

Culturally & Linguistically Diverse Men's Experiences of Perinatal Death in Australia

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Science (Honours)

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Abstract

Globally, people from culturally and linguistically diverse (CALD) families are at a higher risk of experiencing perinatal death and associated adverse pregnancy outcomes. However, while there has been some research concerning men's experiences of grief generally, there has been no Australian research examining CALD men's grief following perinatal death, nor the support experiences and needs that this cohort of bereaved men have. This qualitative study examines interview accounts from a total of 16 participants, including six healthcare service providers and 10 CALD community members (four of whom were men who had personally experienced perinatal death). Thematic analysis identified four themes related to CALD men's grief expression (namely, that CALD men's grief is individual, a changing and enduring process, partner-centred, and expressed through stoic ideals of masculinity), as well as five themes related to support (namely that perinatal death, grief, and following care were found to be associated with stigma, and that CALD men's support is shaped by; religion and ritual, connection to community and family, inhibited self-advocacy, and woman-centred supports). These findings indicate that CALD men may benefit from targeted and culturally-safe mental health, financial, and emotional support following perinatal death. Future research could usefully focus on the culturally-shaped roles that CALD men have following a perinatal death, including in relation to supporting their families. The research points to the strong need for CALD men's specific needs to be included in the development of policy and practice surrounding perinatal death.

Keywords: Culturally and Linguistically Diverse; CALD men; grief; neonatal death; barriers to support; disenfranchised grief.

Declaration

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

September, 2021

Contribution Statement

Thomas Pearson lead the design of this study, including the (high-risk) human research ethics approval application, conducted all participant recruitment, collected all interview data, completed the data analysis, and authored this manuscript.

In addition to providing supervision, [Supervisor], provided participant incentives supported by finding from the Stillbirth Foundation, contributed to the study design with all subsequent revisions, and was the primary applicant for ethics approval.

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Introduction

1.1 Background

In Australia, many families face the potentially traumatic pregnancy outcome of perinatal death. In 2019 alone, 2,843 perinatal deaths, encompassing both stillbirth and neonatal death, occurred in Australia (Australian Institute of Health and Welfare, 2020). Perinatal death is a typically distressing life event that may lead to grief, relationship stress, and poor mental health outcomes (DeBackere et al, 2008; Heazell et al., 2016). While there is a substantial body of literature on women's experiences of perinatal death and resulting grief outcomes, limited research has investigated men's experiences of perinatal death. Obst et al.'s (2020b) analysis of existing international literature demonstrated a consistent lack of recognition of men's experience within healthcare systems, workplaces, family and friendship groups, and the broader community. The review also indicated that the experience of sub-groups of men, including culturally and linguistically diverse (CALD) men, remains under-explored. However, CALD families in Australia experience disproportionately high rates of stillbirth (Davies-Tuck et al., 2017) and may be at increased risk for perinatal death (Belihu et al., 2016), signifying a need for comprehensive research into CALD men's experiences and support following perinatal death. Given this lack of research, the present study aimed to: 1) explore CALD men's experiences of grief following perinatal death; and 2) investigate CALD men's experiences of support, and support needs, following perinatal death.

1.2 Terminology

1.2.1 Perinatal death. While in some literature stillbirth is referred to as a 'loss', there is strong evidence that parents perceive stillbirth as the death of their baby (Kelley & Trinidad, 2012). In response, this thesis uses the term 'perinatal death' to refer to both stillbirth and

neonatal death. Stillbirth is defined as a death in-utero after 20 weeks' gestation or over 400 grams in weight. Neonatal death is defined as the death of a live-born baby within 28 days of birth (Australian Institute of Health and Welfare, 2020). Pregnancies ending in termination due to life-limiting fetal anomaly within the perinatal period have previously shown to accompany perinatal grief for men, so were also considered eligible within this study (Obst et al., 2021b).

1.2.2 Culturally and Linguistically Diverse (CALD). The term culturally and linguistically diverse (CALD) is used both frequently and inconsistently to describe minority, marginalised or under-served groups in various social and health research (Pham et al., 2021). Within this study, the term 'CALD men' is used for brevity in reference to those who self-identify as having a cultural background that is considered different to that of the country in which they live, or a first language that is not the same as the primary language in that country (Australian Bureau of Statistics, 1999). The internal heterogeneity of CALD groups in cross-cultural bereavement research is addressed by Eisenbruch (1984) who states, that:

“a bereaved person's ethnicity is determined not only by the person's country of origin, but also by who he [sic] says he is, what he does, with whom, and how he feels about it”
(p. 325).

Consequently, this research aims to consider the unique and diverse needs of men who identify as CALD (Hugo, 2016). Aboriginal and Torres Strait Islander peoples, as the first peoples of Australia, are not considered to fall within this definition (Pham et al., 2021), and are the focus of research elsewhere (Adane et al., 2019; Kilcullen et al., 2021).

1.2.3 Grief definitions. Grief is commonly understood as a *state* of loss (Stroebe et al., 1993) or as an *emotional response* elicited by involuntary loss (Gharmaz & Milligan, 2006). Within this study, grief refers to the multidimensional *process* which is shaped by a range of

diverse individual factors, and is expressed within the full range of physical, behavioural, cognitive, social, and spiritual aspects of human experience (Burglass, 2010; Greenstreet, 2004).

Theories of grief are provided in the following section.

1.3 Theories and Models of Grief

1.3.1 Disenfranchised grief. Where grief following perinatal death is not openly acknowledged, publicly mourned, or socially supported, it is conceptualised as “disenfranchised grief” (Doka, 1989, p.2). Disenfranchised grief is associated with an increased risk of prolonged, complicated grief, and may be associated with negative health and psychosocial outcomes (Fernández-Alcántara et al., 2021; Sheperd et al., 2021).

Previous research has shown that men's experiences following perinatal death are commonly consistent with instrumental grief, characterised by a mental separation from the loss and an outwardly reduced emotional expression (Obst et al., 2020b, 2021a). Further, men may have a greater tendency to somaticise their psychological pain (Janssen, 2016). Consequently, when an absence of affect may be interpreted as an absence of attachment, men's grief may go unacknowledged and unsupported. Doka and Martin (2011) claim there may be an “affective bias” against individuals who exhibit more stoic grief responses (p. 6). Men, including CALD men, may therefore experience disenfranchised grief following perinatal death. Additionally, if CALD men experience a lack of social recognition for their grief, they may have difficulty acknowledging their own grief as legitimate, which may lead to self-disenfranchisement (Attig, 2004).

1.3.2 Models of grief. Most models of grief have focused on providing a structured and predictable progression of an individual's progress through grief (Davies, 2004; Parkes, 2001). However, determinate progression models, such as Kübler-Ross' (1979) “five stages of grief”

model, have been criticised as simplistic and inaccurate in that the experience of grief may be lifelong (Corr, 2019; Holleman, 1991).

The Dual-Process Model of Coping with Bereavement (DPMC) (Stroebe & Schut, 1999), suggests that 'adaptive' coping requires 'oscillation' between loss-oriented and restoration-oriented coping (p. 1967). The DPMC provides explanation for gender differences in coping with bereavement, where instrumental and stoic grief patterns (often displayed by men) are most strongly associated with restoration-orientation coping, characterised by activities and problem-solving (Stroebe et al., 2001). In comparison, women often display loss-orientation coping, involving feeling and expressing emotional distress (Stroebe et al., 2001; Stroebe & Schut, 2010). However, the DPMC has been criticised for not explicitly including interpersonal and socio-cultural factors that shape an individual's grief (Burglass, 2010). As such, this study primarily utilises a socioecological model of men's grief (SEMMG; Obst et al., 2020b) to examine CALD men's experiences following perinatal death.

1.3.3 A socio-ecological model of men's grief. Socio-ecological models have been broadly applied in the examination of the biological, social, and psychological factors that shape grief experiences and expression across the lifespan (Bronfenbrenner & Morris, 1998; Hua et al., 2020). Following in this theoretical tradition, Obst and colleagues (2020b) proposed a SEMMG (see Figure 1) to identify relationships between individual, interpersonal, community, and public policy factors that shape men's grief and support needs following pregnancy bereavement. This model may be used to examine the interaction between men's roles (e.g. the expectation 'to be strong') and the sociocultural and public policy factors affecting men's individualised grief. For example, woman-centred maternity care and unsupportive workplace policies for bereavement

leave may influence CALD men's presentation of stoic, or partner-focused, grief (McCreight, 2004; Michon et al., 2003).

Given the diverse sociocultural context of CALD men's grief, the present study uses the SEMMG as a theoretical basis for examining the highly varied environmental socio-cultural norms, formal and informal supports, and demographic factors that may contribute to CALD men's grief experiences and varied support needs in Australia (Dune et al., 2021).

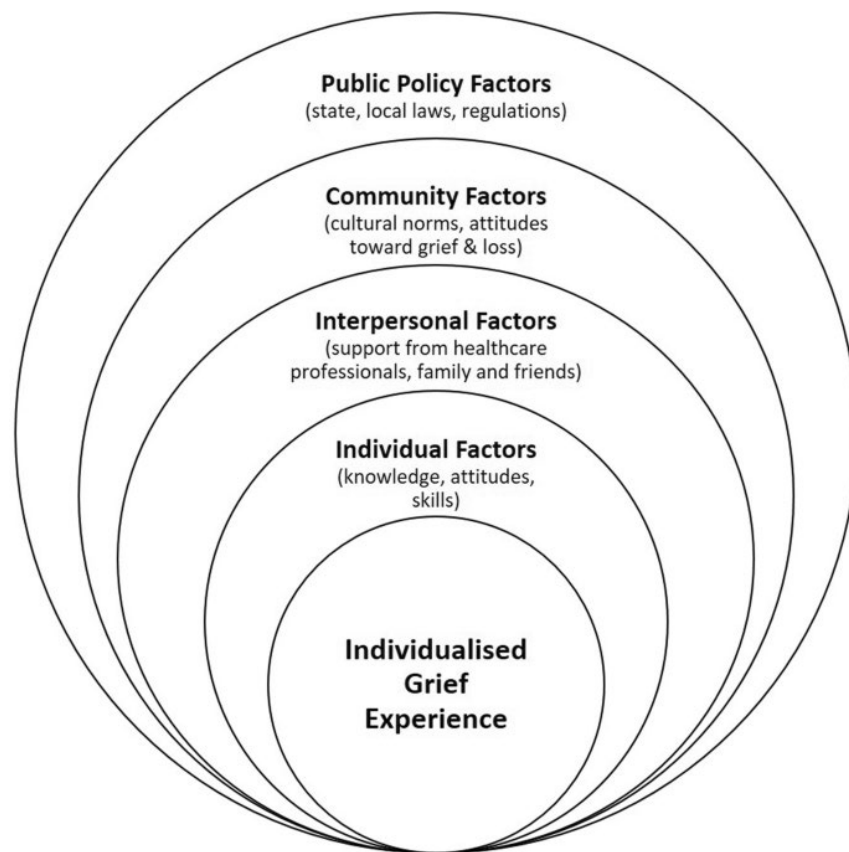


Figure 1. Socioecological Model of Men's Grief.

Adapted from "Men's grief following pregnancy loss and neonatal loss: A systematic review and emerging theoretical model." by K.L. Obst, C. Due, M. Oxlad, and P. Middleton, 2020, *BMC Pregnancy and Childbirth*, 20, p.12. Copyright 2020 by The Author(s).

