Comparing the Lived Experience of Men and Women Bereaved by Stillbirth: A Meta-Synthesis of Qualitative Studies

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Declaration

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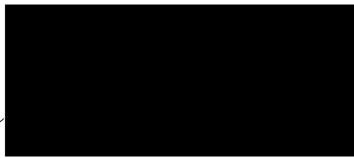

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Comparing the Lived Experience of Men and Women Bereaved by Stillbirth: A Meta-Synthesis of Qualitative Studies

Literature Review

Abstract

Stillbirth rates in Australia have remained stable in the past 20 years, with some 2,000 families affected each year. Despite this, research into the multi-dimensional impact of stillbirth remains limited. Most research to date focusses on the immediate needs of bereaved mothers, particularly grief and the response of health professionals in hospital settings. What is needed from research is a deeper understanding of the impact of stillbirth on fathers, siblings, grandparents, family systems, mental health, relationships, employment and workplace productivity. The relationship between the experience of stillbirth and social constructs, gender, parenting, stigma and attachment also requires closer attention. Surprisingly, the economic impact of stillbirth is poorly described. The direct and indirect costs of stillbirth in Australia from 2016-2020 is estimated to sum $681 million highlighting the need for action to reduce stillbirth and its devastating and pervasive impacts on those bereaved, and Australian society.

Stillbirth affects approximately 2,000 Australian families each year (Australian Institute of Health and Welfare, 2018). For many, the bereavement has life-changing impacts. Over the past 20 years, and despite advances in medicine, the Australian stillbirth rate has remained relatively unchanged (AIHW, 2018). Research into the psychological impact of stillbirth is a growing yet mostly under-researched area. The majority of research to date has focussed on the impact of stillbirth on women and the response of health professionals to such pregnancy outcomes. The broad aim of these studies has been to improve the provision of health care in hospital settings. Stillbirth research has less often considered the experience of men and the cultural and social factors that impact the lived experience of stillbirth for bereaved parents.

This literature review aims to explore what is known about stillbirth and the complex impacts of this experience. It will commence by defining stillbirth, both in an international and Australian context. From here, the multi-dimensional impact of stillbirth will be considered, including not only the emotional and psychological consequences but also the broader reaching financial and social implications of such loss. Important to this body of research, models and theories of grief relevant to stillbirth will be explored and discussed. The cultural experience of stillbirth will also be investigated along with experience by gender. To conclude this review will present key limitations in the literature and recommend areas for future research.

Defining Stillbirth

To appropriately review the literature, it is important to first define common terms in the stillbirth field. In Australia, stillbirth is defined as a baby born without signs of life, whom is of 20 weeks gestational age or weighs 400 grams or more (Hilder, Li, Zeki, & Sullivan, 2014).

Stillbirth is often discussed interchangeably with the term 'fetal death', but it is important to understand the distinction between the two. Fetal death is a broader term which encompasses stages of pregnancy prior to 20 weeks' gestation and does not recognise birth (Perinatal & Maternal Mortality Review Committee, 2013). Due to this distinction, stillbirth is the preferred term used in Australia (Froen et al., 2011).

Neonatal death and perinatal death are also terms used in the stillbirth literature. Neonatal death is defined as the death of a baby in the first 28 days following birth (Hilder et al., 2014). Perinatal deaths are considered the combined sum of neonatal deaths and stillbirths. This sum is commonly reported as a 'perinatal mortality rate' which is reported as the number of perinatal deaths per 1000 births (Hilder et al., 2014). This is distinguished from the World Health Organisation (WHO) who refer to a 'stillbirth rate' as the number of fetal deaths per 1000 births (World Health Organisation, 2016). It should be noted for international comparison that the WHO defines stillbirth as the death of a baby who is of 28 weeks or greater gestation, or weighs 1000 grams or more, or is at least 35 centimeters in length (WHO, 2016). And yet another definition, the ICD-10 classification, describes stillbirth as the death of a baby whom is of 22 weeks or greater gestation, or weighs 500 grams or more, or is at least 25 centimeters in length (WHO, 2016).

It is important to highlight the international differences that exist in defining stillbirth. Similar to Australia, in New Zealand babies are considered stillborn from 20 weeks gestation or from 400 grams birth weight. In Canada, stillbirth encompasses all fetal deaths from 20 weeks gestation or from 500 grams birth weight, while in the United States of America stillbirth includes all fetal deaths from 20 weeks gestation but expressly excludes deaths resulting from termination of pregnancy. The United Kingdom (UK) defines stillbirth as all fetal deaths from 24 weeks gestation, while across Europe, there is greater variation with gestation ranges from 16-26 weeks (Hilder et al., 2014). The variation in stillbirth definitions

creates difficulties in comparing data cross-culturally. The WHO's definition may enable global comparisons but also clearly contributes to under-representation of the prevalence of stillbirth.

Prevalence of Stillbirth

It is estimated that worldwide 7000 women a day experience stillbirth with 2.6 million third trimester stillbirths reported in 2015 (Lawn et al., 2016). Ninety-eight percent of stillbirths occur in low- and middle-income countries (Lawn et al., 2016). Causes of stillbirth gleaned from countries with reliable data indicate that 7.4% of global stillbirths result from congenital abnormality. A staggering 66.4% of disorders found to be associated with stillbirth are modifiable; these include maternal infections, non-communicable disease, nutrition, lifestyle factors, prolonged pregnancies and maternal age greater than 35 years. Causal pathways are also reported to frequently involve placental dysfunction (Lawn et al., 2016).

In Australia, six babies are stillborn each day, accounting for one in every 135 births (Stillbirth Foundation Australia, 2018). In 2012 there were 1,832 stillborn babies in Australia, comprising two-thirds of all perinatal deaths. In their report, Hilder et al. (2014) summarise the causes of stillbirths in Australia. From 2004-2008 the main categories for stillbirths in Australia were antepartum death (21.7%), congenital abnormalities (21.2%) and maternal conditions (12.7%), totalling more than half (55.6%) of all perinatal deaths in Australia over that time. Spontaneous pre-term birth was also a common cause of stillbirth (10.9%) in Australia.

The Australian perinatal mortality rate is reported to have declined steadily from the 1960's to the early 1990's. Although, since 2001, there has been little reported change in perinatal deaths (Hilder et al., 2014). Fluctuations are noted since 2001 to include a fall in the neonatal mortality rate matched by a slight rise in stillbirths. Despite considerable advances in medical technology, the rate of stillbirth in Australia has not declined in two decades

(Hilder et al., 2014). Given that 21.2% of stillbirths result from congenital abnormalities, this plateau in annual stillbirth rates is of marked concern. While Australia has one of the lowest stillbirth rates and is considered one of the safest countries in the world to give birth (Stillbirth Foundation Australia, 2018) the continued loss of life to potentially modifiable and preventable causes requires immediate attention. This has in part been recognised by the Australian government who in March 2018 established a Senate Inquiry into Stillbirth Research and Education in Australia. The inquiry resulted in a National Stillbirth Action Plan and commitment to reducing the Australian stillbirth rate by 20% over the proceeding three years (Commonwealth of Australia, 2018).

The Multi-dimensional Impacts of Stillbirth

The impact of stillbirth is far-reaching and multi-dimensional. Much of the stillbirth literature explores the role health care professionals play in the provision of care to bereaved parents (Watson, Simmonds, LaFontaine & Fockler, 2019; Peters, Lisy, Riitano, Jordan, & Aromataris, 2016). Predominately this research focusses on the provision of maternity care within hospital settings and is typically directed at responses to mothers and the stillborn child (Lisy, Peters, Riitano, Joran, & Aromataris, 2016; Nuzum, Meaney, & O'Donoghue, 2018). Such studies have often focussed on health professional behaviours intending to improve clinical care and in turn potentially improve outcomes related to grief, coping, relationship satisfaction and mental illness for bereaved parents (Kingdon, O'Donnell, Givens, & Turner 2015; Mills et al., 2014).

While the breadth and depth of stillbirth literature is generally agreed as lacking, valuable information has been gleaned from studies to date. Practical recommendations from the literature when responding to parents bereaved by stillbirth include: the importance of acknowledging the baby as a child who has died, allowing parents to spend time with their child, providing a private area away from the often distressing sounds of live, healthy

newborns for parents and families to grieve, and the provision of information on normal reactions to stillbirth, including grief, support services, rights to autopsy and funerals (Basile & Thorsteinsson, 2015; Bond, Raynes-Greenow, & Gordon, 2018).

