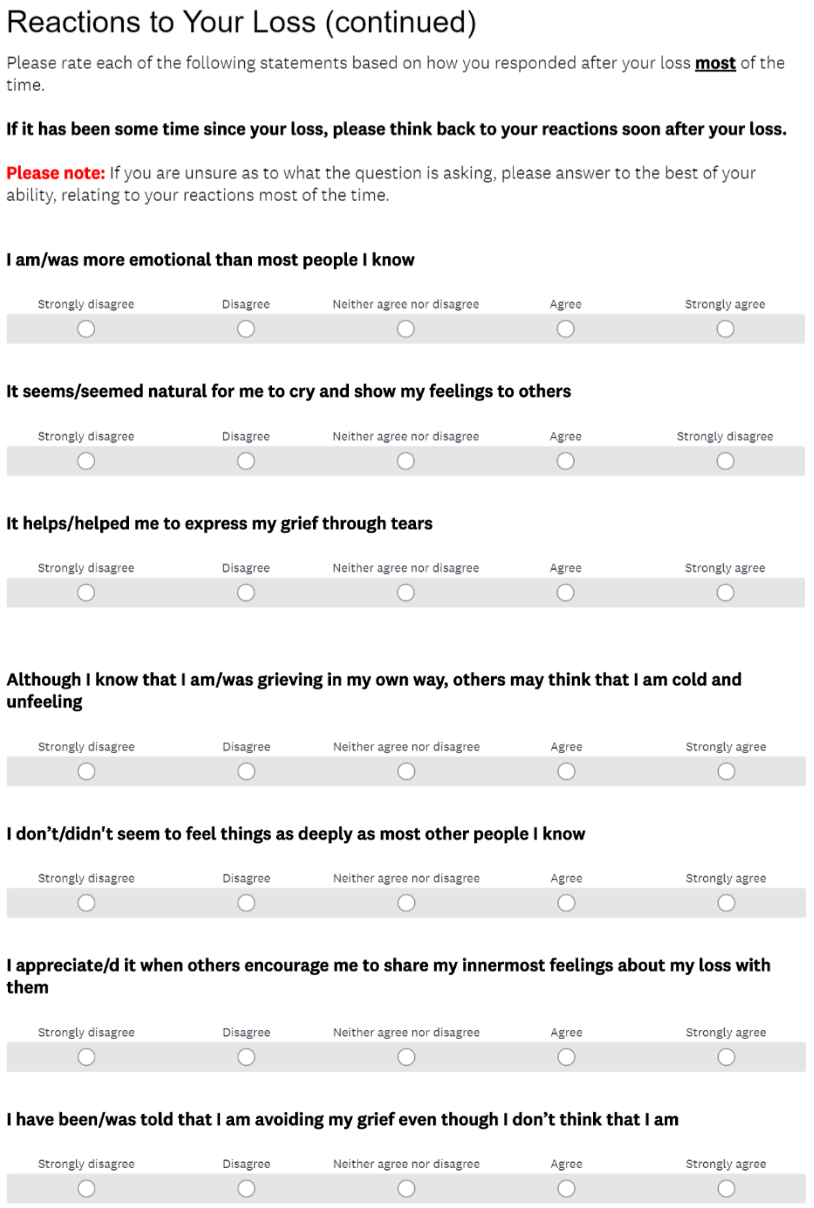


Being a bereaved parent means being a "Second-Class Citizen"

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○

It feels/felt great to be alive

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
○	○	○	○	○



Reactions to Your Loss (continued)

Please rate each of the following statements based on how you responded after your loss **most** of the time.

If it has been some time since your loss, please think back to your reactions soon after your loss.

Please note: If you are unsure as to what the question is asking, please answer to the best of your ability, relating to your reactions most of the time.

I am/was more emotional than most people I know

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○

It seems/seemed natural for me to cry and show my feelings to others

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly disagree
○	○	○	○	○

It helps/helped me to express my grief through tears

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○

Although I know that I am/was grieving in my own way, others may think that I am cold and unfeeling

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○

I don't/didn't seem to feel things as deeply as most other people I know

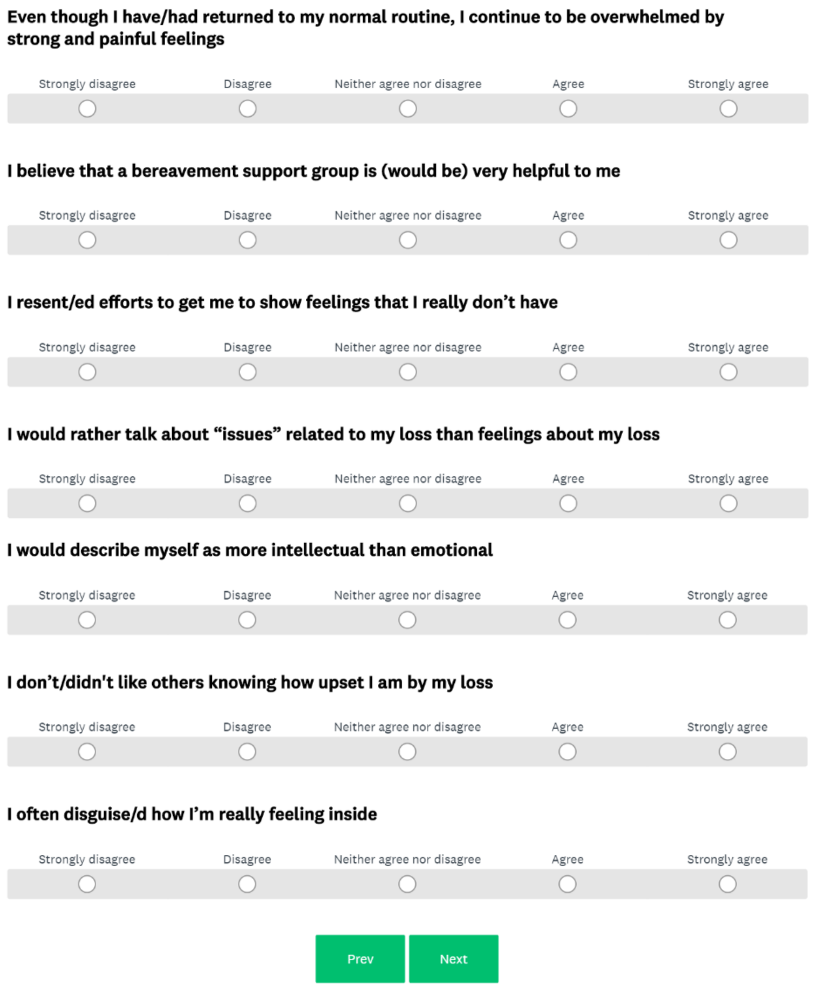
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○