1.4 Perinatal Death in Australia

1.4.1 Rates of perinatal death in the Australian population. In Australia, perinatal death occurs in 9.2 per 1000 births (Australian Institute of Health and Welfare, 2020). This equates to seven stillbirths and 2.2 neonatal deaths per 1000 births. This can be compared with the global mortality rates of 13.9 stillbirths and 17 neonatal deaths per 1000 births (United Nations International Children's Emergency Fund, 2020); 98% of which occurred in low and middle-income countries (Pabón et al., 2019). However, while perinatal deaths in Australia may be comparatively infrequent when compared to global rates, recent public debate has highlighted that Australia may be failing to meet its international obligations to consistently reduce perinatal mortalities (Mowbray, 2019; Lawn et al., 2016). While the Australian general infant mortality rate has steadily decreased, mortalities within the perinatal period have remained relatively consistent since 1993 (Australian Institute of Health and Welfare, 2016), presenting an ongoing public health challenge (Flenady et al., 2020).

1.4.2 Rates of perinatal death in CALD groups. CALD populations may be more likely to experience perinatal death than other groups of people in Australia. For example, estimates suggest that South-Asian and African-born women have double the risk of stillbirth in comparison to Australian-born women (Flenady et al., 2020; Davies-Tuck et al., 2017; Mozooni et al., 2018). A study conducted in Victoria, Australia, compared Australian-born women with Eritrean, Ethiopian, Somalian, and Sudanese born women, finding that women from these countries experienced increased perinatal death and adverse perinatal outcomes (Belihu et al., 2016). Further, migrant women from humanitarian source countries are particularly susceptible to perinatal death risk factors, including late first pregnancy healthcare visits, and unplanned and post-term births (Gibson-Helm et al., 2015). These findings reflect a global trend, where migrant

women and those from CALD backgrounds are more vulnerable to adverse perinatal health outcomes and perinatal death (Heslehurst et al., 2018). Consequently, perinatal death within CALD communities warrants further examination to understand the grief and support needs of these over-represented, but under-served, populations.

1.5 Outcomes and Impacts of Perinatal Death

1.5.1 The mental health outcomes of perinatal death. Bereaved parents typically experience a period of grief following a perinatal death (Nazum et al., 2018; Heazell et al., 2016). This period of grief is commonly associated with a range of negative psychological symptoms, including higher rates of depression, anxiety, post-traumatic stress disorder (PTSD), suicidal ideation, panic, and social phobia (Gold & Johnson, 2014; Burden et al., 2016). Such consequences are not limited to the immediate period following the death. For example, one estimate indicated that 30-35% of bereaved mothers from high-income countries may experience grief-related depressive symptoms for at least four years after stillbirth (Burden et al., 2016). Similarly, neonatal death often results in clinical levels of depression for mothers and prolonged grief (Lacasse & Cacciatore, 2014; Youngblut & Brooten, 2018).

Findings regarding men's experiences of psychological morbidity following perinatal death are varied, particularly when compared with women. While some research suggests that fathers show lower levels of psychological morbidity than women following perinatal death (Due et al., 2017; Jones et al., 2019; Turton et al., 2006; Heazell et al., 2016; Badenhorst et al., 2006), others have shown that men may experience symptoms of grief and PTSD similarly to women (Badenhorst et al., 2006; Turton et al., 2006). Further, Due and colleagues' (2017) systematic review demonstrated that some men are hesitant to disclose their feelings, are generally interviewed alongside their partners, and have elevated scores on avoidance scales following

pregnancy loss. Consequently, the impact of social desirability bias, where men desire to appear stoic or strong, may make it difficult to accurately compare men's general mental health and grief outcomes with their female partners.

1.5.2 The impact of perinatal death of life satisfaction and relationships. Bereaved families in general often experience reduced quality of life and family wellbeing (Troxel & Matthews, 2004; Fernandez-Sola et al., 2020). In relation to perinatal death, there is evidence to suggest that bereaved couples may have a higher likelihood of relationship breakdown, anxiety, and depression during subsequent pregnancies (Gravensteen et al., 2018; Hughes & Riches, 2003; Turton et al., 2009). Heterosexual fathers often report relationship dissatisfaction, with increased relationship conflict and generalised social isolation, following perinatal death (Avelin et al., 2013; Campbell-Jackson et al., 2014). For some, social isolation may be accompanied by engagement in avoidance and coping behaviours, such as increased alcohol consumption (Jones, 2019; Ashbourne et al., 2013). Experiences of stigma, discrimination, and a loss of social status are also common among men, resulting in a lack of social recognition for bereaved fatherhood identity (Pollock et al., 2021; Jones et al., 2019; Ashbourne et al., 2013). However, research has also highlighted the complex nature of grief following a perinatal death. Specifically, psychological distress is subject to individual differences in attachment, social support, and quality of partner relationships (Scheidt et al., 2012) and some fathers may experience a sense of deepened connection with their partners (Avelin, 2013).

1.5.3 Grief expression and grief pattern following perinatal death amongst men. As noted in Section 1.3.1, research suggests that men may adopt "masculine" expressions of grief following perinatal death (Jones et al., 2019, p.2), that is, expressions of grief that may be more consistent with instrumental grief patterns (Doka & Martin 2000) and restoration-oriented

patterns (Stoebe & Schut, 2010). For example, some men express grief related to this form of bereavement by becoming 'stoic' and trying to cope in isolation (Obst et al., 2019; Samuelsson et al., 2001; Doucet, 2006; Dermott, 2008). Additionally, heterosexual men have been found to adopt a 'supporter' role within the relationship with their (female) partners following perinatal death (Bonnette & Broom, 2012; O'Leary & Thorwick, 2005). Research concerning the impact of this supporter role is mixed; some suggest this role may lessen the impact of grief following perinatal death for fathers (Franz et al., 2021), while others suggest this role may prevent men from processing their own grief (Obst et al., 2019a).

1.6 CALD Men's Experiences of Perinatal Death

1.6.1 Previous research on perinatal death experiences amongst CALD men. Obst and colleagues' (2020b) systematic review noted an absence of research exploring the experiences of bereaved fathers from CALD backgrounds following pregnancy loss. The review found 16 studies had incidentally recruited small numbers of CALD participants as part of larger samples, although, none of these studies explore cultural differences in grief and support following perinatal death. As such, to the best of the author's knowledge, the present study is the first study designed to explore CALD men's grief and support needs following perinatal death.

1.6.2 Death and bereavement in CALD communities. Following a socio-ecological approach, there are range of socio-cultural predictors which may shape CALD men's experiences of perinatal death and grief. For example, these experiences may be shaped by CALD men's experiences of pregnancy, culturally informed transition to fatherhood, and levels of stigma around mental illness.

Pregnancy is commonly considered a rite of passage, constituting a major life transition for fathers (Cote-Arsenault et al., 2009). This rite of passage is guided by the social context in

which people live (Genesoni & Tallandini, 2009). Consequently, cultural understandings of fatherhood are likely to shape CALD men's experiences following perinatal death. Additionally, previous research emphasised the diversity in which death, dying, and grief is recognized and understood around the world (Irish et al., 1993). Diversity in cultural understandings of death has led to variation in funeral and burial practices, which in turn is thought to affect grief (Hoy, 2013). In particular, the reduction of overt bereavement rituals within Western societies has consistently been criticised as minimising cultural and social expression of bereavement (Eisenbruch, 1984; Ata & Morrison, 2005). Moreover, Lin and colleagues' (2020) scoping review demonstrated prevalence of stigma towards mental ill-health at a population level within the US, Spain, Taiwan, Korea, Saudi Arabia. CALD men in Australia may receive less social support for their grief due to the stigmatisation of grief by the general population, and also experience stigma resulting from cultural norms and beliefs associated with specific CALD community groups (Hailemariam et al., 2019; Blignault et al., 2009; Knifton, 2012). Research has also identified social isolation among bereaved CALD men and a reduced uptake of healthcare systems relating to marginalisation (Pabón et al., 2019). Consequently, competing socio-cultural environments, stigma, and a lack of support for cultural mourning processes may negatively impact CALD men's capacity to grieve perinatal death in Australia.

Alternatively, CALD men may experience protective factors associated with their cultural background, and cohesiveness of some cultural groups. Protective factors, such as religious beliefs, family and community cohesiveness, and learned resilience have been shown to reduce stress and support grief-related processes amongst CALD men (Boyd-Franklin, 2003; Blank et al., 2002; Khawaja et al., 2021).

1.6.3 Religion. Religions, conceptualised phenomenologically, are systems of “activities and beliefs directed toward that which is perceived to be of sacred value and transforming power” (Livingston, 2008 p.3). Previous research has shown that religious beliefs may offer support, mediate psychological distress following perinatal death, and dynamically interact with grief processes for bereaved parents, including in CALD populations (Wright, 2020; Allahdadian & Irajpour, 2015). Religion is commonly associated with cultural beliefs and has been shown to shape expressions of grief and mental health among bereaved CALD populations following death more generally (Khawaja et al., 2019; Snider & McPhedran, 2013). This study recognises that culture and religion are inextricably linked within CALD communities and may shape CALD men’s experiences of grief and support following perinatal death in Australia (Pereira-Salgado et al., 2018; Bakker & Paris, 2013; Kain 2021).

1.7 Support Following Perinatal Death

1.7.1 Informal and formal support in perinatal death. Supports and services are commonly conceptualised as either formal or informal (Lyons & Zarit, 1999), with formal supports being health services, healthcare professionals, or mental health programs, and informal supports include community support through peers, friends, and family.

Previous research has shown that men are often overlooked by formal supports in both pregnancy and grief following perinatal death (McCreight, 2004; O’Leary & Thorwick, 2005; Ellis et al., 2016; Erlandsson et al., 2011), and are less likely to access bereavement care services (Manuel, 2018). Additionally, research shows that men are consistently less likely to seek formal support for mental health difficulties associated with grief more generally (Gulliver et al., 2010; Saga-Ouriaghli et al., 2019). Barriers to access include clinician bias towards masculine stereotypes (Mahalik et al., 2012), the avoidance of open emotional expression (Cochran &

Rabinowitz, 2003), and tendency to self-medicate with alcohol and drugs (Möller-Leimkühler, 2002; Galdas et al., 2005). CALD populations have also been shown to access mental health services at lower rates than other Australians (Henderson et al., 2011), potentially due to racial discrimination, social isolation, low health literacy, lack of translators, and/or a lack of trust and unfamiliarity with the Australian healthcare system (Hughson et al., 2018; Au et al., 2019).

It is also notable that some health practices dealing with perinatal death in Australia may be culturally insensitive or stigmatising for CALD populations (Wohler & Dantas, 2017). For example, health practices in Australia include the use of autopsy and tissue collection, in the investigation of perinatal deaths. However, this practice may not be appropriate within cultural contexts which uphold the sanctity of the body after death (Hill et al., 2018). In addition, while recommendations to hold a baby following stillbirth are potentially beneficial to a parent's future wellbeing (Kingdon et al., 2015; Redshaw et al., 2016), this practice may be inconsistent with religious or cultural practices which emphasis expedient burial (Balkan, 2015).

Finally, in terms of informal support, men often experience social isolation following perinatal death, which has strong interactions with low levels of informal support options (O'Leary et al., 2006) that may otherwise assist men in the absence of formal supports. This may be particularly the case for CALD men who can experience higher rates of social isolation (Wright-St Clair, 2017; Barr et al., 2020).

1.7.2 Guidelines for perinatal care in Australia. The Perinatal Society of Australia and New Zealand (PSANZ) provides clinical guidelines to inform quality bereavement care practices after perinatal death within Australia (PSANZ, 2020, Section 3-9). The guidelines encourage health practitioners to ask bereaved parents what their cultural, religious, and spiritual needs may be, while avoiding cultural stereotypes and culture-based assumptions, and focus on the need to

recognise that diversity exists within cultural groups and between individuals. They also suggest practitioners be prepared to support cultural needs by contacting “appropriate support services”, although appropriate support services are not defined (p.8).