Health professionals, particularly midwives and obstetricians, have been found to have a positive impact on parents' emotional and psychological processing of this often traumatic experience when they treat parents with empathy, humanity and respect (Bond et al., 2018). Health professionals are also encouraged to refer to the stillborn baby by their name if given, and appropriately acknowledge the distress of stillbirth (Aiyelaagbe, Scott, Holmes, Lane, & Heazell, 2017). Conversely, parents report increased distress when their deceased child is not acknowledged, when their emotions are not appropriately addressed and when they are not informed of what to expect, emotionally, psychologically and practically following stillbirth (Bond et al., 2018; Cacciatore, Erlandsson, & Radestad, 2013). Lived experience accounts of those bereaved by stillbirth discuss the marked impact apathetic responses from health professionals had on their psychological wellbeing in the immediate and longer-term (Aiyelaagbe et al., 2017). Consistent with intense emotional experiences, those bereaved by stillbirth are reported to easily recall their experience in detail, along with the helpful or harmful responses of health professionals. Consistent with these lived experience accounts research shows how health professionals respond to stillbirth in the hospital setting can have a direct impact on longer-term psychological symptoms (Bakhbakhi, Burden, Storey, & Siassakos, 2017; Basile & Thorsteinsson 2015).

Research exploring the impact of stillbirth on bereaved parents beyond hospital admission has generally focussed on mental health outcomes, impact on relationships and grief (Avelin, Radestad, Saflund, Wredling, & Erlandsson, 2013; Christiansen, Olff, & Elkilt, 2014; Hennegan, Henderson, & Redshaw 2015). This research is often focussed on the experience of mothers. Review of such studies suggests differences exist in the lived

experience of stillbirth between mothers and fathers, although this is rarely explicitly explored.

Longer term impacts of stillbirth are reported to include parental and family grief, including disenfranchised grief, relationship difficulties, parental mental illness including depression, anxiety and post-traumatic stress disorder, substance use, chronic pain, financial stress and employment difficulties (Cacciatore, 2013). Grief concerning to stillbirth will be discussed in more detail later in this review. Burden et al. (2016) explored the psychosocial impact of stillbirth on parents and their families via a systematic review seeking to improve worldwide bereavement care. They identified themes shared by parents and families (anxiety over other children, chronic pain and fatigue, avoidance of memories), themes present only in mothers (altered body image and impact on quality of life) and themes specific to fathers (grief suppression, avoidance, increased substance use and employment difficulties (Burden et al., 2016).

Despite this, studies comparing the experiences of mothers and fathers in recent literature are very limited. Smaller examples of literature have investigated the impact of stillbirth on bereaved fathers (Obst & Due, 2019; Samuelsson, Radestad, & Segesten, 2001). Hennegan et al. (2015) discussed fathers as the forgotten mourners of stillbirth. They found that the quality of fathers' relationship with their partner, being able to protect their partner and to grieve in their own manner were important factors for fathers bereaved by stillbirth (Hennegan et al., 2015). Bonnette and Broom (2011) discussed the cultural construct of the male role within Australian society and how this interplay impacts on fathers bereaved by stillbirth. They found that fathers face complex tensions between social roles of being a man, father and husband and that this significantly impacted their expression of grief. Obst and Due (2019) identified that bereaved Australian men need male-specific, flexible support options and greater recognition throughout a pregnancy and early in their grief.

Even fewer studies consider the impact of social constructs on the experience of stillbirth. One such study considering the role stigma plays in stillbirth found that stigma impacted on female social identities of "patient", "mother" and "full citizen" (Brierley-Jones, Crawley, Lomax, & Ayers, 2014).

The current body of literature on stillbirth provides valuable information and recommendations to improve patient care. Evident in the literature is researcher frustration with a lack of funding to explore the well-known long-term impacts of stillbirth. Also, the literature focuses heavily on high-income countries, and the varying definitions of stillbirth complicates cross-cultural comparisons. This suggests that understanding of stillbirth is predominately based on western populations with quality obstetric care. As already highlighted, stillbirth research has focussed heavily on the impact of stillbirth on mothers. What is now required is further investigation of the impact stillbirth has on fathers, grandparents, siblings and health professionals. Moreover, stillbirth researchers need to quantify the social and economic costs of stillbirth as a means to incite attention and increase funding. Economic quantification of stillbirth has commenced in some countries, including Australia, which will be discussed next in this review. Available research confirms what is known by those bereaved by stillbirth, the impacts are far-reaching and may last years or decades warranting a broader focus, greater research funding and increased social attention.

The Economic Cost of Stillbirth

The economic cost of stillbirth is generally poorly conceptualised and described (Heazell et al., 2016). Attempts have been made to quantify the impact of stillbirth in economic terms, beyond the tangible. In a narrative review, higher rates of depression and anxiety were found in couples who had experienced stillbirth compared to those who had not (Ogwulu, Jackson, Heazell, & Roberts, 2015). Ogwulu et al. (2015) argue that the psychological effects of stillbirth adversely impact on the daily functioning, relationships and

employment of those bereaved and that these factors lead to significant economic implications. This is supported by Heazell et al. (2016) whose systematic review found stillbirth requires more resources than live birth both in the perinatal period and subsequent pregnancies. They also identified that the indirect and intangible costs of stillbirth are often met by families alone.

The Stillbirth Foundation Australia (2016) also investigated the economic impact of stillbirth in Australia considering three types of costs, direct, such as hospital costs and counselling, indirect, such as funeral costs, absenteeism and divorce, and intangible costs such as the impact on mental wellbeing, relationships and families. They argue that the intangible costs of stillbirth are particularly poorly documented, resulting in an underestimation of the true impact of stillbirth (Stillbirth Foundation Australia, 2016). Based on current stillbirth rates and estimated population growth, the number of stillbirths in Australia is expected to increase to 2,700 in 2020 (Stillbirth Foundation Australia, 2016). The direct and indirect costs of stillbirth from 2016-2020 were estimated to be $681.4 million. Additionally, the health and wellbeing cost of the stillborn child for the same period was estimated to be $7.5 billion (Stillbirth Foundation Australia, 2016). Awareness of the economic consequences of stillbirth is vital to ensure appropriate allocation of financial and human resources, consideration of the needs of health services, and to appropriately inform policy and economic decisions.

Stillbirth and Grief: Theories and Frameworks

Several griefs concepts exist in the stillbirth literature. These include disenfranchised grief, ambiguous loss and complicated grief, which may include delayed or suspended grief. Amongst stillbirth researchers, grief is a well-accepted, normal and even expected, response to this traumatic event (Christiansen, 2017; Clower, 2014) which is demonstrated by the significant number of grief-related studies in the stillbirth literature (Avelin et al., 2013; Hutti

et al., 2017). Regrettably, this attitude is not always shared by societies in which parents and families experience stillbirth and their grief associated with such a significant loss.

Grief, in its simplest form, can be defined as an emotional response to loss. It is understood to be a deeply personal process which is generally regarded to follow a fairly predictable pattern. Grief is typically characterised by temporary impairment of day-to-day functioning, emotional distress, social withdrawal, intrusive thoughts, and feelings of numbness and yearning which can continue for varying amounts of time (Kersting & Wagner, 2012). Grief is also now accepted as a natural, non-pathological phenomenon whose expression is strongly influenced by social and cultural practices and values. Relevant to awareness of grief following stillbirth is an understanding that attachment to an unborn baby begins before birth (Christiansen et al., 2014). However, this may not be well understood by those responding to, or supporting, those bereaved by stillbirth.

A common experience acknowledged in the literature in response to stillbirth is that of disenfranchised grief (Lang et al., 2011). Disenfranchised grief is defined as grief that is unable to be expressed freely, taking away the social right to mourn one’s loss; or rather grief that is deeply felt but not socially recognised (Golan & Leichtentritt, 2016; Kelley & Trinidad, 2012).

Along with disenfranchised grief, ambiguous loss is also a concept found in the stillbirth literature. This notion considers the ambiguity of parents’ experience of grief and loss and the perceptions of health professionals, family, friends and society to this loss. Ambiguous loss can be considered the experience of grief for something that is perceived as ‘never was’ or ‘cannot be’, by either those bereaved, those supporting them or the society in which they live (Lang et al., 2011; Golan & Leichtentritt, 2016). The stillbirth literature clearly demonstrates that parents often experience grief with the same intensity and meaning

of the loss of any child (Golan & Leichtentritt, 2016) and society's inability to recognise this leads to an experience of ambiguous loss.