I appreciate/d it when others encourage me to share my innermost feelings about my loss with them

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○

I have been/was told that I am avoiding my grief even though I don't think that I am

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○



Even though I have/had returned to my normal routine, I continue to be overwhelmed by strong and painful feelings

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○

I believe that a bereavement support group is (would be) very helpful to me

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○

I resent/ed efforts to get me to show feelings that I really don't have

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○

I would rather talk about "issues" related to my loss than feelings about my loss

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○

I would describe myself as more intellectual than emotional

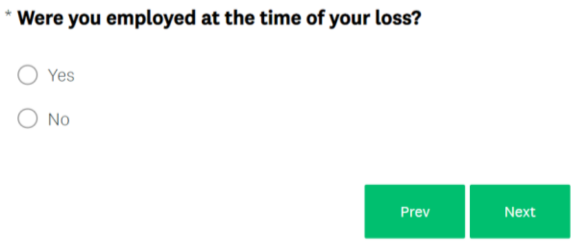
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○

I don't/didn't like others knowing how upset I am by my loss

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○

I often disguise/d how I'm really feeling inside

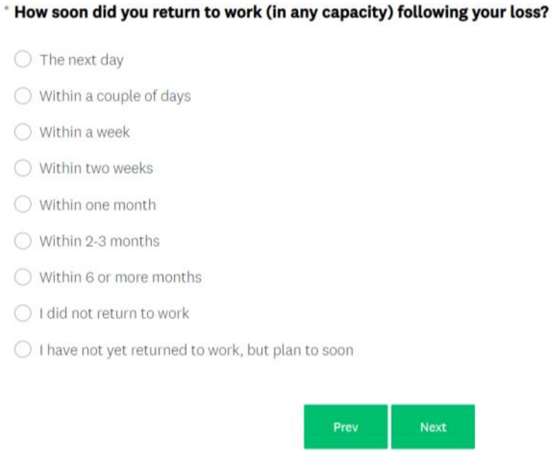
Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○



* **Were you employed at the time of your loss?**

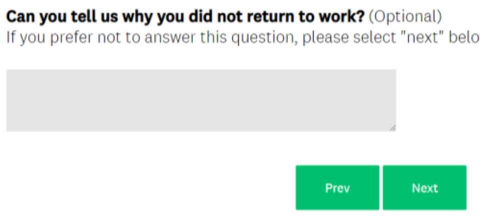
○ Yes

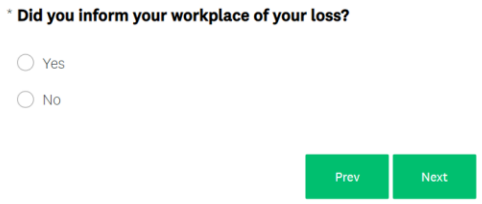
○ No



* **How soon did you return to work (in any capacity) following your loss?**

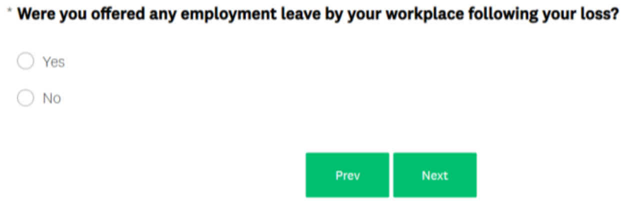
○ The next day
○ Within a couple of days
○ Within a week
○ Within two weeks
○ Within one month
○ Within 2-3 months
○ Within 6 or more months
○ I did not return to work
○ I have not yet returned to work, but plan to soon


Can you tell us why you did not return to work? (Optional)
If you prefer not to answer this question, please select "next" below.


* **Did you inform your workplace of your loss?**

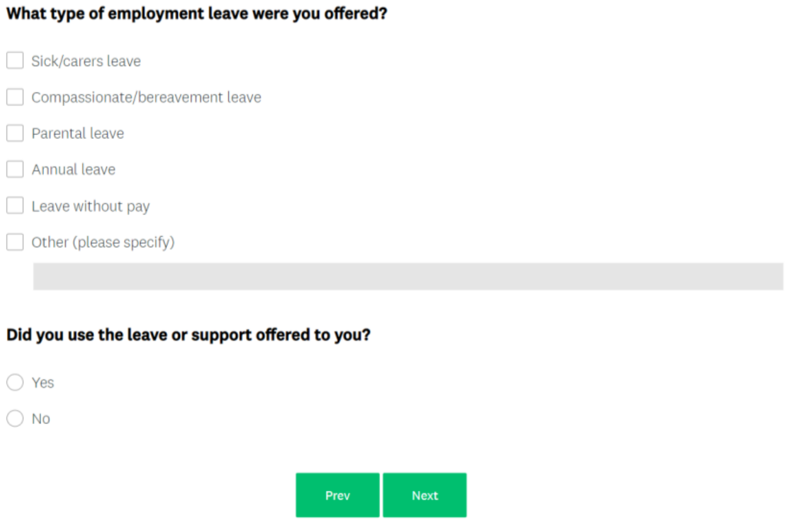
○ Yes

○ No


* **Were you offered any employment leave by your workplace following your loss?**

○ Yes

○ No


What type of employment leave were you offered?