It is notable that there are no CALD-specific guidelines for perinatal death bereavement care in Australia. This is problematic for a range of reasons, including where socio-cultural factors may impact on best-practice care. For example, it is not known how decisions, such as to hold the baby following death, may affect CALD men's grief (Wilson et al., 2015).

1.8 Aims and Research Questions

Given the lack of research documented in this chapter, this study aimed to: 1) explore CALD men's experiences of grief following perinatal death; and 2) to investigate CALD men experiences of support, including the support needs that they have, following perinatal death.

Method

2.1 Design

This study utilised a contextualist epistemological approach, simultaneously acknowledging the validity of subjective participant accounts, and contributing research recommendations within the healthcare context (Madill et al., 2000). Consequently, the analysis took both a theoretical and latent approach (Braun and Clarke, 2019a). Specially, reflexive thematic analysis was used to analyse the data (Braun and Clarke, 2019a). In adherence with inductive coding, the aim was not to collect evidence for a particular hypothesis (Braun & Clarke, 2006), but to understand generally how men from CALD backgrounds experience grief and support following perinatal death. In addition to the inductive coding approach, the analysis utilised the analytical framework derived from Obst et al.'s (2020b) SEMMG to structure the themes and final discussion (Gale et al., 2013). In this final deductive stage, the data corpus was

explored for the sociocultural and structural contexts that shaped the semantic content of the interview data (Braun and Clarke, 2006).

2.2 Participants

In total, 16 participants were included in the study. Participants were drawn from two key groups of informants, with the view to triangulating the data to compare perspectives on grief and support following perinatal death for CALD men (Tracy, 2010). Group One (see Table 1) included six health service providers (HSPs) from a variety of health disciplines (midwifery, $n=2$; mental health, $n=2$; hospital chaplains, $n=1$; healthcare service CEO, $n=1$). Group Two (see Table 2) included 10 CALD community members who were either community leaders (CL) with experience working with CALD men following perinatal death in Australia ($n=6$; $M_{age}=47$, $SD=10.26$), or CALD men who had personally experienced neonatal death ($n=2$) or stillbirth ($n=2$; $M_{age}=40$, $SD=2.54$). Two CALD women CLs worked with their communities in this area and had personal experience of perinatal death.

Table 1

Health Service Provider Participant Characteristics

Name	Age	Occupation	Country of Birth	Cultural Background	State	Language Spoken at Home	Gender	Education
█	35	Clinical Psychologist	Australia	Anglo-Saxon	QLD	English	F	PhD
█	46	Midwife Specialist	Australia	Caucasian	WA	English	F	Bachelor
█	43	Psychologist	Columbia	Columbian	NSW	Spanish	F	Masters
█	27	Midwife	Australia	Peruvian, Dutch	SA	English	F	Bachelor

Name	Age	Occupation	Country of Birth	Cultural Background	State	Language Spoken at Home	Gender	Education
█	48	Hospital Chaplin	India	Indian	WA	Malayalam	M	Masters
█	44	Healthcare service CEO	Australia	Caucasian	NSW	English	F	Diploma

Table 2

CALD Community Member Participant Characteristics

Name	Country of Birth	Cultural Background	State	Language	Gender	Religion	Education
█	Bangladesh	Bangladesh	NT	Bangla	M	Islam	Masters
█	Hong Kong	Chinese	NSW	Cantonese	F	Christian	Certificate IV
█	South Sudan	South Sudanese	VIC	Dinka	M	Christian	Masters
█	South Sudan	South Sudanese	VIC	Arabic	F	Christian	Diploma
█	Rwanda	Rwandan	SA	Kinyarwanda	M	Christian	Bachelor
█	China	Chinese	NSW	Mandarin	F	NA	Masters
█*	Rwanda	Rwanda	SA	Kinyarwanda	M	Christian	Bachelor

Name	Country of Birth	Cultural Background	State	Language	Gender	Religion	Education
█*	Singapore	Singaporean	SA	Cantonese, Mandarin	M	Christian	Masters
█*	France	French	NSW	French	M	Not religious	Bachelor
█*	Brazil	Brazilian	QLD	Portuguese	M	Not religious	Masters

* specifies CALD man with personal experience of perinatal death

2.2.2 Inclusion criteria. Group One participants were required to have experience working with CALD men after a perinatal death in the last two decades within Australia. Group Two participants were required to self-identify as CALD and were either community leaders with experience working with CALD men following perinatal death, or had experienced a perinatal death themselves during the previous 12 years in Australia. This criterion was initially 10 years, but was extended to 12 to include one participant who wished to do an interview, and whose experience of perinatal death was 12 years ago. CALD men who had experienced perinatal death within the previous six months were not included, to minimise potential distress. While self-identification as CALD was the official criteria, participants were considered from a CALD background if they were born, or had a parent born, in a non-English speaking country, and/or who did not speak English at home.

2.3 Procedure

This study received full ethics approval from the University of Adelaide Human Research Ethics Committee on 31 March 2021, approval number H-2021-048. Information about the

study, study flyer (Appendix A), and participant information sheets (Appendices B-D) were disseminated electronically to health service clinics, ($n=72$), individual healthcare professionals ($n=52$), community support organisations ($n=67$), individual CALD community leaders ($n=20$), CALD community groups ($n=100$), and perinatal research organisations ($n=9$) based in Australia. The information sheet invited potential participants to email or call the researchers to express interest in participation. The total response rate was low (9.4%). As such, snowball sampling was also used, where interviewees were asked to share information about the study through their networks, resulting in nine participants (56% of total participants). Snowball sampling with community organisations resulted in the recruitment of six (60%) participants of the Group Two sample. In comparison, Group One was locationally diverse and recruited independently; snowball sampling resulted in one (16.7%) of the Group One participants.

Participants who expressed interest in an interview were contacted to schedule a time and provided with a consent form (Appendix E). The majority of interviews were conducted via videoconference ($n=14$), while two CALD men with personal experience of perinatal death elected phone ($n=1$) or in-person ($n=1$) interviews. Informed consent was gained from all participants. Videoconferencing can reliably and economically support research for diverse and geographically isolated populations (Gray et al., 2020; Boland et al., 2021) and may better suit CALD populations in qualitative studies (Ahangari et al, 2021).

Participants answered a series of semi-structured interview questions based on previous literature (Obst et al., 2019b, 2020b; Samuelsson et al., 2001; Appendix F). Interviews included demographic questions (e.g., age, gender) and questions about grief, support experiences, and barriers and facilitators to support. Following the first interview, the interview questions were assessed by all researchers and two questions were added relating to CALD men's experiences of

support (Appendix F, Items 1-2). Seven interviews were conducted with community leaders and health professionals before the first interview with a CALD man who had experienced perinatal death. Questions regarding financial responsibility, perceived social pressure, burial arrangements, and specific barriers to healthcare were introduced or amended at this time (Appendix F, Items 3-5). While there are various approaches to sampling in interview-based studies, this thesis used data saturation to determine sample size (Braun & Clarke, 2019b). Data saturation from Group One was reached by the fifth interview, and Group Two by the ninth; in both groups a further interview was conducted to confirm no new information.

Interviews lasted an average of 61.24 minutes ($SD=19.82$). Group One averaged 49.83 minutes ($SD=5.49$), Group Two averaged 69.45 minutes ($SD=20.73$). Men from CALD backgrounds and community leaders received a \$50 voucher for participation. All interviews were conducted between April and August 2021. Interviews were transcribed verbatim including pauses and laughter, to capture relevant contextual information according to the orthographic method (Braun & Clarke, 2006). The researcher removed all personally-identifying information from the transcriptions. Participants could choose to review their transcript and make any changes; 12 participants (75%) chose to do so, although none requested changes.

An audit trail was kept by the researcher in line with Tracy's (2010) criteria for enhancing methodological rigour in qualitative research. The audit trail consisted of reflection on the interview process, interview questions, codes and themes, copies of communication with participants, and meeting notes. The audit trail provided direction for the analytical strategy and interpretation of themes.

2.4 Personal Reflexivity Statement

The author is a non-CALD, white, Australian-born man, with one child. Although not having experienced perinatal death within the context of his immediate family, the author has encountered multiple instances of perinatal death, within family and friends. The author's knowledge of this research topic, and the Australian healthcare system, may have influenced interviews. Similarly, the researchers' Western cultural background may have influenced interviews and data analysis.

2.5 Data Analysis

The six steps of thematic analysis as outlined by Braun and Clarke (2006) were followed. The data analysis conducted was informed by the SEMMG (Obst et al., 2020b, 2021a), through an iterative, data-driven approach. Codes were identified first at a semantic level, with initial data familiarisation and domain summary coding to identify inductive, bottom-up codes within the data sets (Braun & Clarke, 2019b). Subsequently, codes were examined in approximation to the SEMMG, whereby they were contextualised as either relating to public policy, community, interpersonal, individual, and individualised grief factors, with this context informing the development of themes. Next, codes were developed into fully realised themes (Braun & Clarke, 2019a). Triangulation between participant groups occurred throughout the analysis (Patton, 1999). When possible, the perspectives of CALD men with experience of perinatal death were highlighted, including when at contrast with CL's perspectives.

Results

3.1 Overview

Thematic analysis identified nine themes in relation to the research questions (see Figure 2). Four themes were related to CALD men's grief expression (namely that CALD men's grief is

individual, a changing and enduring process, partner-centred, and expressed through stoic ideals of masculinity), as well as five themes relating to support (namely that perinatal death, grief, and following care were found to be associated with stigma, and that CALD men’s support is shaped by; religion and ritual, connection to community and family, inhibited self-advocacy, and woman-centred supports).

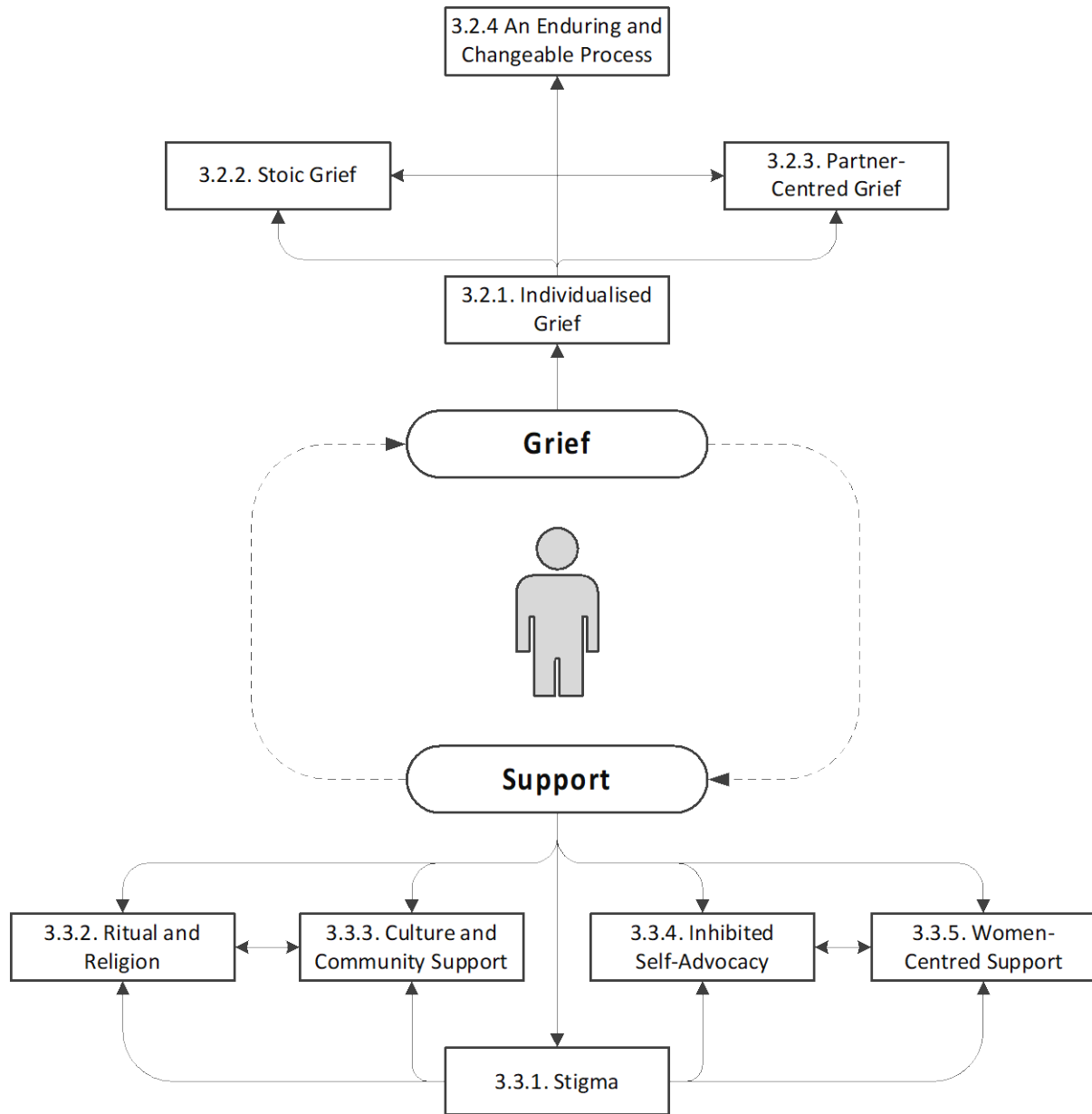


Figure 2. Thematic Map.