Lang et al. (2011) examined sources of ambiguity and disenfranchised grief for parents bereaved by perinatal loss. Numerous categories of ambiguity and disenfranchised grief emerged relating to the viability of the pregnancy, the physical process of pregnancy loss, making arrangements for their child's remains, and sharing their loss with others. The study highlighted multiple sources of ambiguity and disenfranchised grief faced by couples during interactions with health professionals, family, friends and society (Lang et al., 2011).

Kersting and Wagner (2012) consider the experience of complicated grief following stillbirth, miscarriage and neonatal death. Complicated grief symptoms are more disruptive, pervasive and longer lasting than normal grief, with complicated grief more likely to occur in response to sudden or traumatic loss (Kersting & Wagner, 2012). Stillbirth has long been recognised as a traumatic life experience. Predictors of complicated grief related to stillbirth have included lack of social support, pre-existing relationship difficulties, and absence of surviving children (Kersting & Wagner, 2012). Complicated grief is also particularly high after termination of a pregnancy due to fetal abnormality (Kersting & Wagner, 2012). Finally, Kersting and Wagner (2012) also hypothesise that gender differences in patterns of grief potentially exacerbate the decline in the relationship between bereaved parents.

Disenfranchised grief is also argued to play a role in the efficacy of stillbirth research. It is hypothesised that disenfranchised grief, as a function of lack of social recognition, may contribute to sampling difficulty of those bereaved by stillbirth, thus contributing to a limited understanding of the true impact of stillbirth.

Gender Differences in the Experience of Stillbirth

Little research has deliberately considered the similarities and differences experienced by men and women bereaved by stillbirth. Studies that set out to compare these experiences

have overwhelmingly focussed on grief, where differences have been found (Cacciatore et al., 2013; Christiansen et al., 2014). McCarthy (2002) found that in response to stillbirth women grieve more openly than men and that at 12-month follow-up, the grieving process remained active for both parents. Cacciatore et al. (2013) explored fathers' experience of bereavement care following stillbirth and highlighted the importance of person-centred bereavement care tailored for fathers. In their 2017 study, Tseng et al. (2017) explored the impact that perinatal loss, including stillbirth, had on couples perceptions of grief, marital relationship and social support. Couples without living children, religious beliefs and an infertility history before the loss felt more grief (Tseng et al., 2017). Furthermore, couples reported more grief if marital satisfaction was low, socio-emotional support from the husband's parents was low or if they had never participated in a ritual for their deceased baby. Overall, mothers reported more grief than fathers (Tseng et al., 2017).

Campbell-Jackson, Bezance and Horsch (2014) explored mothers and fathers experience of becoming a parent to a child born after a previous stillbirth. They found that both experienced high levels of anxiety, guilt and difficulty bonding during the subsequent pregancy and after the child was born. Similar to Tseng et al. (2017), differences regarding grief were identified. Fathers in particular reported lack of opportunities to grieve. Through phenomenological analysis, five themes, living with uncertainty, coping with uncertainty, relationship with the next child, the continuing grief process and identity as a parent, were identified as contributing to this experience. Unlike Tseng et al. (2017), Campbell-Jackson et al. (2014) found that overall fathers' experience of stillbirth was similar to mothers.

The majority of research on the experience and impact of stillbirth by gender focuses on grief (Avelin et al., 2013) which is a significant limitation in the literature. Further research is needed to compare and better understand the lived experience of women and men

bereaved by stillbirth, including not only grief but also social, psychological and employment needs and outcomes.

Stillbirth and Culture

A small body of literature focuses on the experience of stillbirth in a cultural context. These studies explore stillbirth in regions and countries such as South-East Asia (Cheer, 2016), Pakistan (Hamid, Malik, & Richard, 2014), Nigeria (Kuti & Ilesanmi, 2011), sub-Sahara Africa (Kiguli, Munabi, & Ssegujja, 2016) and India (Roberts et al., 2017). Even less research has considered religious beliefs and their impact on stillbirth, such as Muslim and Ultraorthodox Jewish women (Hamama-Raz, Hartman, & Buchbinder, 2014; Sutan & Miskam, 2012).

In their review of South-East Asian women bereaved by stillbirth Cheer (2016) identified a construct they refer to as the ‘interconnectedness’ between complex experiences influenced by cultural and systemic factors. They state that South-East Asian women's sociocultural experiences and their engagement with health care systems influenced how they managed and reconciled their bereavement. Similarly, Gopichandran, Subramaniam and Kalsingh (2018) argue that the social and cultural context strongly influences the psychological impact of stillbirth. They explored the impact of stillbirth on Indian women who reported experiencing grief and guilt which were amplified by an insensitive health system, attitudes of health care providers, friends, and neighbours, as well as strained marital relationship and financial burdens.

Hamid et al. (2014) considered the experience of stillbirth in Pakistan, the country with the third highest stillbirth rate in the world, and found that stillbirth not being recognised by tradition and religion as a loss comparable to that of a live baby has serious implications for bereaved women. They suggested the need to understand community and health care provider perspectives when developing prevention and management strategies for stillbirth

and recommended that in order to be effective Pakistani government stillbirth policies must be informed by culture and the beliefs and practices of the communities within which these losses occur (Hamid et al., 2014).

In 2017, Roberts et al. (2017) revealed the impact of stillbirth on Indian men. Qualitative themes included men's dual burden and right to medical and reproductive decision-making power. They found that wives of Indian men were discouraged from expressing their grief and pushed to conceive again. Quantitative data showed Indian men with a history of stillbirth reported greater anxiety and depression and perceived less social support. Interestingly, they also presented with more egalitarian views towards women than men without stillbirth experience. Of concern, fathers of stillborn babies were more likely to be emotionally or physically abusive (Roberts et al., 2017).

Considering a religious viewpoint, Sutan and Miskam (2012) explored the impact of stillbirth on Muslim women. The majority of respondents identified their husbands and families as decision makers with regards to their health care and practices following stillbirth, rather than themselves. Of significance, Muslim women’s identification with their religion during their time of grief had a positive impact on their sense of self-worth. Muslim women bereaved by stillbirth also reported appreciation of religious reminders in their time of grief, especially when it came from their husband, family or close friends. Sutan and Miskam (2012) recommend ongoing support for Muslim woman following stillbirth should involve their husbands and consider their religious values and beliefs.

Hamama-Raz et al. (2014) investigated how Israeli Ultraorthodox Jewish women cope with stillbirth. They found that the loss of the baby was experienced as a test to the women's belief in God, and was perceived as a way to experience God's love. As a result, stillbirth saw Israeli Ultraorthodox Jewish women's faith strengthen, which was found to provide relief, calm, and confidence. Interestingly, the meaning participants attributed to their

loss enabled them to move on. Hamama-Raz et al. (2014) argue that awareness and understanding of the ethnic meaning of stillbirth is an important step to implementing culture-sensitive psychosocial interventions.

Review of this small body of literature has highlighted the importance of culturally sensitive psychosocial training, education and responses to those bereaved by stillbirth. This research also highlights the impact of stillbirth on fathers and the family system and the importance of integrating these groups in education and health care responses. Research findings highlight the potential protective and helpful role religion can play in response to stillbirth, particularly concerning the experience of grief. Overall, the consideration of cultural and religious factors when developing training, education and practices in response to stillbirth can be argued as essential.

Limitations and Implications for Future Research

This review has identified numerous limitations within the stillbirth literature. These limitations, along with recommendations for future research, are offered below.

Differing definitions of stillbirth is an important limitation that contributes to difficulties in data collection and comparison. Notably, worldwide rates are reported consistent with the WHO definition which is less inclusive than the definitions used in many developed countries. This leads to significant under-representation of the true rate and impact of stillbirth. Additionally, the stillbirth literature predominately focusses on samples from high-income and developed countries which also generally have high-quality obstetric care. Thus, understanding of the impact of stillbirth in low to middle-income and less developed nations, and those with poorer quality obstetric care is significantly lacking. Given these limitations, it is recommended that researchers should clearly articulate the definition of stillbirth being employed and that ideally the most inclusive definition should be used including quantifying the economic cost of stillbirth. Further research on stillbirth in low and

middle-income countries, and in nations who do not have access to high-quality obstetric care, is also recommended.