☐ Sick/carers leave

☐ Compassionate/bereavement leave

☐ Parental leave

☐ Annual leave

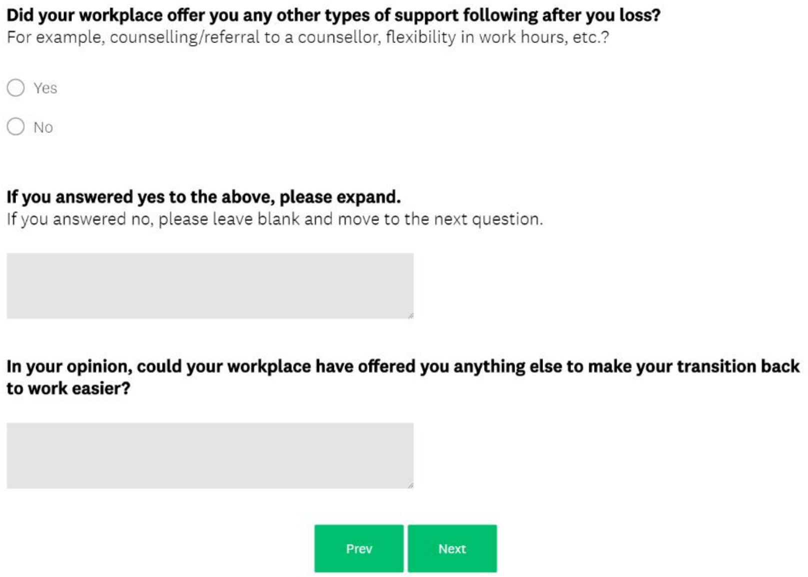
☐ Leave without pay

☐ Other (please specify)

Did you use the leave or support offered to you?

○ Yes

○ No



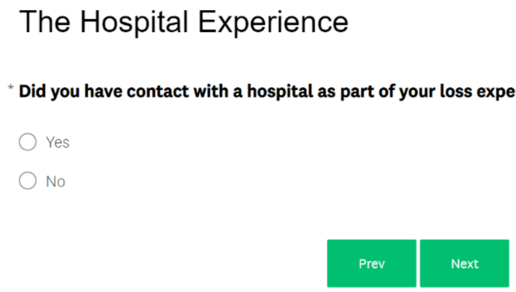
Did your workplace offer you any other types of support following after you loss?
For example, counselling/referral to a counsellor, flexibility in work hours, etc.?

○ Yes

○ No

If you answered yes to the above, please expand.
If you answered no, please leave blank and move to the next question.

In your opinion, could your workplace have offered you anything else to make your transition back to work easier?

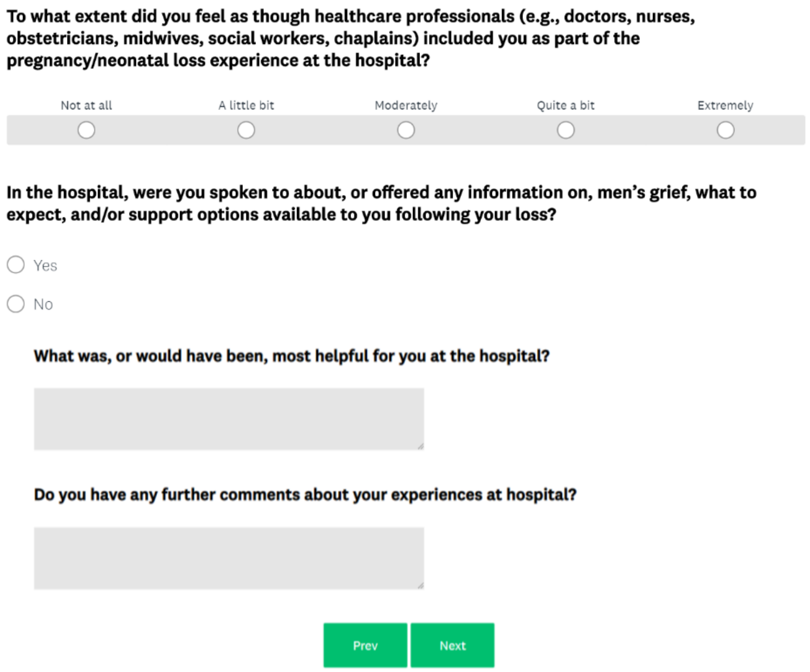


The Hospital Experience

* **Did you have contact with a hospital as part of your loss experience?**

○ Yes

○ No



To what extent did you feel as though healthcare professionals (e.g., doctors, nurses, obstetricians, midwives, social workers, chaplains) included you as part of the pregnancy/neonatal loss experience at the hospital?