3.2 Themes Relating to CALD Men's Grief

3.2.1 Individualised grief. While data analysis identified aspects of CALD men's grief which were consistent across participants (as discussed in later themes), it was evident that, overall, experiences of grief were highly individualised, reflecting each distinct pregnancy. Julie (HSP) explained that CALD men's reactions were largely unpredictable when considering the gestational age of the baby at time of death:

“It is very individualised, so there might be some men who have an extreme sense of loss, and it might be very early in the pregnancy. There might be those who feel quite disconnected until right into later in the pregnancy.”

█, Clinical Psychologist).

However, CALD participants highlighted culturally-perceived differences between stillbirth and neonatal death, which were predicted to shape their grief responses. █ explained how men's grief in her community was shaped by cultural differences:

“That one [stillbirth] we can say ‘ah it is not good, no one saw’. Maybe the baby was like, three months, four months. Doesn't matter. But the baby you saw [neonatal death], it's like a human being. And then you think, the year comes, I saw my baby, it was supposed to be this year. I was supposed to be doing this. So, we think different.”

█, South Sudanese CL).

Here, CLs generally expected CALD men's grief at stillbirth to be comparatively reduced, where neonatal death was considered “a real baby, and the loss much [more] painful” (Cerulean, China, CL). However, one CALD man with personal experience of stillbirth noted that stillbirth grief was not easier to grieve when compared to neonatal deaths: “for stillborn... what photo do you have? And what memories? So, some people say that is the hardest part”

(██████, Singapore). Therefore, HSPs and CALD men with personal experiences of perinatal death did not necessarily share the views expressed by CLs.

Additionally, the gender of the child (“[If] boy shall die, the man really, really sad” (██████, South Sudan, CL)) and previous miscarriage experiences (“We had a miscarriage at nine weeks, for the first child, and then we had a second pregnancy, obviously a bit more stressful” (Patrick, Rwanda)) were factors described by CALD participants as affecting their grief responses following perinatal death. Migration experiences also factored in here; for example, ██████ associated his prior confidence in safe Australian healthcare with further distress:

“We come from Africa, with a million countries which are not as advanced as Australia. So, actually, losing a baby is not something that comes as possible in this country. Because we thought the medical advances here are higher. There's a lot of things which are available here, which are not available back in Africa...So it was a different kind of shock as well, but also what that means is that, you know, no other pregnancy actually could be just worry free for us.

(██████, Rwandan refugee who experienced neonatal death).

The incidents of grief reported within this study can be each understood as a unique example within a highly varied group, shaped by the biological, psychological, and sociocultural factors of each account. Importantly, the gender, gestational age, expectations for Australian healthcare, and CALD background were significant factors that were framed to impact participant responses.

3.2.2 Stoic grief. CALD community members and HSPs expressed that CALD men restricted outward displays of emotion during grief. Stoic responses were generally framed as

resulting from normative, gendered expectations of grief following perinatal death, despite underlying affect, such as sadness or hopelessness. For example, [REDACTED] (HSP) noted that:

“...it's more appropriate for women to be expressive in emotions and for men to be kind of stoic holders of stability. And there might be shame about falling apart. But real, real sadness, real, real depression and real sadness of the loss.”

([REDACTED], Clinical Psychologist).

Participants discussed gendered norms of men's grief as aligning with cultural values of male stoicism. For example, [REDACTED] (China, CL) described “...in Chinese culture there's a poem saying that men can lose their blood, but not losing their tear”. Pauline, a South Sudanese elder, similarly said: “Our men, they don't cry, but they cry inside.” Whilst being framed as culturally-normative, both participant groups reported that appearing stoic could be difficult for CALD men, associated with hidden emotional strain and self-reproach. [REDACTED] reflected on his experience:

“I've cried. I've never cried so much in my life... I really cry too; I think until three am or so. And what happened was the doctor said, “his heartbeat stopped.” Around that time... So I don't, I just can sense it. So that, even though I'm not proud to say I cried so much, but that was my grieving process.”

([REDACTED], Singapore).

Similarly, [REDACTED], (Rwanda) whose baby died at 11 days old, shared the importance and difficulty of his stoic response when caring for his wife:

“Yeah, to be honest it was quite bewildering and very difficult, but obviously I knew I had to be strong, you know for my wife as well, because... if I broke down, I don't think

she could have handled it herself. So, I had to be strong for the whole family. But it was very difficult.”

(██████████, Rwanda).

CALD men's experiences of perinatal death, in cases of both stillbirth and neonatal death, were described by participants as resulting in stoic patterns of grief, informed by culturally-normative expectations for CALD men.

3.2.3 Partner-centred grief. Both groups of participants noted that CALD men's stoic grief was associated with culturally-normative responsibilities to care for (female) partners following perinatal death. Olive, a health service CEO, noted, “they do put themselves at the back of what their wife's needs are”. HSP participants also reported that CALD men often only engaged in mental health support to support their partners:

“They come [to therapy] mostly to support their partners. And so I do always make the point of asking them both about how they are doing and they [men] tend to reflect the question back to their partners. So, it's kind of, I need to be okay, in order to support her because she was the one who gave birth to the baby we lost.”

(██████████, Psychologist).

Indeed, all CALD men participants expressed how their grief was shaped by support roles to their partners and broader families. ██████████, a French migrant who experienced neonatal death, said: “I did all of the legwork because she was distraught, in regards to the birth certificate, the funeral home, and naming the child.” ██████████, an Islamic leader, indicated that practical and supportive roles were expected of CALD men in his community, even when contradicting traditional gendered roles:

“...when [perinatal death] happens, he has to help. He helps around the house.

Traditionally in our culture the boys are the bread-earner. In Muslim culture, people generally expect men try to work outside the house and girls generally are responsible for inside the house.”

(██████, Bangladesh).

In addition to taking on responsibility for practical matters such as funerals and household tasks, participants reported that CALD men returned to work to keep earning money, often at the cost of their own ability to grieve. HSP participants speculated that the low uptake of health services by men from CALD backgrounds following perinatal death was informed by “the expectation that the man needs to move on, and go back to work, and support a family” (██████, Psychologist).

However, despite challenging obligations, CALD men also reported indirectly benefiting from instrumental grief orientations and supporter roles. For example, ██████, a Brazilian man who had experienced a stillbirth, expressed satisfaction with supporting his partner which he associated with liberated self-expression:

“By being there for her, it helps me also, obviously, with dealing with everything. And we speak a lot, and I, because she feels a lot, because she's somebody that feels a lot, feels the world, she's very sensitive. She's allowing me, I had to learn to be more sensitive as well. And I express myself and open myself and this is one of the wonders of having a partner that is very sensitive. That you are also allowed to explore that side of yourself that somehow you shut down because you're a man, and you learn to be tough.”

(██████, Brazil).

Additionally, [REDACTED] identified that his partner-centred focus was associated with a distressing interaction with his child, who died two hours after birth:

“I decided following the delivery that for my recovery and mental health...not to see the child...I tried not to look, instead focusing on my wife... [Baby] was not fully-formed, I didn't want the picture of the un-formed child, who was blue, to haunt me... [Instead] I was focusing on my wife, and she was hungry. So, I went and got food.”

([REDACTED], France).

[REDACTED]'s partner-centred and instrumental grief presentation was framed as a reaction to the emotionally-traumatic death. Partner-centred grief was also explicitly associated with stoicism by CALD participants. For example, [REDACTED] explained that a period of reduced affect permitted him to support his family following the stillbirth of his baby:

“You're able to not feel the pain for a short period of time to fix it. I feel, emotionally to going through the grief where, yeah, I did have my grief and cry, then in the process of facing death, and having to deal with funeral and things like that, there was that numbness of grief to be able to still function, to care for others, to do for my wife and even for the grandparents.”

([REDACTED], Singapore).

[REDACTED] discussed stoicism as an adaptive reaction to the practical obligations and responsibilities he had following perinatal death. Overall, participants indicated that sociocultural expectations of CALD men's gendered responsibilities shaped both stoic and partner-centred grief responses. Partner-centred grief, while in some cases presented as a potential barrier to CALD men's grief and support needs, was also communicated to be an important and beneficial role after perinatal death.

3.2.4 An enduring changeable process. Consistent with the conceptualisation of grief as a process (Buglass, 2010), CALD men who experienced perinatal death reported that their grief endured over time, including past subsequent pregnancies. For example, [REDACTED], whose baby girl died in the neonatal period, explained:

“So, when we lost her, we had only one child. She was going to be the second and so, at that point, I thought, maybe if we have another child and that’s going to be closure. We will stop worrying because we have had almost compensation, if you can call it that, for the lack of a better word, with another child. But yeah, even after having other children, it’s just a void that can’t be filled. Because she was unique in her own way.”

([REDACTED], Rwanda).

HSP participants also noted that grief was enduring, although some expressed an opinion that: “[grief] lessens the intensity with time” ([REDACTED], psychologist). A reduction of intense emotional experience over time was also reported by CALD men participants. For example, Dominic recounted how his intense experiences of grief (following stillbirth) became, to his surprise, replaced with different emotions:

“We held him, I looked at him and... When I think of [my stillborn baby] I have this warm feeling. Like it’s a good feeling. I don’t feel guilty... Yes there’s the sadness. There’s always is if you ever lost somebody in the family, you know that, there’s this sadness. It’s always there. But then again, I don’t... I don’t feel... Yeah... I feel this warmth...”

([REDACTED], Brazil).

Here, HSP and CALD men participants expressed the expectation that grief following perinatal death is an enduring, yet changing process, which was individualised and expected to impact on some CALD men over an extended period.

3.3 Themes Surrounding Support Following Perinatal Death

3.3.1 Stigma. Participants reported that CALD men experienced isolation after perinatal death, due to stigma. For example, Harrison (France), who experienced a neonatal death two hours after birth, stated: “It would be alienating to share what happened, imagine what a downer that would be”. [REDACTED] (South Sudan, CL) said: “We don't talk about baby die”. Many of the CL participants expressed that perinatal death (both stillbirth and neonatal death) were culturally considered “taboo” ([REDACTED], South Sudan) or “a curse” ([REDACTED], Hong Kong, CL). Speaking of migrant Chinese families, [REDACTED] explained:

“They will not invite any family or friends to come. Because they feel [perinatal death] is very shame. And also kind of like, I have very bad fortune, I don't want to pass this to you. So, this is in our culture. So, for the family, it's very isolate, and is a very sensitive topic. So, they will not disclose to families or friends”.