Other limitations in the field include the narrow focus of research and issues with sampling. Lack of social recognition of stillbirth may be contributing to sampling difficulty of those bereaved by stillbirth, and in turn, contributing to a limited understanding of the full impact of stillbirth. Further research is needed on the relationship between social factors, including stigma, on stillbirth and experiences of disenfranchised grief, and targeted social education plans are needed to help destigmatise stillbirth. The narrow focus of research to date has resulted in minimal knowledge about the impact responding to stillbirth has on health care professionals. Therefore, additional research is needed to understand the impact of stillbirth on this population. Such research is needed not only to learn more about how to protect the wellbeing of these professionals but also to identify their training needs, so they can better respond to those bereaved by stillbirth in an evidence-based manner.

At present, much of the stillbirth research has focussed on the impact on women; significantly less is known about the impact on other family members. Knowledge of the impact of stillbirth on fathers is markedly underdeveloped and impact on the family system, including grandparents and siblings, is poorly understood. Further research is needed on the multi-dimensional impact of stillbirth on bereaved fathers but also on the wider family system including current or future siblings and grandparents. Partially due to the paucity of research about the impact on fathers, the stillbirth literature also currently fails to explicitly explore differences in the lived experience of mothers and fathers despite research identifying differences in the experience of grief. Comparisons beyond the experience of grief are limited at best and thus, more research is needed to understand similarities and differences between men and women bereaved by stillbirth.

More recently, questions have been raised about the economic costs of stillbirth. This is a new area of research which requires ongoing development. With improved ability to quantify and demonstrate the social and economic costs of stillbirth, stronger arguments for research funding, education and social movements to shift attitudes and stigma could be realised.

In Australia, a multi-cultural society, the impact of complex cultural diversity on the experience of stillbirth also needs to be considered. Stillbirth research in Australia needs to include investigation of the cultural needs of parents and how information, education, training and provision of health care can be culturally appropriate. This includes research on the impact of stillbirth within Australia's Indigenous population to ensure that information and education for Indigenous Australians bereaved by stillbirth is culturally appropriate and is provided by culturally competent health professionals.

Conclusion

This literature review set out to understand the complex impacts of stillbirth. It commenced by defining stillbirth, highlighting international differences and the challenges this creates for accurate data collection. A review of the impact of stillbirth revealed short-term outcomes such as grief and bereavement and summarised current best practice recommendations for hospital settings. Longer term implications revealed stillbirths' potential to impact relationships, mental health, wellbeing, employment and workplace productivity. A consideration of grief related to stillbirth found those bereaved experience grief within the social constructs of stigma, parenting, attachment and gender roles leading to experiences of disenfranchised grief and ambiguity. These factors also contributed to gender differences in the experience of grief between parents reported in some research. Consideration of the economic cost of stillbirth highlighted the extensive cost to those bereaved, health systems, society and the economy as a whole. Available research

highlighted that stillbirth costs more than live birth and bereaved parents are typically meeting the indirect and intangible costs of stillbirth on their own. The cultural experience of stillbirth was also examined, reinforcing the strong role social constructs have on the experience of stillbirth. Lastly, this review presented important limitations in the literature and proposed recommendations for future research. This review has highlighted that stillbirth can no longer be viewed as a woman's medical issue. Stillbirth must now be considered as a social issue having marked impact on health, mental health, family systems, relationships, workplace productivity and the economy, and must be given commensurate attention and funding.

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Comparing the Lived Experience of Men and Women Bereaved by Stillbirth: A Meta-Synthesis of Qualitative Studies

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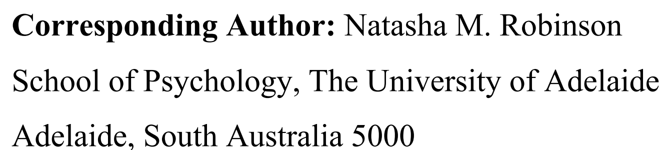

Author note: This article is intended for submission to the *PLOS ONE* journal. The journal guidelines specify that the manuscript can be any length. There are no restrictions on word count, number of figures, or amount of supporting information. Concise discussion of findings is encouraged. The total length of the current manuscript is 84 pages (6774 words) with the article written for the purpose of the thesis requirements of between 5,000 and 8,000 words.

Abstract

Background

This study aimed to investigate the lived experience of men and women bereaved by stillbirth with consideration given to associated social and cultural factors. A secondary aim was to present grief and support guidelines for those responding to men and women bereaved by stillbirth.

Methods/Findings

Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) methods were drawn upon in the collection and analysis of existing data sets. A systematic review of eight electronic databases was undertaken. Studies were included if they reported primary, qualitative data regarding men and women's lived experience of stillbirth and were published in English between 2009 and 2019. Studies were assessed for methodological quality using the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI). Data was synthesised using a meta-aggregative approach.

Fifty-one studies from fifteen countries were included yielding 280 findings. The synthesis of these findings resulted in six categories *Shock and Grief*; *Support Needs; Gender, Culture, Social Norms and Faith; Parenting a Child who has Died; Education and Information;* and *Mementoes and Rituals*. These findings represented 2,773 participants (2,462 women and 311 men) and 2,691 stillborn babies.

Conclusions

Profound grief was found to be a universal experience for men and women bereaved by stillbirth regardless of ethnicity, culture, religion, faith or social role or status. Bereaved men and women yearned for their baby to be recognised as a child who had died and to have their role of parent legitimised by the healthcare system, family, friends and colleagues.

Regardless of gender, culture or faith men and women bereaved by stillbirth found compassionate, empathic, humanistic support promoted their coping and recovery.

Grief and support guidelines call for a multidisciplinary approach to responding to stillbirth where bereaved parents are acknowledged to live within a broader social, cultural, ethnic, familial and religious/spiritual structure.

In Australia, stillbirth is defined as a baby born without signs of life, who is of 20 weeks' gestational age or weighs 400 grams or more.[1] The Australian perinatal mortality rate, which includes stillbirth (also referred to as fetal death) and neonatal death (death of a live born baby within 28 days of birth) saw a steady decline from the 1960s to the early 1990s[2]. Since 1995 there has been a small decline in neonatal deaths, but relatively no change to the rate of stillbirth.[1,2] This is despite considerable advances in medical technology, and Australia being one of the safest countries in the world to give birth.[2] Practically these rates represent some 2,000 Australian families who are affected by stillbirth each year, amounting to the loss of approximately six babies per day. While stillbirth remains an under-researched area, it is widely agreed that such a loss is a significant, and often traumatic, life event with far-reaching and long-term personal and system impacts.[3]

It was not until 2018 that the Australian government began to recognise the needs of those affected by stillbirth and undertook a Senate Inquiry. This inquiry has resulted in a National Stillbirth Action Plan and a commitment to reduce the rate of stillbirths in Australia by 20% over the next three years. Promisingly, sixteen recommendations encompassing prevention, investigation and improving support to families and clinicians were presented.[4]

The stillbirth literature typically focusses on the investigation of short-term impacts such as grief, bereavement and best practice recommendations for health professionals in hospital settings.[5-10] As such, several grief concepts, including disenfranchised grief, ambiguous loss and complicated grief, which may include delayed or suspended grief, are reported in the stillbirth literature.[11-14] Research into stillbirth-related grief has found that the bereaved experience grief within the social constructs of stigma, parenting, attachment and gender roles.[15-17] These factors are also reported to contribute to identified gender differences in the experience of grief between parents.[8,9] One such difference found is that women grieve

more openly than men, with the grieving process remaining active for both parents at 12-month follow-up.[18]

Research which investigates the longer-term impacts of stillbirth identifies consequences for relationships, mental health, wellbeing, employment and workplace productivity.[19,20,21,9,22] Typically, this research focusses on the experience of women. Review of such studies suggests differences exist in the lived experience of stillbirth between men and women, although this is rarely explicitly explored.

Markedly smaller examples of literature have investigated the impact of stillbirth on bereaved fathers.[23,24,8,25] Hennegan et al.[22] described fathers as the forgotten mourners of stillbirth and found that the quality of the fathers' relationship with their partner, being able to protect their partner and grieve in their own way were important factors for fathers bereaved by stillbirth. In Australia, Bonnette and Broom[23] discussed the cultural construct of the male role within Australian society and how this interplay impacts on fathers bereaved by stillbirth. They found that fathers face complex tensions between social roles of being a man, father and husband and that this significantly impacted on their expression of grief. To date, understanding the impact stillbirth has on bereaved fathers is markedly underdeveloped, while even less is known about the broader impact on the family system, including siblings and grandparents.