Not at all	A little bit	Moderately	Quite a bit	Extremely
○	○	○	○	○

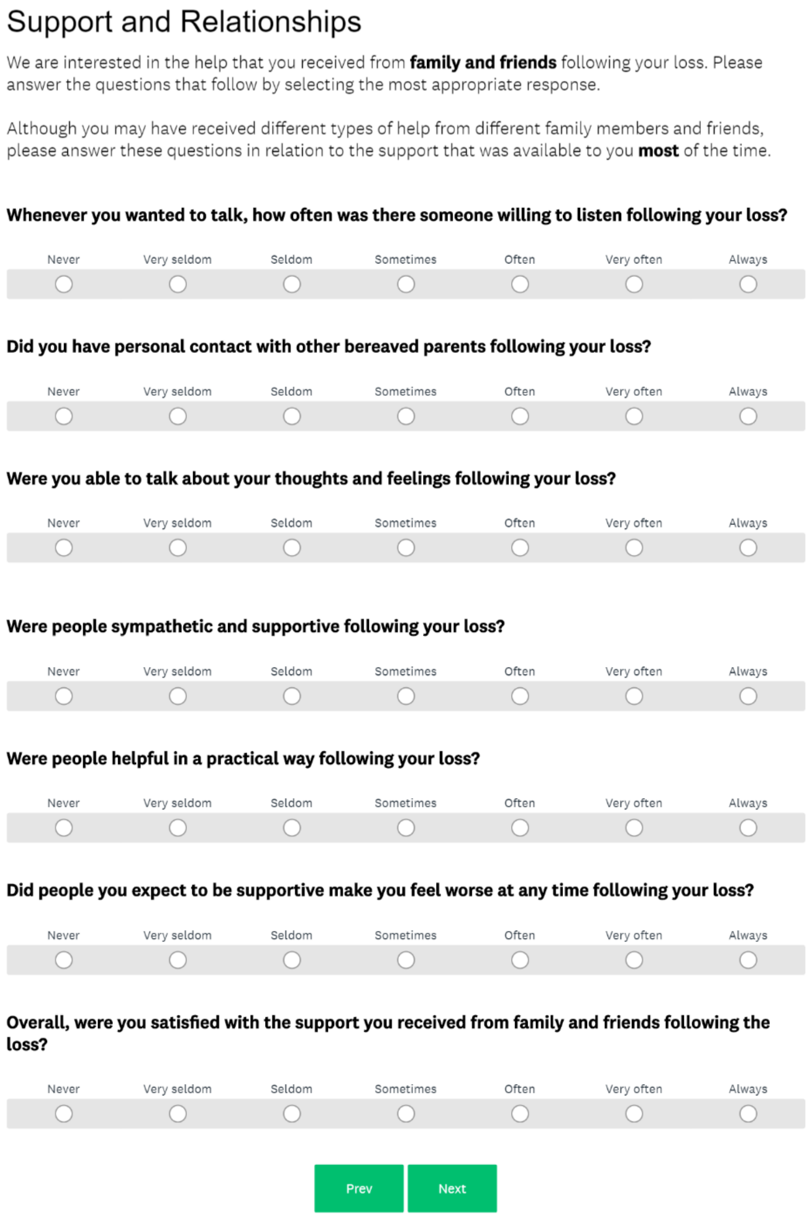
In the hospital, were you spoken to about, or offered any information on, men's grief, what to expect, and/or support options available to you following your loss?

○ Yes

○ No

What was, or would have been, most helpful for you at the hospital?

Do you have any further comments about your experiences at hospital?



Support and Relationships

We are interested in the help that you received from **family and friends** following your loss. Please answer the questions that follow by selecting the most appropriate response.

Although you may have received different types of help from different family members and friends, please answer these questions in relation to the support that was available to you **most** of the time.

Whenever you wanted to talk, how often was there someone willing to listen following your loss?

Never	Very seldom	Seldom	Sometimes	Often	Very often	Always
○	○	○	○	○	○	○

Did you have personal contact with other bereaved parents following your loss?

Never	Very seldom	Seldom	Sometimes	Often	Very often	Always
○	○	○	○	○	○	○

Were you able to talk about your thoughts and feelings following your loss?

Never	Very seldom	Seldom	Sometimes	Often	Very often	Always
○	○	○	○	○	○	○

Were people sympathetic and supportive following your loss?

Never	Very seldom	Seldom	Sometimes	Often	Very often	Always
○	○	○	○	○	○	○

Were people helpful in a practical way following your loss?

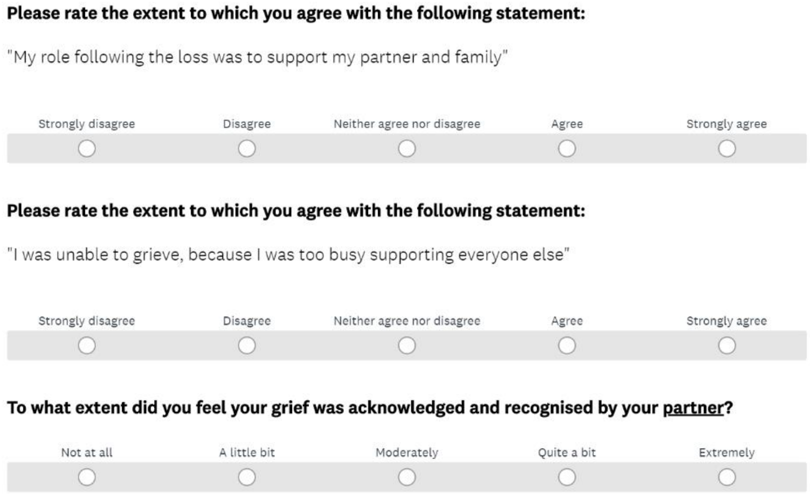
Never	Very seldom	Seldom	Sometimes	Often	Very often	Always
○	○	○	○	○	○	○

Did people you expect to be supportive make you feel worse at any time following your loss?

Never	Very seldom	Seldom	Sometimes	Often	Very often	Always
○	○	○	○	○	○	○

Overall, were you satisfied with the support you received from family and friends following the loss?

Never	Very seldom	Seldom	Sometimes	Often	Very often	Always
○	○	○	○	○	○	○



Please rate the extent to which you agree with the following statement:

"My role following the loss was to support my partner and family"