([REDACTED], China).

Stigma surrounding perinatal death was commonly attributed towards women. For example, [REDACTED] (Rwanda) said: “Some people did actually blame my wife, culturally.” In particular, CLs from African countries explained how stillbirth was stigmatised when framed as resulting from factors including in-utero nutrition, “baby wasn't fed well” ([REDACTED], CL, South Sudan). [REDACTED] framed some mother's choices of clothing, nutrition, and family planning as causal to stillbirth, and publicly scrutinised within his community:

“Now the stigma might be if children are too close in age. So if there's no gap and people may be whispering ‘the mom didn't get time to heal from the first child and she end up having another child so...if he, if he's too close [in age], they may say ‘Look I think they didn't gauge it’. Again, also it depends, how they will seeing this mom while pregnant, so they may judge, according to what she was eating. Maybe she wasn't eating healthy things because people talk, people share. And also...is the clothing too tight?... When in the community, is she wearing tight jeans?”

(██████████, Rwanda).

However, factors relating to both CALD women and men were associated with stigma surrounding perinatal death within some communities. For example, HSPs reported CALD men's genetics and infertility being blamed for perinatal death:

“Sometimes with perinatal loss, when it's happening privately, there is shame and stigma about fertility and reproductive potential and why [perinatal death] has occurred. Because in different cultures there is a lot of shame that, with men, if there's a fertility difficulty, sometimes they can be lost due to chromosomal difficulties... that is deeply shaming [and] therefore less shared.”

(██████████, Clinical Psychologist).

Community members also reported that there was cultural stigma surrounding mental health help-seeking, increasing the likelihood that men from CALD backgrounds were unlikely to seek support:

“[Men] they're not, you know, [choosing] to go to see the doctor. That's why, you know, we have very low service...low rates for people going to use the mental health service. It's also another taboo in the community.”

██████████, Chinese CL).

Overall, bereaved CALD men were seen as facing stigma associated with perinatal death, both in terms of the causes of the death and the subsequent pathways to seeking support.

3.3.2 Ritual and religion. While not all CALD men and CLs in this study reported religious affiliation, both CL and HSP participants described the significance of religion and ritual in shaping grief for CALD men. ██████████, an ecumenical hospital chaplain, explained:

“When they are very much connected with their religion and their culture, about the loss of the baby, their grief is much, much lower. But if a person cannot connect with their religion or culture, I think they don't know what to do. There's no conclusion.”

(██████████, HSP).

Similarly, even where not considering themselves religious, CALD men participants reported that ritual was important following perinatal death. For example, ██████████ described creating his own personalised “healing” ritual after stillbirth:

“And then we did a ritual with close friends and we put his ashes on the river, not far from where I am right now actually. In a place called [redacted] beach, was beautiful. It's very beautiful ceremony. Very important. It's very healing, very soothing, very sad. But it brought us together.”

(██████████, Brazil).

Importantly, participants reported that religious burial practices often followed prescriptive processes that changed depending on whether a baby was stillborn or died in the neonatal period. Neonatal death was typically considered different from stillbirth. Solomon explained:

“They pray together a little, they don't do 40 days like a born one. A born one they do twice. In the... after the dead, three days, and then a day of burials. And then the 40 days

after that, yes, that is the born one, they do 40 days. But the one, that [unborn one]... then they just pray once.”

(██████████, South Sudan).

In general, parents who experienced a stillbirth did not report the same grief rituals as parents who experienced a neonatal death, framed as resulting from the culturally-perceived significance of the death. ██████████ further said: “baby unborn we don't count it as human”.

Importantly, HSPs generally conveyed that CALD men did not always have access to cultural norms or community supports, especially for those who were migrants or from ethnic minorities. Hospital chaplain ██████████ said:

“Even though you probably can say that, ‘oh they have a Hindu priest here’, but the Hindu priests here may not be able to give the whole answer for what they are looking for, because as I said to you, even though they are Hindus they are coming from different cultures and different background, so that they all have different kinds of religious rituals, you know, the rituals are different.”

(██████████, HSP).

Overall, culture, religion, migration status, community beliefs, and type of perinatal death (stillbirth or neonatal death) were interacting factors that affected CALD men's access to culturally-normative rituals following death. Participants indicated that such rituals functioned as bereavement support, and shaped grief expression following perinatal death.

3.3.3 Culture and community support. In addition to grieving rituals, HSP participants noted that CALD men experience support from religious and cultural communities. For example, Sandra (HSP) reported that CALD men received: “really good cultural support in their

community, through their churches, [and] through their mosques". CALD community and religious groups were also described as providing practical support for families:

“So, if a child is died today we will be spending maybe a week, going to their family gathering in the evening. Ladies will be cooking food and people share. Men may help in the cooking food as well. But each member of the family will be bringing a dish and shared in the evening.”

(██████████, Rwanda, CL).

However, HSPs and CLs also reported that some CALD men were at risk of disconnection from family and communities:

“I think [men] have lower rates of having religion or go to local church. Female, more active, you know, to attend a local church to join some active group, a learning class. But for male...Yeah, they don't have this kind of a social connection”

(██████████, China, CL).

Within a support context, both social recognition of perinatal death and community engagement (often through religious practice) were generally seen as beneficial. However, CALD men also highlighted personal desires for privacy. ██████████ said: “people respond with pity and sympathy...but we had already done our grieving. It is like you being reminded all the time”. Here, community support, and the provision of social recognition for their loss, could not fully address the grief that was experienced by CALD men. ██████████ said:

“They were as supportive as they could, community was around, they did help. But some of these things are just private, when people are there, yes, go with them, but, at the end of the day when you make your bed alone, sleepy, thinking about these things. That's when it hits you.”

(██████, Rwanda).

In general, CALD men were reported to experience social support following perinatal death through proactive religious and community groups, although this support was affected by factors such as gender and preferences by some men for privacy.

3.3.4 Inhibited self-advocacy. Both groups of participants highlighted a range of barriers to CALD men accessing support following perinatal death. These included access itself:

“sometimes they don't show up” (██████, South Sudan), language barriers, and systemic challenges associated with healthcare following perinatal death: “there's lots of silence, not a lot of support and the support services work in silos so they don't coordinate with each other” (██████, Psychologist). One private practice midwife, ██████, expressed the view that some HSPs did not acknowledge cultural differences within their service approach, saying some health professionals: “really don't see culture as something important”.

Both participants groups acknowledged that cultural norms surrounding healthcare could leave CALD men with the impression that “I can't ask the question” (██████, Hong Kong). CLs reported that a strong respect for medical authority prevented some CALD men from advocating for themselves and their partners. ██████ said: “This is a cultural thing... we would respect the doctor...he knows better.” Here, participants portrayed CALD men as facing difficulty self-advocating within healthcare situations due to uncertainty and low health literacy. Maurice recounted an event where a CALD man's respect of medical authority competed with his desire to be with his wife during a difficult labour which ultimately resulted in the death of both his wife and baby. Here, distrust of ‘mainstream’ medical practitioners was framed as adding distress within the already stressful situation:

“The outcome was, “Your baby and your wife died, and we couldn't help”. The man wanted to follow, but they said ‘no, stay here’. I think that’s the thing, doctors, no matter what the circumstances, let the person see what is happening. Those here, and also in the mainstream, have to remember that the trust between the multi-cultural sometimes is not 100%. So if you just take my wife and children, my child, and I tried to come with you, but you said, ‘no don’t come’, and then you come up with a such sad story. It could lead to some other thoughts.”

(██████████, Rwanda, CL).

Similarly, ██████████ indicated that he faced difficulties engaging with legal and medical professionals and self-advocating his desires during his baby’s autopsy:

“My wish was to pursue this rigorously because I think that they did something wrong, I wanted to pursue it, but every time I want to go there I just had too much emotional strain to handle it. And that in itself makes me feel guilty, sometimes... like I let her down because... I should be able to fight for her. Just this for her. She was robbed of life of someone else's doing and every time I try to get invested in it and try to find legal ways I can’t follow it or I just feel like I can't handle it. Mostly I just feel I need to escape from that as quickly as I can.”

(██████████, Rwanda).

██████████’s experience of “dismissive” medical staff and contradictions between prior medical recommendations and subsequent procedures led to his described conviction of medical malpractice. In this instance, ██████████’s grief was complicated with feelings of guilt.

In general, cultural respect for medical authority, distrust of medical process, low health literacy and language barriers were all attested to complicate CALD men's advocacy for themselves and their partners, further complicating and prolonging grief.

3.3.5 Woman-centred support. HSPs reported that, within woman-centred pregnancy and birth care models, it was difficult to include men in formal support services following perinatal death. [REDACTED], a clinical midwife specialist, reported that:

“...we are so woman-focused. I do really try and acknowledge men, whilst they're here, and when I see them, in fact, just to check in on them, but because we are a women's hospital, our primary focus is the woman and her mental health...”

([REDACTED], HSP).

This tension was evident in both groups of participants' accounts, particularly since men are not formally patients of the healthcare service when perinatal death occurs: “it's more focused on the mum, because obviously, she's the patient and the husband is the support person.” (Kaitlin, HSP). Here, HSPs reported difficulties in supporting CALD men while simultaneously providing best-practice care for bereaved mothers. Specifically, cultural and religious practices surrounding burial and death, which CALD men may be responsible for, were difficult to facilitate in hospital environment. Sandra recounted that a Muslim man's desire to take his baby for ceremonial washing immediately after death conflicted with the midwives' intent for the mother to hold her baby:

“I find it hard sometimes because I'm a pretty independent kind of person and I...I get irritated with the powerful Muslim men overruling their women. So, I have to step back and recognise my feelings and keep those to myself. Because that's their culture and that's the way they do it, and I have to accept that. But I find it difficult because I'm like...”

‘God damn it... just let her have some time with a baby or let her cry it's okay’ or ‘don't take the baby away’... I'm all for women.”

(██████, HSP).

CLs also noted that, while woman-centred care was important, CALD men may feel that their own needs are not met in healthcare systems where: “men may feel that it's all about the woman and they're not welcome” (██████, HSP). The lack of support for men also existed outside the hospital system. David, a Singaporean man who experienced stillbirth, recounted his experience of seeking a support group:

“[In] most of the support groups there are more women than men. So, it is a bit awkward at times. I mean, in the group where the majority is woman, they grieve, they cry, but I do remember many times, I think I was the only guy there.”

(██████, Singapore).

Many of the participants testified to CALD men's preference for peer support programs” “men will stick with the men, and support one another” (██████, HSP). CLs also expressed that need for “men to men” peer support (CL, Rwanda).

Overall, CALD men who experience perinatal death in Australia were reported to face challenges in accessing and seeking support within woman-centred healthcare in hospital settings, and in perinatal support groups in the community. In hospital settings, tensions were seen where religious and cultural practices were sometimes at odds with medical priorities, potentially negatively affecting men's grief.

Discussion

4.1 Overview

This study begins to address a significant gap in the literature surrounding CALD men's experiences of grief and support following perinatal death. Two interrelating themes identified were CALD men's grief expression as stoic and partner-centred, both characteristic of instrumental grief patterns (Doka & Martin, 2000). Stoic and partner-centred grief patterns also reflect research with other (Western) samples of bereaved fathers (Bonnette & Broome, 2011; Kelley & Trinidad, 2012; Avelin et al., 2013; Robb & Ruxton, 2018; Jones et al., 2019; Obst et al., 2020b, 2021a). Accounts of CALD men's grief were highly individualised, reflecting a complex interplay of cultural, interpersonal, and individual factors unique to each participant (Obst et al., 2020b). However, distinct from previous research, the underlying socio-cultural factors reported to shape grief expressions were variable, including stigma, religious norms, and culturally-bound gendered expectations surrounding bereavement ritual and grief.