Partially due to the paucity of research about the impact on fathers, the stillbirth literature also currently fails to explicitly compare the lived experience of mothers and fathers despite there being identified differences in the experience of grief. Comparisons beyond the experience of grief are limited at best, and thus, more research is needed to understand similarities and differences between men and women bereaved by stillbirth. Such research has the potential to inform the development of support and intervention services which are better tailored to the specific needs of mothers and fathers.

This study focussed explicitly on stillbirth, excluding the lived experience of men and woman bereaved by perinatal loss before twenty weeks' gestation. It is acknowledged that differing arguments exist in the literature regarding the impact of loss in relation to gestational age. One line of argument has been that the impact of loss for parents is marked regardless of the type, time or reason for the loss.[26] Others argue that the impact of loss is less associated with gestational age and more related to factors such as social support and parental attachment.[27,9] Building on this, but somewhat in contrast, it has been argued that parental attachment intensifies with increased gestational age, resulting in greater impact on the bereaved for later losses.[28] For the current study, to address a significant gap in the literature, it was decided to focus on the lived experience of stillbirth according to the Australian definition.

This paper presents a meta-synthesis of qualitative studies with a primary research aim of investigating the lived experience of men and woman bereaved by stillbirth. In doing so, consideration is given to cultural expectations and social factors related to gender, birth, parenting, attachment and relationship roles and how these impact parents' lived experience of stillbirth. The work of Lisy et al.[10] aimed to investigate parents' experience of care received during and after stillbirth. Similarly, Peters et al.[29] explored the meaningfulness of non-pharmacological care for parents experiencing stillbirth. These meta-syntheses focused on the experience of care and recommended strategies and implications for health professionals from diagnosis through to post-birth. The current paper acknowledges and builds on the work of Lisy et al.[10] and Peters et al.[29] by exploring the lived experience of stillbirth beyond the care provided by health professionals with an emphasis on men and women's grief and support needs. This includes consideration of men and women's needs before diagnosis, beyond the hospital encounter and implications for other care providers, such as family members and chaplaincy, in addition to health professionals. As a result, a

secondary aim of this paper is to present grief and support guidelines for those responding to men and women bereaved by stillbirth. These guidelines are presented with a systems focus and include consideration of training and governance implications. In response to the current literature and in the context of these research aims, four hypotheses are proposed. It is predicted that:

1. Social and cultural factors will impact men and women's lived experience of stillbirth. More specifically, it is hypothesised that cultural norms associated with gender, parenting and relationship roles will result in differences in the lived experience of stillbirth between men and women.
2. There will be differences in the experience of grief between men and women in response to stillbirth as a result of cultural and social factors.
3. Social norms associated with male gender, fatherhood, and what it means to be a spouse will lead to a delayed or suppressed expression of grief for men when compared to women.
4. The grief and support needs of men and women bereaved by stillbirth will extend beyond the hospital encounter and outside the clinical care team. Specifically, family, allied health professionals and pastoral care will play important roles in meeting the grief and support needs of men and women bereaved by stillbirth.

Method

Search Strategy

Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA)[30] methods were drawn upon in the collection and analysis of existing data sets. A systematic review of eight electronic databases (PubMed, PsychINFO, CINAHL, Embase, Scopus, Sociological Abstracts, Web of Science and ProQuest: Global Dissertations and Theses) for the period from database commencement up to October 2018, was undertaken to identify

eligible studies that examined men and women's lived experience of stillbirth. Search terms were developed according to the indexing processes of each database and included terms such as *stillbirth; fetal death; perinatal death; men; women; parent; father; mother; qualitative* and appropriate variants (Appendix A). Search terms were reviewed by an expert research librarian to ensure accuracy. Additionally, reference lists of eligible articles were manually reviewed to identify any relevant articles not captured by the initial search.

Eligibility Criteria and Study Selection

For inclusion, studies were required to meet a set of pre-determined eligibility criteria. Studies were included if they reported qualitative data regarding men and women's lived experience of stillbirth, consisted of primary data from the perspective of those bereaved from stillbirth and were published in English between 2009 and 2019. Included studies were limited to the past ten years to encompass the most current and subsequently broadest definitions of stillbirth around the world to capture a representative sample of recent lived experience. Qualitative data were defined as data obtained by qualitative data collection methods (e.g., interviews or focus groups) or analysed using qualitative methods (e.g., thematic analysis, content analysis). Studies were excluded if they were quantitative, not primary data (e.g., letters to the editor, opinion pieces) or were not full articles (e.g., conference abstracts, brief reports). Studies reporting the lived experience of bereavement due to termination or miscarriage were excluded as were those where it was not possible to separate data for those bereaved by stillbirth from those bereaved by miscarriage or others forms of pregnancy loss.

The initial searches yielded 12,092 potential studies for inclusion (See Figure 1). After removal of duplicates, the pool of potential studies was narrowed to 6,864. Subsequently, the titles and abstracts of these articles were screened against the inclusion and exclusion criteria, leaving 479 articles. A randomly selected subset of 345 potentially eligible

studies were co-screened by the author (NR) and a second researcher (MO) to minimise selection bias. Inter-rater agreement was high (99%, $K = .94$, $p < .05$)[31], with any discrepancies discussed and resolved by consensus. The full-text versions of the 479 articles were reviewed, and their eligibility was re-assessed against the inclusion/exclusion criteria, resulting in 56 eligible studies. These 56 studies were then assessed for methodological quality. After appraisal, 51 qualitative studies were included in the comprehensive review and meta-synthesis.