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○

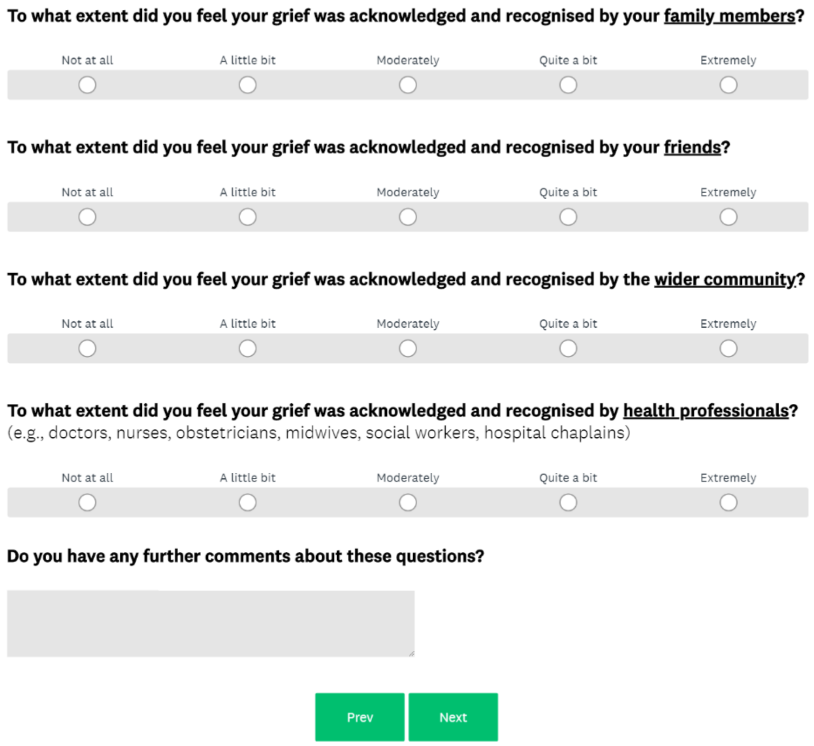
Please rate the extent to which you agree with the following statement:

"I was unable to grieve, because I was too busy supporting everyone else"

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○

To what extent did you feel your grief was acknowledged and recognised by your partner?

Not at all	A little bit	Moderately	Quite a bit	Extremely
○	○	○	○	○



To what extent did you feel your grief was acknowledged and recognised by your family members?

Not at all	A little bit	Moderately	Quite a bit	Extremely
○	○	○	○	○

To what extent did you feel your grief was acknowledged and recognised by your friends?

Not at all	A little bit	Moderately	Quite a bit	Extremely
○	○	○	○	○

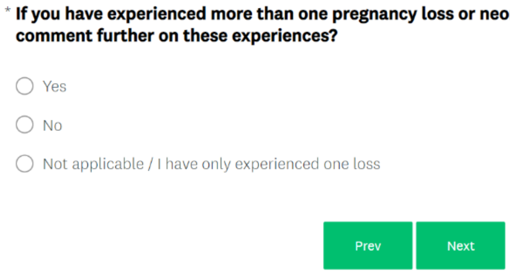
To what extent did you feel your grief was acknowledged and recognised by the wider community?

Not at all	A little bit	Moderately	Quite a bit	Extremely
○	○	○	○	○

To what extent did you feel your grief was acknowledged and recognised by health professionals?
(e.g., doctors, nurses, obstetricians, midwives, social workers, hospital chaplains)

Not at all	A little bit	Moderately	Quite a bit	Extremely
○	○	○	○	○

Do you have any further comments about these questions?

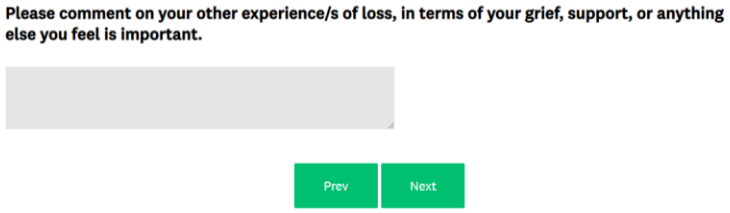


* **If you have experienced more than one pregnancy loss or neonatal loss, would you like to comment further on these experiences?**

○ Yes

○ No

○ Not applicable / I have only experienced one loss



Please comment on your other experience/s of loss, in terms of your grief, support, or anything else you feel is important.

Seeking Help

Thinking about your own actions, feelings and beliefs, please indicate how much you personally agree or disagree with each statement by the most appropriate response. There are no correct or wrong answers to the items. You should give the responses that most accurately describe your personal actions, feelings and beliefs. It is best if you respond with your first impression when answering.

Please note: the following questions do not relate directly to your experience of loss. Instead, please answer them in relation to your general actions and beliefs.

I never ask for help

Strongly disagree	Disagree	Agree	Strongly agree
○	○	○	○

It bothers me when I have to ask for help

Strongly disagree	Disagree	Agree	Strongly agree
○	○	○	○

I ask for help when I need it

Strongly disagree	Disagree	Agree	Strongly agree
○	○	○	○

I am not ashamed to ask for help

Strongly disagree	Disagree	Agree	Strongly agree
○	○	○	○

I hate asking for help

Strongly disagree	Disagree	Agree	Strongly agree
○	○	○	○

It's important for a man to take risks, even if he might get hurt

Strongly disagree	Disagree	More or less disagree	Undecided	More or less agree	Agree	Strongly agree
○	○	○	○	○	○	○

When the going gets tough, men should get tough

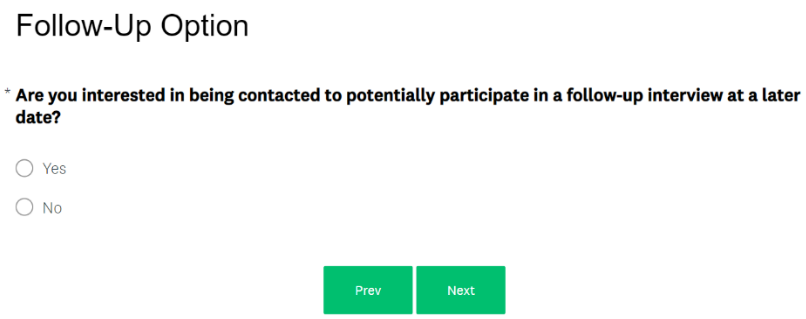
Strongly disagree	Disagree	More or less disagree	Undecided	More or less agree	Agree	Strongly agree
○	○	○	○	○	○	○

I think a young man should try to be physically tough, even if he's not big

Strongly disagree	Disagree	More or less disagree	Undecided	More or less agree	Agree	Strongly agree
○	○	○	○	○	○	○

Is there anything else you would like to add/say in regards to your experience following pregnancy/neonatal loss that you feel this survey has not covered? (optional)

Do you have any feedback on this survey? (optional)