In line with prior research, CALD men in this study reported that strenuous roles and responsibilities made it difficult to grieve perinatal death (Ekelin et al., 2009; Campbell-Jackson et al., 2014; Obst et al., 2019b). Additionally, CALD men were represented by HSP participants as 'supporters' of their partners (O'Leary & Thorwich, 2006; Obst, 2019b). Taken together, these findings are consistent with the concept of an 'affective bias', where CALD men experience disenfranchised grief if instrumental grief processes go unrecognised. This may lead to a misperception that men, including CALD men, do not require as much support as women following perinatal death (Doka & Martin, 2011).

However, CALD men also highlighted the importance of focusing on their (female) partners during grief (Armstrong, 2001; Hamama-Raz, 2010). Instances of stoic grief were

framed by CALD participants as purposeful within the culturally-informed roles and responsibilities CALD men enacted in support of their families. Instrumental grief was represented as adaptive, enabling CALD men to fulfill their culturally informed support roles, and as a reaction to the distressing death. This is consistent with previous research highlighting the importance of male partner-support roles in enhancing recovery and responding to pregnancy related trauma (Daniels et al., 2020; Franz et al., 2021).

CALD men's predominantly restoration-oriented grief responses could be characterised as 'maladaptive' within a DPMC, where healthy adaptive coping is characterised by "oscillation" between both loss-oriented processes and restoration-oriented processes (Stroebe et al., 2007, p. 1967). Assessing the dominant restoration-oriented grief responses of some CALD men as 'maladaptive' would be a coarse oversimplification. CALD men's grief responses can also be considered adaptive to important culturally-informed responsibilities, stigma of open emotional expression, and the need some CALD men have to process traumatic pregnancy outcomes. Consequently, this study's findings support previous criticism of the DPMC as not explicitly including interpersonal and socio-cultural factors (Burglass, 2010) and supports a socioecological (SEMMG) approach following perinatal death, attending to the complex and interconnected way that cultural values, beliefs, and attitudes shape individual grief responses (Obst et al., 2020b; 2021a).

Throughout the interviews, participants indicated that stigma shaped CALD men's grief and support following perinatal death. Prior research has demonstrated stigma following perinatal death for mothers in countries such as the UK (Brierley-Jones et al., 2015), Tanzania (Haws et al., 2010), and Uganda (Kiguli et al., 2015). In the present study, women being blamed for perinatal death was shown (Burden et al., 2016); however, participants also described how

CALD men's infertility and genetics could be blamed for perinatal death. Globally, genetic testing during family planning has increased (Allyse et al., 2015) and parents are increasingly more likely to investigate the genetic basis for a pregnancy associated with both biological parents (Sleeboom-Faulkner, 2011). While previous research has shown that some Western fathers pursue autopsy specifically to preclude genetic causes when understanding a perinatal death's cause (Meaney, et al., 2014), some CALD women, such as from South-Asian backgrounds, are less likely to receive prenatal genetic screening (Rowe, 2004), perhaps due to cultural attitudes and stigma. Where CALD women may have been historically more likely to be blamed for perinatal death, increases in genetic testing among both parents may explain this study's finding that CALD men may also be blamed for, and experience stigma, following perinatal death.

Previous literature has found variable results in terms of the potential different grief outcomes in stillbirth as compared to neonatal death (Schaap, 2017). In this study, there was variation wherein some CLs expressed the view that, within CALD communities, stillbirth was considered less significant than perinatal death. This is consistent with religious and cultural beliefs where foetuses are sometimes considered 'pre-human' (Khorfan & Padela, 2010, p.102) and therefore attributed less personal and public grief. This is also consistent within literature demonstrating that the lack of social recognition for stillbirth in some countries led CALD mothers to question whether "they were truly a mother" (Pollock et al., 2020 p.215; Haws et al., 2010; Kiguli et al., 2015; Paudel et al., 2018).

However, within this study, HSPs and one CALD man who experienced stillbirth specified that they did not agree with the higher significance attributed to neonatal death by some CLs, instead stating that the ambiguity and hidden nature of stillbirth complicated grief and

subsequent support. These findings are consistent with previous literature indicating that stillbirths are also highly significant to bereaved parents, leading to disenfranchised grief when the baby is not publicly recognised (Lang et al., 2011; Kelley & Trinidad, 2012). Consequently, while all participant groups suggested that CALD men received support within their cultural and religious communities, this was likely to be more pronounced for neonatal death than stillbirth.

Although previous research has inconsistently reported feelings of guilt amongst fathers following perinatal death (Badenhorst et al., 2006), feelings of guilt were identified within this study. Specifically, CLs and CALD men with personal experience of neonatal death reported instances of guilt when CALD men were unable to achieve desired outcomes when interacting with healthcare and legal services following perinatal death. Taken together, these findings are significant as complicated and prolonged grief is commonly associated with disenfranchisement and enduring guilt (Fernández-Alcántara et al., 2021) and self-blame (Kersting & Wagner, 2012; Li et al., 2019).

Research into complicated and prolonged grief shows that bereaved parents may rely on dysfunctional coping patterns, and experience relationship distress and unacknowledged pain (Ellen & Brett, 2020; Mehran et al., 2013). Prolonged grief has also been shown to be associated with stigma, whereby individuals' enduring grief is not recognised by the broader society (Eisma, 2018). Further, previous research has shown that perinatal death is strongly associated with complicated grief (Kersting & Wagner, 2012). The stigma, disenfranchised grief, guilt, and enduring grief reported in this study suggest that some CALD men may be at increased risk of prolonged and complicated grief following perinatal death. Subsequently, this research contributes to broader investigations into the poorer pregnancy health, wellbeing, and perinatal

outcomes amongst CALD and migrant populations, where guilt may endure into subsequent pregnancies (Heslehurst et al., 2018; Abubakar et al., 2018).

Consistent with previous research, CALD participants shared that a strong respect for medical authority, distrust of medical practice, cultural stigma, and a lack of knowledge of support were barriers to CALD men's ability to communicate and make informed decisions within the Australian healthcare system (Wohler & Dantas, 2017; Ahmed et al., 2017; Jones, 2019). These findings can be contextualised in the broader literature, where people from CALD backgrounds are less likely to access mental health and healthcare in Australia (Henderson & Kendall, 2011; Hughson et al., 2018; Au et al., 2019). Here, self-advocacy and health literacy are important, enabling patients to gain maximum benefit from medical support (Vessey, 1997; Test et al., 2005; Ramirez et al., 2016).

A key tension in the study relates to how CALD men might fit into Australia's woman-centred perinatal healthcare system. Healthcare in Australia follows a woman-centred approach to midwifery, policy documentation, and support following perinatal death (Council of Australian Government Health Council [COAG], 2019; Brady et al., 2019; Leap, 2013). Significantly, this approach is seen to mitigate risk in situations of family domestic violence, which exists within some CALD families (Horiuchi et al., 2009; Ghafournia, 2011; Anthony et al., 2020). However, the current study found that CALD men faced difficulty advocating for, and understanding, their needs in the context of woman-centred supports, particularly in relation to the enactment of cultural rituals. Here, HSPs reported difficulty caring for bereaved CALD men within a woman-centred approach to pregnancy healthcare which is consistent with previous research on men from the general population (McCreight, 2004; Obst, 2019b; Samuelsson et al., 2001) Consequently, men from CALD backgrounds may benefit from specific health education

interventions to enable self-management and healthcare navigation strategies (Lambert et al., 2021). Inclusive language and male specific supports may better support CALD men's self-advocacy. Specifically, CALD men's important culturally-defined roles as 'supporters' may be welcomed within a woman-centred healthcare approach, where strong supports for men may also indirectly support women (Obst et al., 2019a).

4.1.1 Implications and support recommendations. In addition to the clear theoretical implications discussed above, this research has resulted in the following practical recommendations: while perinatal bereavement care guidelines acknowledge the importance of culturally-informed care following perinatal death (PSANZ, 2020, Section 3-9), there remains a lack of culturally-specific supports available. This research identified a need for support groups and assistance for CALD men to self-advocate following perinatal death. CALD men may benefit from supported medical investigations into cause of death, which support privacy, are transparent in translation, and are culturally appropriate. Given that socially acknowledged grief leads to reductions of stress and grief (Lang et al. 2011; Aoun et al., 2020), it is evident that support services must acknowledge CALD men's significant loss following perinatal death. While also considering the historic under-reporting of domestic violence within CALD families in Australia (Ghafournia, 2011; Anthony et al., 2020), it is advisable that CALD men, where reasonable, are proactively engaged within Australia's perinatal healthcare to support both themselves and their female partners (COAG Health Council, 2019). Future bereavement care guidelines should consider the important culturally-shaped roles that CALD men play to support their families, and how woman-centred perinatal care systems can both be maintained and extended to accommodate CALD men without impacting the quality of care for women.

Consistent with a socio-ecological model, a multi-level approach, considering community, workplace, and individual grief presentations, may best address CALD men's support needs. For instance, previous research has recognised how peer-run CALD community organisations support members with healthcare visits, translation, and support in Australia (Macnimara & Camit, 2016). It is strongly recommended that formal health services recognise the need for greater collaboration with CALD communities, potentially leading to increased access and the development of more effective health intervention and education programs for CALD families following perinatal death. Reciprocally, health service practitioners may benefit with the improvement of language and translator services, cultural safety training, and a practical understanding how CALD men's cultural and religious beliefs and rituals may best be supported within healthcare environments. Further, it remains necessary for improved financial assistance for families who may receive minimal practical and financial support following perinatal death. This may be especially significant for CALD men, who may have reduced access to these supports compared to the general Australian population (Ahmed et al., 2017). Consistent with previous research, increased financial aid, leave provisions, and workplace support for men are needed (Obst et al., 2019a, 2020a).

4.1.2 Strengths. Tracy's (2010) "Big Tent" criteria for qualitative research was followed when conducting this research. Specifically, an audit trail was employed to ensure rigorous self-reflexivity and transparent research. Additionally, by recruiting participants from a range of healthcare, support, and community backgrounds, triangulation of the themes enhanced the credibility of the author's representation of participant responses (Tobin & Begley, 2004). Additionally, there is little research on the psychological wellbeing, grief, and health-outcomes

following perinatal death for CALD men (Obst et al., 2020b). This study represents the first exploration into CALD men's grief and experiences of support following perinatal death

4.1.3 Limitations. This study recruited a small sample of CALD men who had personally experienced perinatal death. Further, CALD members were largely religious, coming from dominantly Abrahamic religions (Christianity, and Islam; Şenel, 2018). Although notably, CALD men with personal experience of perinatal death were less religious than CLs. Similarly, CALD participants were largely well educated, which also may not be representative of all CALD men (Abdelkerim et al., 2012). Additionally, due to the snowball sampling method, many participants were closely associated with community groups and likely received higher rates of community-based support following perinatal death. While the purpose of thematic analysis is not to provide a generalisable sample (Braun & Clarke, 2013), the results of this study may not reflect the experiences of all CALD men experiencing bereavement in Australia, many of whom may not receive equivalent community support, or have the same religious or educational backgrounds, as those within this study.