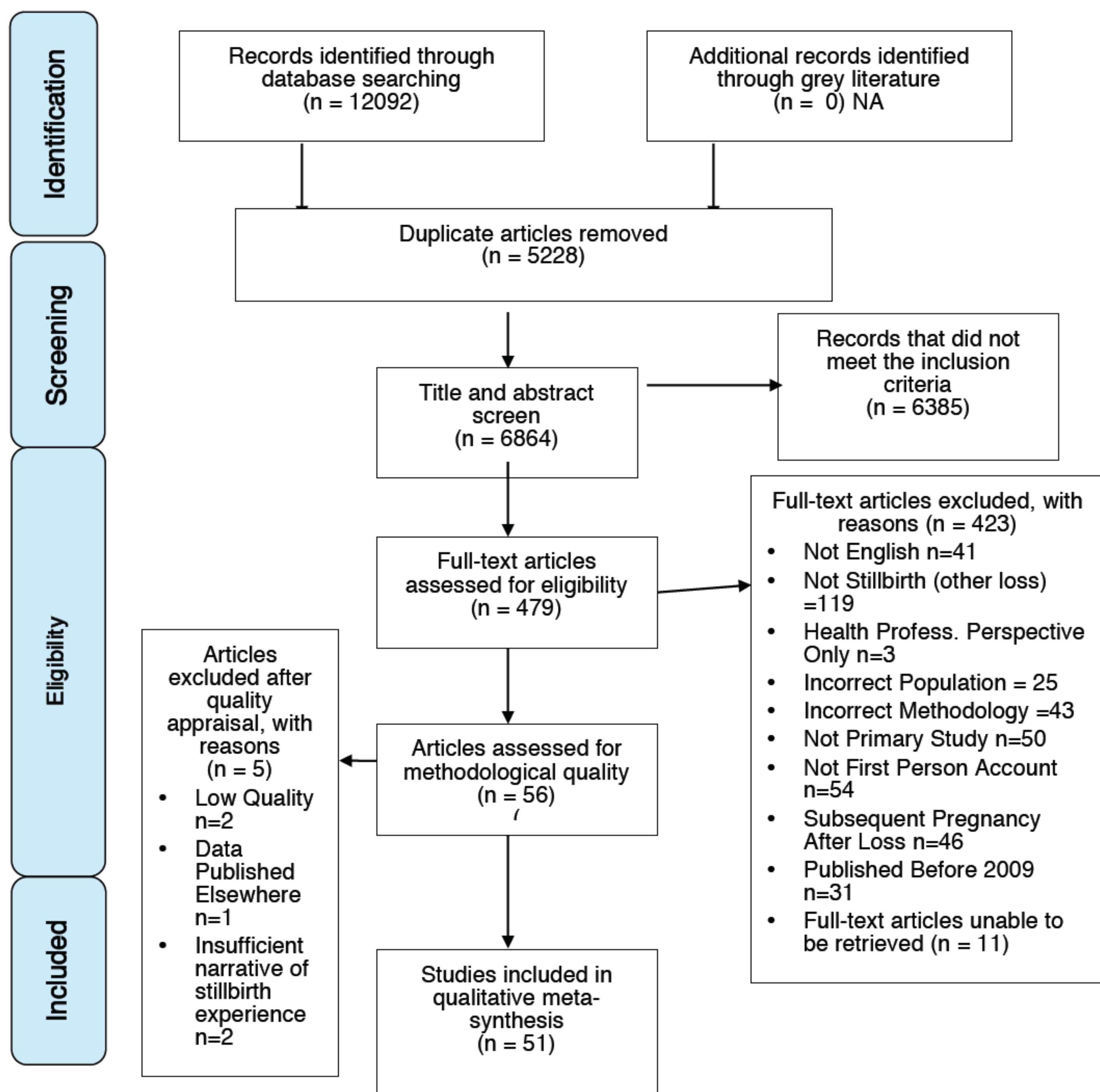

Figure 1. Search and article selection process for the comprehensive systematic review and meta-synthesis. (Adapted PRISMA Flow Chart).[30]

Assessment of Methodological Quality

All studies that satisfied the inclusion criteria were assessed for methodological quality using a standardised critical appraisal instrument, the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI).[32,33] Quality assessment was undertaken by the primary researcher (NR), with twenty-five percent also assessed by a second researcher (MO). Any discrepancies were discussed and resolved by consensus. Studies were assessed as high quality if they met seven to ten of the JBI-QARI appraisal criteria. Studies scoring between four and six were assessed as moderate quality and studies scoring three or lower were considered low in methodological quality and excluded from analyses. It is acknowledged that while a quality assessment of methodology is an important aspect of a comprehensive systematic review, it is limited by the information published. This proxy measure of quality, therefore, informs an assessment of what was reported rather than the full methodological protocol undertaken by researchers. Such quality tools also currently lack the sophistication to account for trends in research, including reporting quality requirements at the time of publication.

Data Extraction

PRISMA[30] methods were drawn upon for this review. Key information for each study was gathered using a purposely designed data extraction form. Data extracted included specific information about participant demographics (e.g., age, gender, culture, relationship status), details of stillbirth experience (e.g., number of children who have died, gestational age, time since loss), study methodology (e.g., recruitment method, method of analysis) and findings aligned with the research questions (e.g., grief, support needs). Where available, themes identified by the authors of each of the studies were extracted verbatim with illustrations to support each finding. Where themes were not reported, findings were

extracted from the narrative in the form of statements made by the authors. These findings were agreed by the primary researcher (NR) and a second researcher (MO).

Qualitative Data Synthesis

Data were synthesised using a meta-aggregative approach. Findings were grouped into categories based on similar or shared meaning until a synthesis of findings was reached. Categories were then aggregated, according to similarity of meaning, to produce a set of synthesised findings used to inform evidence-based practice. Consistent with the meta-aggregative approach of qualitative synthesis, each finding was assigned one of three levels of credibility.[34] These included, unequivocal, evidence beyond reasonable doubt, directly reported or observed findings not open to challenge; credible, findings that were plausible interpretations given the theoretical framework and data presented; and unsupported, findings that were not supported by the presented data. Only unequivocal and credible findings were included in the meta-synthesis.[33]

Results

Quality Appraisal

Of the fifty-six studies assessed for methodological quality, fifty-one were of high or moderate quality scoring four or more on the JBI-QARI. Two studies were excluded for being low quality, one was removed as a duplicate study (i.e., for publishing the same data twice) and two were excluded for having insufficient narrative of the stillbirth experience to support the findings. A summary of quality appraisal for all included studies can be found in Table 1. Of the fifty-one included studies forty-eight were assessed as high quality and three were assessed as moderate. The criteria most frequently not, or partially, met were Question 7 (influence of the researcher on the research) no=41, unclear=2; Question 6 (statement locating the researcher culturally or theoretically) no=37, unclear=6; and Question 1

(congruity between philosophical perspective and the research methodology) no=7, unclear=20.

Table 1

Quality Appraisal of Included Qualitative Studies

Study	***Question 1*** Is there congruity between the stated philosophical perspective and the research methodology?	***Question 2*** Is there congruity between the research methodology and the research questions or objectives?	***Question 3*** Is there congruity between the research methodology and the methods used to collect data?	***Question 4*** Is there congruity between the research methodology and the representation and analysis of data?	***Question 5*** Is there congruity between the research methodology and the interpretation of results?	***Question 6*** Is there a statement locating the researcher culturally or theoretically?	***Question 7*** Is the influence of the researcher on the research, and vice-versa, addressed?	***Question 8*** Are participants, and their voices, adequately represented?	***Question 9*** Is the research ethical according to current criteria or, from recent studies, and is there evidence of ethical approval by an appropriate body?	***Question 10*** Do the conclusions drawn in the research report flow from the analysis, or interpretation of the data?
Allahdadian et al. 2016[35]	⌓	●	●	●	●	⌓	○	●	●	●
Allahdadian et al. 2015[36]	⌓	●	●	●	●	○	○	●	●	●
Arango 2014[37]	●	●	●	●	●	⌓	●	●	●	●
Avelin et al. 2013[19]	⌓	●	●	●	●	○	○	⌓	⌓	⌓
Avelin et al. 2012[38]	⌓	●	●	●	●	○	○	●	●	●
Avelin et al. 2011[39]	⌓	●	●	●	●	○	○	●	●	●
Bond et al. 2018[7]	○	●	⌓	●	●	○	○	●	●	●

Table 1

Quality Appraisal of Included Qualitative Studies

Bonnette & Broom 2011[23]	●	●	●	●	●	●	●	●	●	●
Brierly 2018[40]	●	●	●	●	●	●	○	●	●	●
Brierley-Jones et al. 2014[16]	⌓	●	●	●	●	○	○	●	⌓	●
Cacciatore 2010[41]	●	●	●	●	●	○	○	⌓	●	●
Cacciatore et al. 2013[8]	⌓	●	●	●	●	○	○	●	●	●
Downe et al. 2013[42]	●	●	●	●	●	●	●	●	●	●
Due et al. 2018[43]	●	●	●	●	●	○	●	●	●	●
Golan & Leichtentritt 2016[12]	●	●	●	●	●	○	○	●	●	●
Gopichandran et al. 2018[44]	○	●	●	●	●	○	○	●	●	●
Hamama-Rez et al. 2014[45]	●	●	●	●	●	○	○	●	●	●
Horey et al. 2012[46]	⌓	●	●	●	●	○	○	●	●	●
Huberty et al. 2014[47]	○	●	●	●	●	○	○	●	●	●
Human 2017[48]	●	●	●	●	●	○	○	●	●	●
Human 2014[49]	○	●	●	●	●	○	○	●	●	●
Jones 2010[50]	●	●	●	●	●	●	●	●	●	●
Kelley & Trinidad 2012[51]	⌓	●	●	●	●	○	○	●	●	●
Kiguli 2015[52]	⌓	●	●	●	●	○	○	●	●	●
King 2017[53]	●	●	●	●	●	●	●	●	●	●
Lee 2012[54]	○	●	●	●	●	○	○	●	●	●
Lindgren 2013[55]	●	●	●	●	●	○	○	●	●	●

Table 1

Quality Appraisal of Included Qualitative Studies

Malm 2011[56]	⌓	●	●	●	●	○	○	●	●	●
Malm 2010[57]	○	●	●	●	●	○	○	●	●	●
Meaney 2014[58]	●	●	●	●	●	●	○	○	●	●
Murphy 2012[59]	⌓	●	●	●	●	○	○	●	●	●
Murphy 2012[60]	●	●	●	●	●	○	○	●	●	●
Murphy & Thomas 2013[61]	⌓	●	●	●	●	⌓	○	●	●	●
Norlund 2012[62]	○	⌓	●	●	●	○	○	●	●	●
Nuzum 2018[63]	●	●	●	●	●	○	○	●	●	●
Nuzum 2017[64]	●	●	●	●	●	○	○	●	●	●
Nuzum 2017[65]	●	●	●	●	●	⌓	○	●	●	●
Osman 2017[66]	●	●	●	●	●	⌓	○	●	●	●
Pena 2009[67]	●	●	●	●	●	●	●	●	●	●
Percentage (%)*	49	98	98	100	100	15	15	94	94	98