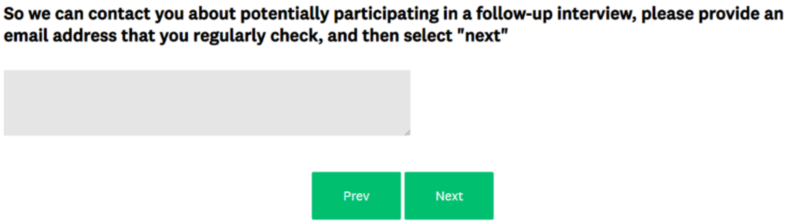


Follow-Up Option

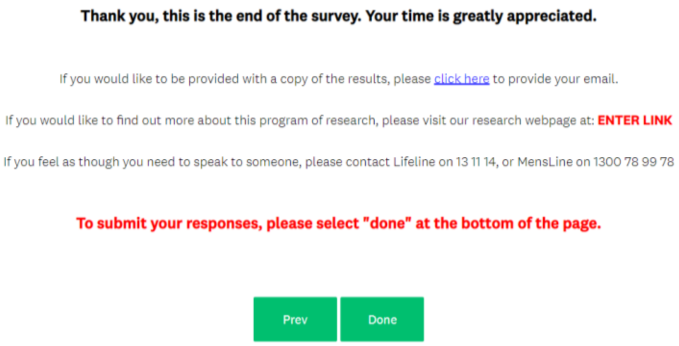
* **Are you interested in being contacted to potentially participate in a follow-up interview at a later date?**

○ Yes

○ No



So we can contact you about potentially participating in a follow-up interview, please provide an email address that you regularly check, and then select "next"



Thank you, this is the end of the survey. Your time is greatly appreciated.

If you would like to be provided with a copy of the results, please click here to provide your email.

If you would like to find out more about this program of research, please visit our research webpage at: **ENTER LINK**

If you feel as though you need to speak to someone, please contact Lifeline on 13 11 14, or MensLine on 1300 78 99 78

To submit your responses, please select "done" at the bottom of the page.

THE UNIVERSITY
of ADELAIDE

APPENDIX 13. Industry report

Research report and summary: Australian men’s experiences of grief and support after pregnancy loss and neonatal death

Background

Pregnancy loss and neonatal death are potentially devastating outcomes of pregnancy and birth. Sadly in Australia, one in four families will experience a miscarriage, six babies every day are born still, and up to 1000 babies die in the Neonatal Intensive Care Unit each year.

The psychological and emotional impact of these losses for parents and families is profound. However, historically, **there has been limited research into the impact of pregnancy loss and neonatal death on men/fathers**, leaving a significant gap in knowledge concerning how to best support fathers in the event of a loss.

This gap is important, given potential gendered differences concerning grief styles, help-seeking and service access. In general, grief styles range from intuitive (emotion-focused) to instrumental (activity-focused). Early research found that men typically display more activity-focused styles of grief. However, most interventions for grief have centred on emotion-focused styles (e.g., counselling, support groups). While many men do seek emotional support for mental health concerns, research suggests that services can fail to fully engage men, and drop-out rates among men are generally quite high.

This research therefore sought to understand how men grieve after pregnancy loss and neonatal death, to inform future bereavement care and support services.

The research program

1

Systematic review

2

Nationwide survey

3

Qualitative studies

This program of research involved three phases. First, we conducted a **systematic review**, which involved collecting and summarising the findings of all previous published studies on men’s experiences of grief after pregnancy loss and neonatal death.

Second, we conducted a **nationwide online survey** to ask Aussie men about their experiences of grief and support after a pregnancy loss or neonatal death.

Finally, we conducted individual, **in-depth interviews** with men who had experienced a medical termination of pregnancy for life-limiting foetal anomaly (TOPFA), as this loss types had been particularly under-explored in previous research.

Study One: Key findings

Systematic review

Following a rigorous search of four academic databases, we identified 46 articles which had been published between 1998 and 2018 on men's grief after a pregnancy loss and/or neonatal death. We used these studies to explore two research questions:

How do men experience grief?

Men's grief experiences were highly varied. Studies using validated measures of grief suggested that on average, men typically did not score in a 'high' grief range, and had lower grief scores than women. However, some studies noted that current grief measures may not fully capture men's grief, particularly if they grieve in a more activity-focused way, rather than an emotion-focused way.

In interview studies, some men reported that losing their baby was devastating and led to intense grief (regardless of pregnancy length). However, others felt their partners experienced worse grief than them. Regardless of the grief reaction, men seemed to face unique tasks and challenges that could complicate or delay the timing of their grief. These included feelings of having to support their partner and family, helplessness or powerlessness (especially during labour/birth), and responsibilities like caring for other children, completing paperwork, and informing other people of the loss. Overall, many men grieved in an activity-focused way, and desires to 'keep busy' or 'move forward' were common.

What factors impact grief for men?

Sixteen studies looked at factors that may be associated to worsened or improved grief responses in men. We grouped these factors into four domains or levels:

At the ***individual level,*** men who had a strong attachment to their baby, or had experienced multiple pregnancy losses, generally had more intense grief responses.

At the ***interpersonal level***, men who had a good relationship with their partner and could talk about their loss, or received support and acknowledgement from family, friends and healthcare professionals, had less intense grief. Many men also felt their primary role was to support their partner. While this role was helpful to some, others suppressed their own grief which was not helpful in the long-term.

At the ***community level***, stigma surrounding pregnancy loss had the potential to lead to increased distress and feelings of isolation. Many men also felt a need to "be strong" or hide their grief from others, due to cultural attitudes surrounding male role expectations.

At the ***system/policy level***, many men felt 'out of place' in hospitals, and that pregnancy loss support services were generally geared more toward women, and/or emotion-focused grief styles. Men also typically returned to work early following their loss, and felt there were less opportunities to take paternity of bereavement leave compared to women.