A further challenge in this study was the lack of a shared definition of perinatal death. Previous research has shown that sociocultural practices and beliefs can lead to the misclassification and underreporting of stillbirth in cross-cultural settings (Zakar et al., 2018). Whilst community members generally reported perceiving differences between neonatal death and stillbirth, the differences were generally drawn from the distinction of neonatal death being associated with a live birth. It was unclear if some CALD community participants would have chosen to differentiate stillbirth from miscarriage, or neonatal death from other infant mortalities, if not for the clinical definition provided by the researchers. Especially considering stillbirths, amongst other 'unborn' deaths, are underreported in countries such as China, India, Pakistan, and

Middle African and South East Asian countries, from which this study's CALD participants emigrated (Roberts et al; 2012; Stanton et al., 2006). Moreover, previous research has criticised cross-linguistic equivalence of language, where translations frequently miss important semantic nuances (Dobrovolskij, & Piirainen, 2010). Future research may benefit from demarcating stillbirth as distinct from neonatal death within participants' own language (Regmi et al, 2010).

4.1.4 Future research. It remains necessary for future research to explore the experiences of gay, bisexual, and/or transgender men following a perinatal death, including those who utilise surrogacy, who come from CALD backgrounds, and who may experience dual-disenfranchisement in receiving support and accessing appropriate health service provision following perinatal death (Due et al., 2017; Stafford-Bell et al., 2014). Additionally, while this research has aimed to address a significant research gap by examining the experiences, support and stigma for CALD men in a high-income country, previous estimates indicate 98% of global stillbirths occur in low- and middle-income countries (Lawn et al., 2011). Further, the stigmatisation of stillbirth has been shown to be especially prevalent in these countries (Burden et al., 2016). Taken together, future research may benefit by showing consideration for those countries and cultures with higher prevalence of perinatal death and perinatal death stigma. Future research may also consider the way in which cultural views of perinatal death may translate within the emerging context, such as where CALD men may experience stigma following prenatal genetic testing.

4.1.5 Conclusion. This study provides important and novel insights into CALD men's grief and support needs following perinatal death. CALD men's grief was shown to be associated with interpersonal, community, and socio-cultural factors that broadly fit a SEMMG following Obst and colleagues (2020b); although the study demonstrates clear possibilities for

modifications to this model. Specifically, cultural, interpersonal, and public policy factors were found to interact, particularly where CALD men's respect for medical authority and difficulties navigating woman-centred care act as self-advocacy barriers following perinatal death. These findings indicate that CALD men may benefit from targeted and culturally safe mental health, financial, and emotional support following perinatal death. In particular, the study points to the clear need to consider intersections of culture and gender norms for CALD men, who are likely to experience isolation and disenfranchised grief following perinatal death.

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Appendix A:*Participant Flyer*

Researchers from the School of Psychology at The University of Adelaide
are conducting a study called:

**"CULTURALLY AND LINGUISTICALLY DIVERSE MEN'S
EXPERIENCES OF PERINATAL DEATH IN AUSTRALIA"**

We would love to talk with you if you are:

**A MAN FROM A CULTURALLY AND LINGUISTICALLY DIVERSE
BACKGROUND**
(for example, your first language is not English)

WHO HAS EXPERIENCED PERINATAL DEATH.
(that is, a baby who died at or after 20 weeks gestation or up to 28 days
following a live birth)

or

**YOU ARE A LEADER WITHIN A CULTURALLY AND LINGUISTICALLY
DIVERSE COMMUNITY (CALD).**

or

**YOU ARE A HEALTH SERVICE PROVIDER WORKING WITH CALD MEN
FOLLOWING A PERINATAL DEATH.**

In the interview, we will ask you questions about grief
following perinatal death for men in your community. We would
also like to understand the support needs of (CALD) men whose
baby died in the perinatal period in your community.

THE INTERVIEW WILL LAST FOR APPROXIMATELY 60 MINUTES.

We will do the interview on the phone or a video call. If you are in
Adelaide and would like to meet up, we can do that too.

If you are interested in doing an interview or would like more
information, please contact Thom Pearson


[REDACTED]

or call Dr. Clemence Due on [REDACTED]

LOOKING FORWARD TO TALKING WITH YOU!

THIS RESEARCH IS BEING SUPERVISED BY DR.
CLEMENCE DUE, IT HAS BEEN APPROVED BY THE
UNIVERSITY OF ADELAIDE HUMAN RESEARCH
ETHICS COMMITTEE.

THE APPROVAL NUMBER IS H-2021-048



**THE UNIVERSITY
of ADELAIDE**

Appendix B:*Participant Information Sheet – Community Leader***PARTICIPANT INFORMATION SHEET**

PROJECT TITLE: Culturally and linguistically diverse (CALD) men's experiences of perinatal death in Australia.

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER:

PRINCIPAL INVESTIGATOR: Dr Clemence Due

STUDENT RESEARCHER: Mr. Thomas Pearson

STUDENT'S DEGREE: Honours Bachelors or Psychological Science

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 aims to improve our understandings of culturally and linguistically diverse (CALD) men's experiences of perinatal death in Australia. Perinatal death includes stillborn babies born at or after 20 weeks' gestation, and babies who die up to 28 days after birth. The findings of this

study may be used to develop Australian perinatal bereavement care guidelines for culturally and linguistically diverse men, so men can be better supported in the future.

Who is undertaking the project?

This project is being conducted by Thomas Pearson. It will form the basis for his degree of Bachelor of Psychological Science (Honours) at the University of Adelaide, under the supervision of Dr Clemence Due and Ms Kate Obst.

Why am I being invited to participate?

You are being invited to participate because you are a community leader and have some knowledge about grief following perinatal death – as well as support needs - for men in your community.

What am I being invited to do?

You are being invited to participate in an interview regarding your experiences of culturally and linguistically diverse men's grief and support needs following perinatal death. Interviews can take place at a location suitable to you if you are in Adelaide, or over the telephone or through videoconference if you are interstate or if you prefer this option. The interview will be audio recorded, so that the interview can be typed and analysed. All personally identifying information will be removed from the transcript and you will have a chance to read this and make changes.

How much time will my involvement in the project take?

The 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 there is a comprehensive list of supports that you may wish to access on this Information Sheet. These include telephone helplines, online forums, and organisations relevant to perinatal death.

In addition, if you are very distressed the researchers will follow up with you to make sure you are alright.

You can also choose not to answer questions, or to end the interview at any time.

In the event that you experience a large amount of distress, or are at risk of harm, the researchers may contact your preferred health-care provider/GP on your behalf. However, this will only occur if you give the researchers permission to contact your preferred health-care provider on your behalf.

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 culturally and linguistically diverse men following perinatal death.

You will also receive a \$40 shopping voucher as a thank you for your time.

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 (October 2021).

What will happen to my information?

Subject to any legal requirements to disclose, all information you provide will remain confidential . Your name and any identifying information 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. As the sample size is small, complete anonymity cannot be guaranteed. However, the utmost care will be taken to ensure that no personal identifying details are revealed.

The project will be written up in the form of a journal article, which will be submitted for publication to peer-reviewed journals. We 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 we will send you a copy of this report if you wish.

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 Thomas via email: thomas.pearson@student.adelaide.edu.au or Dr Due (phone: 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-2021-048). 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 Thomas ([REDACTED]) to organise a time and place for an interview.

Yours sincerely,

Mr. Thomas Pearson

Dr Clemence Due

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

<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

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 C:*Participant Information Sheet –Health Service Professional***PARTICIPANT INFORMATION SHEET**

PROJECT TITLE: Culturally and linguistically diverse (CALD) men's experiences of perinatal death in Australia.

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER:

PRINCIPAL INVESTIGATOR: Dr Clemence Due

STUDENT RESEARCHER: Mr. Thomas Pearson

STUDENT'S DEGREE: Honours Bachelors or Psychological Science

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 culturally and linguistically diverse (CALD) men's experiences of perinatal death (the death of a baby between 20 weeks of gestation and 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 CALD men's grief and subsequent support needs following perinatal death is lacking. The findings of this study may be used to develop a comprehensive theory of CALD men's grief, to inform Australian perinatal bereavement care guidelines, so men can be better supported in the future.

Who is undertaking the project?

This project is being conducted by Thomas Pearson. It will form the basis for his degree of Bachelor of Psychological Science (Honours) at the University of Adelaide, under the supervision of Dr Clemence Due and Ms Kate Obst.

Why am I being invited to participate?

You are being invited to participate if you are Health Professional who has experience working with CALD men through a period of perinatal loss in the previous 10 years

What am I being invited to do?

You are being invited to participate in an interview regarding your experiences of CALD men's grief following pregnancy perinatal loss. Interviews will take place can take place at the University of Adelaide (North Terrace Campus), over the telephone, via Zoom, 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.

In the event that you experience a large amount of distress, or are at risk of harm, the researchers may contact your preferred health-care provider/GP on your behalf. However, this will only occur if you give the researchers permission to contact your preferred health-care provider on your behalf.

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?

Subject to any legal requirements to disclose, all information you provide will remain confidential. Your name and any identifying information 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. As the sample size is small, complete anonymity cannot be guaranteed. However, the utmost care will be taken to ensure that no personal identifying details are revealed.

The project will be written up in the form of a journal article, which will be submitted for publication to peer-reviewed journals. We 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 we will send you a copy of this report if you wish.

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 Thomas email:

[REDACTED]

[REDACTED]

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-2021-048). 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 Thomas (email: thomas.pearson@student.adelaide.edu.au) to organise a time and place for an interview.

Yours sincerely,

Mr. Thomas Pearson

Dr Clemence Due

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

<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

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 D:

Participant Information Sheet – CALD man with lived experience.

**PARTICIPANT INFORMATION SHEET**

PROJECT TITLE: Culturally and linguistically diverse (CALD) men's experiences of perinatal death in Australia.

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2021-048

PRINCIPAL INVESTIGATOR: Dr Clemence Due

STUDENT RESEARCHER: Mr. Thomas Pearson

STUDENT'S DEGREE: Honours Bachelors or Psychological Science

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 aims to improve our understandings of culturally and linguistically diverse men's experiences of perinatal death in Australia. Perinatal death includes stillborn babies born at or

after 20 weeks' of gestation and babies who die up to 28 days after birth. The findings of this study may be used to develop Australian perinatal bereavement care guidelines for culturally and linguistically diverse men, so men can be better supported in the future.

Who is undertaking the project?

This project is being conducted by Thomas Pearson. It will form the basis for his degree of Bachelor of Psychological Science (Honours) at the University of Adelaide, under the supervision of Dr Clemence Due and Ms Kate Obst.

Why am I being invited to participate?

You are being invited to participate because you have experience of perinatal death and come from a culturally and linguistically diverse background (for example, you speak a language other than English as your primary language).

What am I being invited to do?

You are being invited to participate in an interview regarding your experiences of perinatal death and the support you had or would like to have had.

Interviews can take place at a location suitable to you if you are in Adelaide, or over the telephone or through videoconference if you are interstate or if you prefer this option. The interview will be audio recorded, so that the interview can be typed up and analysed. All personally identifying information will be removed from the transcript and you will have a chance to read this and make changes.

How much time will my involvement in the project take?

The 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 there is a comprehensive list of supports that you may wish to access on this Information Sheet. These include telephone helplines, online forums, and organisations relevant to perinatal death.

In addition, if you are very distressed the researchers will follow up with you to make sure you are alright. You can also choose not to answer questions, or to end the interview at any time.

In the event that you experience a large amount of distress, or are at risk of harm, the researchers may contact your preferred health-care provider/GP on your behalf. However, this will only occur if you give the researchers permission to contact your preferred health-care provider on your behalf.

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 culturally and linguistically diverse men following perinatal death. You will also receive a \$40 shopping voucher as a thank you for your time.

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 (October 2021).

What will happen to my information?

Subject to any legal requirements to disclose, all information you provide will remain

confidential . Your name and any identifying information 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. As the sample size is small, complete anonymity cannot be guaranteed. However, the utmost care will be taken to ensure that no personal identifying details are revealed.