Note. Key: Yes = ●; Unclear = ⌓ ; No = ○. *Percentage indicates the proportion of questions answered Yes (●).[32]

Study Characteristics

The characteristics of the fifty-one studies included in the meta-synthesis can be found in Table 2. Studies originated from diverse countries with most studies being conducted in Sweden ($N_{studies}$ = 10), the United States of America ($N_{studies}$ = 8), the United Kingdom ($N_{studies}$ = 8), Australia ($N_{studies}$ = 5) and Ireland ($N_{studies}$ = 4). Other countries where research was conducted included Taiwan ($N_{studies}$ = 3), India ($N_{studies}$ = 2), Iran ($N_{studies}$ = 2), Israel ($N_{studies}$ = 2) and South Africa ($N_{studies}$ = 2). Single studies were conducted in Japan, Malaysia, New Zealand, Somaliland and Uganda. Twenty-nine studies included only women (mothers), eighteen included men and women (parents), and four included only men (fathers). Qualitative data were collected via interviews ($N_{studies}$ = 35), questionnaire/online survey ($N_{studies}$ = 11) and focus groups ($N_{studies}$ = 5). Qualitative methods of analyses included Content Analysis (thematic analysis; $N_{studies}$ =19), Interpretive Phenomenological Analysis ($N_{studies}$ = 7), Phenomenology ($N_{studies}$ = 6) and Grounded Theory ($N_{studies}$ =6). Less frequently used qualitative methods included Exploratory Descriptive ($N_{studies}$ =3), Inductive Content Analysis ($N_{studies}$ =3), Narrative Analysis ($N_{studies}$ =2), Qualitative Descriptive ($N_{studies}$ =2), Framework Analysis ($N_{studies}$ =1), Auto-ethnography ($N_{studies}$ =1), and Discourse Analysis ($N_{studies}$ =1).

Table 2

Characteristics of Included Studies

Study	Country	Methodology	Methods	Participants	Phenomena of Interest
Allahdadian et al. 2016[35]	Iran	Qualitative Content Analysis (thematic analysis)	Participants recruited by purposive sampling. Individual face to face interviews.	20 married women who had experienced a stillbirth. Age range 18-35. Time since loss unspecified. Number of losses unspecified.	Strategies suggested by mothers of stillborn babies regarding provision of maternal mental health in the experience of stillbirth.
Allahdadian et al. 2015[36]	Iran	Qualitative Content Analysis (thematic analysis)	Participants recruited by purposive sampling. Individual face to face interviews.	15 married women who experienced a stillbirth preferably in the last 3 months (time since loss not specified). Age less than 30 n=10; 30-40 n=5. Gestational age: 22-28 weeks n=7, 28-37 weeks n=5, Greater than 37 weeks n=3. Number of losses unspecified.	Social supports needed to improve the health of Iranian mothers after experiencing stillbirth.
Arango 2014[37]	United States of America	Narrative Analysis	Qualitative analysis based on in depth interviews using narrative methodology. Recruitment from a bereaved parents' support group in Northeast United States using purposive and snowball sampling. Participants were mothers who lost an infant through stillbirth or perinatal loss (gestation of 20 weeks or greater), over 18 years of age and not currently pregnant.	10 mothers. 7 mothers were told their baby died before delivery (stillborn). 3 mothers had babies that were born alive but dies shortly after birth (perinatal death).	Identifying beneficial and detrimental interactions with healthcare staff from the time a mother learned her baby has died to hospital discharge. How did mothers' interactions with healthcare staff during the first days following their loss affect a mother's memory of her overall experience? What interactions with staff and services offered were helpful or not helpful with the grieving process?

Table 2

Characteristics of Included Studies

Avelin 2013[19]	Stockholm Sweden	Descriptive statistics of demographic information. Qualitative content analysis (thematic analysis)	Postal questionnaire at three months, one year and two years after stillbirth. Participant recruitment ran continuously for 12 months across five hospitals in Stockholm Sweden.	55 participants (22 men; 33 women) who had experienced a stillbirth in the past 12 months. Mothers aged 22-42. Fathers aged 27-44. Gestational age range 24-43 weeks (mean=34 weeks; median 38 weeks). Number of losses unspecified.	Describing mothers and fathers' grief and its influence on their relationships after the loss of a stillborn baby.
Avelin et al. 2012[38]	Stockholm Sweden	Qualitative Content Analysis (thematic analysis)	Web based questionnaire. Parents recruited through the Swedish National Infant Foundation website. Inclusion criteria: mothers and fathers who had experienced stillbirth, have older children and answered open ended questions about support to siblings who had a stillborn brother or sister.	411 participants (350 women, 61 men). Mothers born between 1938 and 1988 (median 1971). Fathers born between 1949 and 1981 (median 1969). Gestational age Before 28 weeks n=46; At/after 28 weeks n=365. Number of losses unspecified.	Advice parents' would share with other parents based on their own experiences of siblings taking leave of a stillborn sister or brother. A specific aim was to study whether advice differs between parents who lost their child early or late in pregnancy.
Avelin et al. 2011[39]	Sweden	Qualitative Content Analysis (thematic analysis)	Six focus groups. Inclusion criteria were mothers and fathers who have experienced a stillbirth and had other children before the loss, that is, siblings to the stillborn baby. Stillbirth defined as death before or during birth from 22 weeks gestation.	27 (representing 22 families with 39 siblings). Two excluded from the analysis (final analysis 25 participants).	Describing parenthood and the needs of siblings after stillbirth from the parents' perspective

Table 2

Characteristics of Included Studies

Bond et al. 2018[7]	Australia	Mixed methods cross sectional survey. Quantitative data presented with descriptive statistics. Thematic analysis of qualitative data.	Mixed methods questionnaires were sent to bereaved parents of the Sydney Stillbirth Study. Quantitative data presented with descriptive statistics. Thematic analysis of qualitative data.	36 women bereaved by stillbirth	Identifying strategies most valued by parents concerning care following stillbirth in order to improve support and management of grieving families. Describing care received by bereaved parents after stillbirth in Sydney hospitals during their hospital stay, after discharge and through to their follow-up visit, from January 2006 to December 2011.
Bonnette and Broom 2011[23]	Australia	Interpretive qualitative. Thematic analysis drawing on Charmaz 2009.	Interpretive exploratory design. Qualitative interviews, purposive and snowball sampling	12 men bereaved by stillbirth	Exploring how fathers of stillborn children engage with their unborn and stillborn child as fathers and the perceived legitimacy of male grief.
Brierly 2018[40]	United States of America	Interpretive Phenomenological Analysis	Qualitative study using semi-structured interviews of bereaved couples. Inclusion criteria: must be a couple where both are willing to participate in the study, all participants must reside in the USA and be 18 years or older, have experienced stillbirth in the last 3-12 months, one of the partners must have carried the pregnancy lost, all participants must have active Facebook accounts and must have used it to post information related to their loss.	9 couples comprising 18 individual participants	Examining couples' experiences grieving pregnancy loss on Facebook. Specifically, exploring if digital sharing altered the bereavement process and how participants used Facebook for grieving.

Table 2

Characteristics of Included Studies

Brierley-Jones et al. 2014[16]	United Kingdom	Qualitative Content Analysis (thematic analysis)	Recruitment via stillbirth support websites (e.g. SANDS). Self-selecting convenience sample. Questionnaire available online for six months from February to July 2010. Women were excluded if pregnant or if their stillborn baby was born at the same time as a live-born twin. Thematic analysis of five open ended questions.	162 women who had experienced stillbirth (20 weeks gestation or greater) in the UK in the previous 10 years.	Investigating mothers' experiences of stillbirth in the United Kingdom, their opportunities for memory making and sharing, and the effect of such opportunities.
Cacciatore 2010[41]	United States of America	Phenomenology	Self-identifying participants were recruited through the newsletters and email lists of two non-profit organisations that provide services to families after stillbirth. Participants responded to three open qualitative questions and an open-ended narrative.	47 women bereaved by stillbirth	Discovering how the the woman's experience of a baby's death affects her as an individual and within the family system. More specifically, do these loss experiences seem to have long-lasting effects and what factors influence effects for grieving mothers?
Cacciatore et al. 2013[8]	Sweden	Qualitative Content Analysis (inductive manifest)	Online questionnaire available on the Swedish National Infant Foundation website. Inclusion criteria were fathers who had experienced the death of a baby from stillbirth after the 22nd week of gestation between 2000 and April 2010.	131 fathers	Exploring the experiences of grieving fathers regarding interactions with their healthcare providers and the birth and death of their babies.