Study Two: Key findings

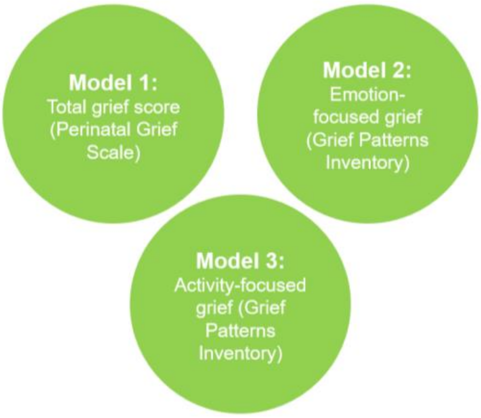
Nationwide survey

To further explore the factors related to grief identified in Study one, we developed an online survey to ask Aussie dads about their experiences of grief and support after pregnancy loss and neonatal death.

The survey included a mix of measures to assess the intensity of men's grief, their grief style, and the factors that might impact grief. These included men's attachment to the baby, how support received from family and friends, and experiences in the hospital and returning to work. Over 270 men from around Australia took part. To analyse the data, we used a combination of summary statistics and a statistical process called 'generalised linear modelling'.

General grief findings

Regardless of loss type or length of pregnancy, men's average grief scores were above the cut-off for what is generally considered to be a 'high' level of grief. Highest grief scores were also found for 'Active Grief', which indicated that men spent a lot of time experiencing feelings of sadness and missing the baby. In contrast, lowest grief scores were on the 'Despair' subscale, which meant that men spent less time experiencing feelings of worthlessness or hopelessness after the death of their baby. In general, men also displayed slightly higher rates of emotion-focused grief, compared to activity-focused grief.



Factors relating to grief

In ***model 1***, looking at a general measure of men's grief, *higher* grief scores were associated with:
- More 'time in attachment' with the baby
- A history of previous pregnancy losses
- 'Supporter role' interfering with grief
- Acknowledgement of grief from friends

In contrast, *lower* grief scores were associated with:
- High levels of social support
- Acknowledgement of grief from family

In ***model 2***, looking at emotion-focused grief styles, *lower* grief scores were associated with more acknowledgement of men's grief from healthcare professionals.

Finally, in ***model 3,*** looking at activity-focused grief styles, *higher* grief scores were associated with:
- More 'time in attachment' with the baby
- 'Supporter role' interfering with grief
- High levels of 'self-reliance'
- Not being offered employment leave

In contrast, *lower* activity-focused grief scores were associated with:
- High 'quality of attachment' with the baby
- Acknowledgement of grief from partner

What do these findings mean?

These findings confirmed that men can and do experience significant grief regardless of how early or late their loss occurs. The findings also suggest that strategies to best support men may vary depending on their grief style. For example, emotion-focused grievers may benefit from higher levels of hospital and healthcare support, whereas activity-focused grievers may benefit from higher levels of social support and acknowledgement of their grief from their partner.

Study Three: Key findings

Workplace experiences

In the nationwide survey, we included some questions to ask men about their experiences of returning to work after pregnancy loss and neonatal death. To analyse the data, we used a combination of summary statistics and 'Content Analysis', a process of identifying patterns or themes from across men's responses to open-ended survey questions.

General findings

Most men (91%) informed their workplace of their loss, and of these, 74% were offered some form of leave by their employer. Men who had a miscarriage were the least likely to be offered any employment leave, and returned to work sooner than men who had a stillbirth or neonatal death. 35% of men were also offered additional support from their employer, such as referral to an Employee Assistance Program (EAP), counselling, or short-term flexibility in work hours/location.

Theme 1: Emotional toll of returning to work

Across loss types, returning to work took an emotional toll on men. Seventeen men reported feeling as though they were not their 'normal self' or emotionally burnt-out, which led to decreased productivity and difficulty coping with their usual tasks/workload.

> "I feel I was forced back into my normal duties way too soon … because of that I am struggling more to cope now."

Theme 2: Need to be with and support partner

Men desired flexibility in work hours to 'be with' their partner after their loss. Men expressed gratitude for employers who "made allowances" for additional leave or ongoing flexibility, which was needed not only for the immediate aftermath of the loss, but also in the weeks/months following and in subsequent pregnancies.

Theme 3: Understanding and recognition

The level of support and understanding men received from their employers and co-workers impacted their grief and ability to return to work. Men expressed dissatisfaction when employers were 'not understanding or forgiving for time off', or made 'little effort' to ask them how they were coping.

> "…the support [my wife] received from her work colleagues was much more open. She could talk about her loss. I, on the other hand, was given the 'I understand', the 'sorry for your loss', a head nod, and a handshake … but not so much on how I was feeling"

In contrast, men expressed appreciation for empathetic employers who provided leave, flexible work, or reduced workload (where desired).

> "My workplace was extremely supportive, allowed me as much time as I needed before returning to work, and then tried their best to ensure my workload was not too overwhelming until I was ready to take on additional tasks."

Theme 4: Work/routine as a helpful distraction

Five men commented that they used work to provide routine or to distract themselves 'from the pain' of the loss. 'Keeping busy' was described as a useful coping mechanism. For these men, offers to take workplace leave were appreciated, however they did not feel these were necessary to accept.

> "It was my choice to get back to work the day after … It has been a great way for me to keep busy but also work through [the loss] mentally while working."

Theme 5: Pressure to return

Despite being offered leave, five men noted financial pressure as the primary reason for an early return to work, resulting in 'burnout', 'breakdown', and reduced productivity.

Overall, while not all men wished to take extended (or any) paid leave following pregnancy loss or neonatal death, they believed leave should be available.

Study Four: Key findings

Interviews with men

In the nationwide survey, we noticed that men who had experienced a medical termination of pregnancy for a life-limiting foetal anomaly (TOPFA) described specific challenges regarding their grief and support. We interviewed 10 men who had experienced a TOPFA between 19 and 37.5 weeks of pregnancy to find out more about their experiences. We analysed the interview data using 'Thematic Analysis', a process of generating common themes from across the interviews. Overall, we generated three main themes, each with two sub-themes.