The project will be written up in the form of a journal article, which will be submitted for publication to peer-reviewed journals. We 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 we will send you a copy of this report if you wish.

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 Thomas via email: thomas.pearson@student.adelaide.edu.au) or Dr Due (phone: 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-2021-048). 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 Thomas (email: thomas.pearson@student.adelaide.edu.au or call his supervisor Clemmi on 8313 6096) to organise a time and place for an interview.

Yours sincerely,

Mr. Thomas Pearson

Dr Clemence Due

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

<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

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 E:

Consent Form:

CONSENT FORM



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

Title:	Culturally and linguistically diverse (CALD) men's' experiences of perinatal death in Australia.
Ethics Approval Number:	H-2021-048

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.
11. In the instance that I experience significant distress, I consent to a researcher contacting my chosen health-care provider on my behalf.
 Yes No

Participant to complete:

Name: _____ Signature: _____ Date: _____

Preferred health-care provider / GP / counsellor: _____

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 F:

Interview guide

Group 1: CALD community leaders :

- **What is your cultural background? And Could you please tell me about your role within the community?**
 - Could you please tell me about the significance of your role within your cultural background?
 - The support/care that you provide within the community?
 - The length of time you have been in this role?
- **Could you tell me how perinatal death is viewed in your community?**
 - How do religious or cultural views within your community shape how perinatal death is understood?
 - Is perinatal death a topic that is openly discussed in your community?
 - Would families experiencing perinatal death talk about it? If yes, to whom?
- **What is perinatal death like for men within your CALD context?**
 - Are men involved in pregnancy and childbirth?
 - How/Do men have an important role in supporting the wife after perinatal death?
 - How/Does perinatal death impact on the perception of men as “fathers”?
 - How do men grieve a perinatal death within your CALD context?
 - Does culture affect understandings of perinatal death? If yes, how?
- **Who within the community would be there to help families and men experiencing perinatal death?**
 - What kind of support would a man encounter from within your cultural/community context?
 - Does the support a man receives differ to the support a woman would receive?
 - For example;
 - Prayer support
 - Food packages support
 - Conversation/emotional support
 - Financial assistance
- **How do you think that CALD men understand perinatal death?**
 - Is there stigma surrounding perinatal death?
 - Is there stigma surrounding men's grief?
 - Are there differences in the way that miscarriage/stillbirth/neonatal death is understood?
 - **(Item 3)** Are there differences in the way that miscarriage/stillbirth/neonatal death is understood? (Stigmatised?)
 - Do you think there are cultural/religious differences in how perinatal death is perceived for people in your community?

- **Do you think there are any specific grief considerations for CALD men?**
 - **(Item 4)** Do you have specific funeral burial, grieving practices that encompass perinatal death?
 - **(Item 5)** What is something you would like medical/ health practitioners to understand about this issue?
 - How do people in your culture/religion grieve a perinatal grief
- **Do men in your community have any specific (bereavement) support needs after perinatal death?**
 - Do you think that men in your community who experience perinatal death process, or grieve, their loss in a specific religious or cultural way?
 - Who are the people that support men in perinatal bereavement.
 - How does the religious or cultural beliefs of your community impact on men bereavement needs?
- **How is supporting bereaved CALD men approached in your community/ community organisation?**
 - Including strategies for taking into account families' personal cultural practices or refugee/migrant status
 - Are there currently any policies in place by your organisation/church/community that address men's bereavement needs?
 - Do you have any strategic partnerships with Health providers for CALD men who you could refer to for further support?
 - What works well in terms of supporting bereaved men?
 - What could be done differently within your community, or the broader society, to support men after perinatal death?
- **Is there anything else that you would like to add?**
- **Would you like to review a copy of your interview transcript once it has been typed up?**
Circle: Y/N
- **Would you like to review an overview of the results of the research before they are finalised?** Circle: Y/N
- **Would you like to receive a copy of my thesis and/or any publications resulting from this research?** Circle: Y/N
- **Collect demographic information (All groups)**
 - Age
 - Gender
 - State of residence
 - Occupation
 - Highest level of education
 - Ethnicity
 - Country of birth
 - Language spoken at home

Group 2: Healthcare professionals

- **Can you please begin by telling me...**
 - About your (professional) background
 - The organisation you're currently employed by (i.e. public maternity hospital, refugee service)
 - Your role
 - The specialist support/care that you provide
 - The length of time you have been in this role
- **How often do you work with/care for culturally diverse men? Which countries do most of your clients come from/were born in?**
- **Can you describe your experiences of working with culturally diverse men who have experienced perinatal death?**
- **How do you think that culturally diverse men understand perinatal death?**
 - Is there stigma surrounding perinatal death?
 - Does this depend on stillbirth or neonatal death?
 - Is there stigma surrounding men's grief?
 - Are there differences in the way that miscarriage/stillbirth/neonatal death is understood within different cultural context's?
 - Do you think there are cultural/religious differences in how perinatal death is perceived for Culturally Diverse men?
- **How do you think culturally diverse men express grief following perinatal death?**
 - Are there differences here between neonatal death and stillbirth?
- **Do you think there are any specific grief needs for culturally diverse men?**
 - Other support from CALD organisations or groups
 - Prompts for culture/religious differences
 - Who do you think in the lives of CALD men, provide support for their needs?
- **Are there any differences in caring for culturally diverse men compared to other people?**
 - *Migration/refugee experience (trauma)*
 - *Social context*
 - *'Cultural' beliefs/practices*
 - *Religious beliefs/practices*
 - *Gender*
 - *Coping strategies*
 - *Expression of grief*
 - *Whole family care*
- **How is supporting bereaved culturally diverse men approached in your organisation?**
 - Including strategies for taking into account families' personal cultural practices or refugee/migrant status

- Are there currently any policies or bereavement care guidelines in place? Or specific training?
 - Do you have any strategic partnerships with CALD support organisations?
 - What could be done differently?
 - **What sort of emotional and psychological supports are usually provided to culturally diverse men following stillbirth and during/after pregnancy and childbirth?**
 - How useful do you think these supports are?
 - What kind of follow up care/ contact is provided to CALD men and their families after perinatal death?
- Does your organisation offer any specific supports to men following perinatal death?**
- *If yes, what are they?*
 - *What works well?*
 - *What could be done differently?*
 - *Is care ongoing/ when does it stop?*
- **Do you feel that there are any challenges you face when it comes to providing support to culturally diverse men following perinatal death?**
 - *Are there any gender differences in relation to challenges in providing this support?*
 - *Are there any cultural or religious differences in relation to challenges in providing this support?*
 - **What would help you and/or your colleagues to better/best care for culturally diverse men following perinatal death?**
 - **What would best-practice for bereavement care for culturally diverse men following perinatal death like in a perfect world?**
 - **Is there anything else that you would like to add?**
 - **Would you like to review a copy of your interview transcript once it has been typed up?**
Circle: Y/N
 - **Would you like to review an overview of the results of the research before they are finalised?** Circle: Y/N
 - **Would you like to receive a copy of my thesis and/or any publications resulting from this research?** Circle: Y/N
 - **Collect demographic information**

Group 3: CALD men

- **Can you tell me about your experiences with pregnancy and childbirth?**
 - Can you tell me about your family? any children?
 - how old are they?
 - What do you see as your role during pregnancy and childbirth?
 - How long ago was your loss?
 - Have you experienced more than one loss?

- At what age of gestation, or, how long after birth did your child die?
- **Have you had any pregnancies following your baby's death?**
 - What have these been like?
 - How have these subsequent pregnancy been impacted by your experiences of perinatal death
- **Can you tell me about your relationship with the baby who died fix this?**
 - Did you interact with your baby?
 - Did you view ultrasound images of your baby?
 - Did you attend obstetric appointments with your partner?
 - Did you name your baby?
- **Can you tell me about your reactions to your baby's stillbirth/death?**
 - Were you outwardly emotional, or did you try to hide your emotions?
 - What kind of emotions did you experience? (E.g., Sadness, anger, guilt)
 - Did you experience any physical responses? (E.g., headaches, body aches, trouble sleeping?)
 - What were some of the thoughts that ran through you mind after your baby died?
- **Has your grief changed over time?**
 - Did your life change because of your baby's death?
 - How has your grief changed?
 - Is there anything you felt made your grief experience more difficult? Or easier?
- Do you feel like your grief was recognised and understood by those around you?**
 - For example, with your spouse, family members, friends, or healthcare professionals?
 - If yes, what type of recognition?
 - Who was the best support? How?
 - Any specific family members who were most supportive? E.g., parents/siblings, etc.?
- **Did the stillbirth/neonatal death affect your relationships?**
 - Prompts for wife/partner (if applicable) or other children (if applicable)
 - Family members
 - Friends
 - Community
- **Do you think that being a man affected your grief? If so, how?**
 - Did you feel responsible to have to care for your wife/partner? (if applicable)
 - Was being a support to your wife/partner important? (if applicable)
 - Do you feel you had opportunity to express your grief in a way that felt natural to you?
- **What helps/ed you manage your grief?**
 - Did you ask anyone for help?
 - Did you share or talk about your grief with anyone?
 - Has your community/religious affiliation/faith been a support to you?
 - Was it easy to find and/or contact someone to talk to about your grief?
- **What were your experiences with medical and health professional like?**

- Did you feel that you received satisfactory care at a hospital?
- Which ward did your wife/partner give birth in?
- What medical professionals were involved in your/your wife/partner's care? (E.g., midwives, social workers, sonographer, obstetricians, etc.)
- Did healthcare staff provide you with adequate information on your baby's medical care/difficulties and the options you had?
- Did you feel like you were able to make informed decisions?
- Did you feel included in hospital care as a father/man?
- Were you offered any information on grief and/or support? For men, specifically?
 - If yes, did you feel that this information was culturally-appropriate/useful?
 - (If applicable) was this information available in your first/preferred language?
- Was there anything that made making decisions following your perinatal death more difficult? Easier?
- Did you have the opportunity to spend time with your baby in hospital?
 - If yes, what was this experience like?
 - What options/care were you offered?
- Do you feel like you had good follow-up care/support from the health system?
 - Did you, or your wife/partner, receive any follow-up calls from your healthcare team?
 - Were you offered any referrals to psychosocial or community supports?
- Do you feel that the doctors and health professionals who cared for you/your partner understood your needs?
- **Did you access any community (bereavement) supports?**
 - E.g., counselling, support groups, online supports?
 - If yes, what were your experiences with these supports? (Good, bad, other?)
- **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 it easy for you to reach out to others for support?
 - What types of supports were available to you?
 - What supports were (or would have been) most helpful to you?
 - Did you have any particularly positive or negative experiences of support?
- **How is stillbirth/neonatal death understood in your cultural background/community/religion**
- Is there stigma surrounding perinatal death?
 - Is there stigma surrounding men's grief?
 - Is perinatal death openly discussed by your community?
 - Does your community observe any rituals/memorials for babies who die during/shortly after pregnancy?
 - What are men's expected roles following perinatal death in your community?

- **Can you identify ways that your experiences were different or more difficult for you than others?**
 - How does your cultural background impact on your experience of your death?
 - What does it mean to be of (e.g., Afghan, Syrian, Ethiopian, Indian) descent and to lose a child in this way?
 - Did the healthcare system as you experienced it, meet your cultural or religious needs during the time of your grief?
- **Were you working at the time?**
 - Did you return to work? If yes, after how long?
 - What was that like?
 - Did you feel that your employer and/or colleagues were supportive?
- **Is there anything else you would like to tell us that you considered important to your experience?**
- **Would you like to review a copy of your interview transcript once it has been typed up?**
Circle: Y/N
- **Would you like to review an overview of the results of the research before they are finalised?** Circle: Y/N
- **Would you like to receive a copy of my thesis and/or any publications resulting from this research?** Circle: Y/N
- **Collect demographic information**