Theme 1: The most difficult choice

Challenges of decision-making
Men described the decision to terminate the pregnancy as "the hardest choice we've ever had to make". The diagnosis of their baby's life-limiting anomaly was a shock, which they all felt unprepared for. However, they all felt it was ultimately the 'right' or 'only' choice in the context of their babies' anomalies.

Stigma surrounding TOPFA
Compared to other pregnancy losses, many participants felt that TOPFA carried stigma or potential judgement from others due to varied opinions surrounding abortion. Stigma could contribute to feelings of guilt or self-blame, which made grief and seeking support difficult.

Theme 2: Neither patient, nor visitor

Where do men fit?
Men's immediate priority was their partner's wellbeing. However, because men weren't officially a 'patient' in the hospital, specific support for them was lacking.

> **"I just didn't give myself a second thought** … or how it was affecting me, because she's the one carrying the baby"

Dual need to support and be supported
It was challenging for many men to support their partner and manage their own grief. They needed direct guidance in the hospital about how to support their partner *and* tailored information about their own grief and options for support.

> "…they kept on saying to me … make sure you keep talking about this and don't sit there and feel as though you can't say anything … you're part of this process … **I didn't want to take away from [wife], but I think what they did really helped**."

Theme 3: Meet me where I am

Contact men directly
Due to focusing more on their partner's needs, men felt they were less likely to seek help for themselves. Men did not receive a telephone call or appointment with the hospital, but felt follow-up directly to men would be important to offer support and/or referrals.

> "There's this sort of, societal thing, this pressure to be the bloke, be the dad … I didn't want to go and look for help after losing [baby] … **I needed someone to check on me**"

Timing of follow-up was also important. Men felt their grief had potential to be 'delayed', once practical responsibilities were taken care of and their partner's distress was less acute.

Tailor support and services
Men coped with their grief in many different ways. Many used sport, activities, hobbies, or going back to work. However, they also needed to balance activities with openly expressing their grief.

Some found counselling helpful, while others felt online grief information and anonymous chats would be more appealing and helpful to them. While online supports for men have increased recently, many struggled to find information and needed guidance on available men-specific support options from healthcare professionals.

Implications and recommendations

It is clear from this research that men can and do experience significant grief after pregnancy loss and neonatal death, requiring tailored information and direct support. While participants in no way wanted to detract from their partner's needs, there was a need to **"consider dad [as] part of the treatment plan"**.

The next step from this research is to develop and trial different supportive interventions specifically for men.

For example, interventions for emotion-focused grievers could include providing formal brief assessment of men's grief and mental health, both in hospital and in the weeks/months following their loss, through follow-up calls directly to fathers.

For activity-focused grievers, interventions could include providing a follow-up telephone service specifically to men, providing direct referrals to the wide range of existing community-based supports where required. Couples-based psychology/counselling sessions could also be beneficial, to foster positive communication and mutual understanding of individual needs so that partners can better support one another.

The research also resulted in a number of recommendations for hospitals, community support, and workplace policies.

Overall recommendations from the program of research include:

- Provide all fathers/partners with information about grief and father-specific supports before leaving the hospital
- Provide direct follow-up contact to fathers/partners after their partner is discharged from hospital to conduct brief screening for mental health concerns and offer referrals to local community-based support services
- Ensure father-specific grief information and support resources developed by community support organisations are displayed and accessible in all hospitals and general practitioner/fertility clinics
- Include content on men's health, including mental health and grieving styles, in standard tertiary education courses for all health professional trainees
- Provide training to employers on responding to pregnancy loss and neonatal death among employees, including a focus on proactively offering men leave and additional support in the weeks/months following a loss

Links to publications

The four studies included in this research have been published as papers in academic peer-reviewed journals. The details of these papers are below.

Published papers:

- Obst, K., Due, C., Oxlad, M., & Middleton, P. (2021). Men's experiences and need for targeted support after termination of pregnancy for foetal anomaly: A qualitative study. *Journal of Clinical Nursing*, *30*(17-18). https://doi.org/10.1111/jocn.15786
- Obst, K., 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). https://doi.org/10.1186/s12884-020-03514-6
- Obst, K. L., Due, C., Oxlad, M., & Middleton, P. (2020). Australian men's experiences of leave provisions and workplace support following pregnancy loss or neonatal death. *Community, Work and Family*, 1-12. https://doi.org/10.1080/13668803.2020.1823319
- 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). https://doi.org/10.1186/s12884-019-2677-9

As well as publishing the research in academic journals, this research has been featured in a training program to educate employers on supporting parents after pregnancy loss and neonatal death, and several media articles/blog posts. Links to these are below.

Media articles and outreach activities:

- Findings contributed to the Baby Loss Project training program for workplaces
- Editorial for the Australian Fatherhood Research Bulletin Autumn Edition
- Article for Westpac Wire
- Blog post for the Healthy Newborn Network
- Blog post for the BMC Series
- Podcast interview for Two Shrinks Pod

Acknowledgements

The researchers would like to acknowledge that we are indebted to the below organisations for their invaluable support in conceptualising the research, distributing information, and/or assisting in the development of the online survey. The reach and success of this research would not have been possible without them.

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Our greatest and heartfelt thanks also goes to the men who participated in this research. Without your generous contributions and bravery in sharing your experiences, this work would not have been possible. We dedicate this research to you, and your beautiful babies whose little lives left stories worth telling.

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This report was prepared by Kate Obst. Kate completed her PhD on men's grief after pregnancy loss and neonatal death at the University of Adelaide in South Australia. She was supervised by A/Prof Clemence Due, Dr Melissa Oxlad and A/Prof Philippa Middleton. Kate was supported financially throughout her PhD by an Australian Government Research Training Program Scholarship, and a Westpac Scholars Trust Future Leaders Scholarship.

To cite this report, please use: Obst K., Due C., Oxlad M. & Middleton P. (2022). Research report and summary: Australian men's experiences of grief and support after pregnancy loss and neonatal death. University of Adelaide, Australia.

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