Table 2

Characteristics of Included Studies

Downe et al. 2013[42]	United Kingdom	Grounded Theory (Constant Comparative Analysis)	Qualitative in-depth interview study conducted face-to-face or via telephone. Respondent recruited from an earlier quantitative survey. Purposive maximum variation sampling utilised. Participants lived in the UK and had experienced an intrauterine death or stillbirth of a baby at 24-42 weeks' gestation between 2000 and 2010.	22 families comprising 25 participants	To obtain bereaved parents' perspectives about their interactions with healthcare staff when their baby dies just before or during labour.
Due et al. 2018[43]	Australia	Qualitative Content Analysis (thematic analysis)	Individual, semi-structured interviews comprised of six core questions were undertaken. Respondents were recruited via advertising on two online forums and in the July 2013 SANDS South Australia newsletter. Eligibility criteria included 18 years of age or older, fluent in English, resident in South Australia at the time of loss and experienced at least one pregnancy loss at any time between conception to birth. Women who experienced multiple losses were also eligible.	15 heterosexual women	Exploring women's engagement with healthcare professionals following pregnancy loss.
Golan & Leichtentritt 2016[12]	Israel	Phenomenology	In-depth interviews with Israeli women who experienced stillbirth after 23 weeks' gestation. Recruitment through snowball sampling.	10 women	Exploring stillbirth in Israel to address unexamined issues and to gain a more in-depth understanding of this phenomena. Also, examining the meaning that

Table 2

Characteristics of Included Studies

					women experienced stillbirth attribute to their loss and the lost baby.
Gopichandran et al. 2018[44]	India	Qualitative Content Analysis (thematic analysis)	Qualitative in-depth interviews. Participants identified through community health workers in the area. Participants were eligible if they had experienced a stillbirth in the last 12 months.	8 women who experienced stillbirth in the past year and 2 health care providers to triangulate data.	The psycho-social impact, aggravating factors, coping styles and health system response to stillbirth (in an Indian context). A family member was present during interviews consistent with Tamil Nadu culture.
Hamama-Raz et al. 2014[45]	Israel	Qualitative content analysis (thematic analysis) influenced by phenomenological-hermeneutic tradition	Semi-structured interviews. Purposive sampling. Eligibility criteria included having experienced stillbirth for the first time, aged 20 years or older, belonging to an Ultraorthodox Jewish community with no psychiatric history.	10 women	Describing and analysing the meaning given to coping with stillbirth among Ultraorthodox Jewish women.
Horey et al. 2012[46]	Australia	Qualitative Content Analysis (thematic analysis)	Secondary analysis of three focus group transcripts using qualitative content analysis. Participants were recruited via newsletters and email networks.	17 parents (14 women, 3 men) of 14 stillborn babies	Bereaved parents' deliberations about autopsy after stillbirth
Huberty et al. 2014[47]	United States of America	Qualitative Exploratory	Exploratory qualitative research design. English speaking women between 19-44 years of age who experienced stillbirth in the previous year. Interviews conducted over the telephone or in person. Purposive and snowball sampling.	24 women	Exploring women's beliefs about physical activity following stillbirth.

Table 2

Characteristics of Included Studies

Human et al. 2017[48]	South Africa	Qualitative Descriptive	Qualitative mixed-methods using exploratory and descriptive research design. Purposive sampling. Inclusion criteria were bereaved women over 16 years of age with a stillbirth between 6-18 months previously. Questionnaires used to obtain demographic data and semi-structured one-on-one interviews were conducted.	25 women	Exploring bereaved mothers' attitudes towards autopsy on their stillborn baby, and the future implications of consenting or non-consenting to autopsy in retrospect.
Human et al. 2014[49]	South Africa	Mixed methods; exploratory and descriptive	Quantitative and qualitative research methods were used in an exploratory and descriptive design to obtain a detailed description of the psychosocial experiences and implications of stillbirth. Purposive sampling, as part of a probability sampling method. Qualitative data captured through semi-structured interviews.	25 women	Improving understanding of the psychosocial implications of stillbirth for the mother and her family. Establishing the effectiveness of crisis intervention and whether it could be recommended when working with bereaved mothers.
Jones 2010[50]	United Kingdom	Reflexive study which emanates from narrative, heuristic and auto/biographical methodologies. Narrative Inquiry (Heuristic)	Purposive and snowball sampling of participants through SANDS support group facilitators and the Birth Trauma Association website.	27 bereaved parents (21 women, 6 men)	Providing a more complex understanding of mothers' and fathers' narratives of grief and loss following the death of a child. Exploring how parents give meaning to their experiences in light of existing discourses regarding parenthood, grief, loss, gender and medicine. Exploring some of the ways parents continue

Table 2

Characteristics of Included Studies

					or sever the relationship with the child who had died. Exploring possible gender differences in grief expression following the death of a baby.
Kelley & Trinidad 2012[51]	United States of America	Qualitative iterative discourse analysis	Secondary qualitative analysis of transcript data from three semi-structured focus groups conducted with parents, and two focus groups with OBGYNs. Participants recruited via parent hospital guild groups and then snowball sampling through friends and guild members. Detailed demographic data were not collected.	22 (12 mothers, 2 fathers, 8 OBGYNs) *query error in totals, 6 mothers from focus group 5 not included in total.	In-depth accounts of parents' experiences of stillbirth within the context of the clinical encounter, focusing on parents' emotional and personal accounts, their perceptions of in hospital and post-hospital communication and support, and their bereavement process and attempts to give meaning to their child's death.
Kiguli et al. 2015[52]	Uganda	Qualitative Content Analysis (thematic analysis)	In-depth interviews. Participants purposively recruited from hospital maternity wards registers. Further, recruitment was undertaken through community leaders and other participants.	29 including 22 women, 7 men of which 14 women had a stillbirth, 6 men fathered a stillborn child, 4 grandmothers, 1 grandfather and 4 traditional birth attendants.	Exploring local definitions and perceived causes of stillbirths and coping mechanisms employed by families affected by stillbirth in rural eastern Uganda.
King 2017[53]	United States of America	Phenomenology	Phenomenological exploration via individual interview. Purposive sampling. Inclusion criteria included: an intact couple; both partners needing aged 18 years or older at time of stillbirth; couples married for at least 6 months at the time of stillbirth; participants are the biological parents of the stillborn; couples spoke English;	16 (8 men, 8 women)	Developing a deep understanding about the clinical encounter for couples. The focus was on the hospital experience for couples following notification of stillbirth. Similarities and differences in how mothers and fathers described the clinical encounter were examined.

Table 2

Characteristics of Included Studies

			the stillbirth took place in the past 10 years; the couple was able to participate in the interview together.		
Lee 2012[54]	Australia	Qualitative Content Analysis (thematic analysis)	Online survey of women who experienced stillbirth in Queensland Australia between February and May 2010. Study embedded in the 2010 Having a Baby in Queensland survey. Purposive sampling via letter 3 months' post loss.	14 women	Describing Australian women's experience of late pregnancy loss, with an emphasis on their experiences with the health care system.
Lindgren et al. 2013[55]	Stockholm Sweden	Qualitative Content Analysis (thematic analysis)	Qualitative descriptive study including semi-structured interviews. Recruited via the website hosted by the Swedish National Infant Foundation.	23 women	Investigating mothers' experiences of saying goodbye to their baby when discharged from the hospital.
Malm et al. 2011[56]	Stockholm Sweden	Qualitative Content Analysis (thematic analysis)	Semi-constructed questions during face-to-face interviews with mothers bereaved by stillbirth. Purposive sampling within a small Swedish hospital. Participants also recruited via information posted on the Swedish National Infant Fund website.	26 women	Mothers' experiences during the time before to receiving news that their baby had died.
Malm et al. 2011[57]	Stockholm Sweden	Inductive Qualitative Content Analysis	In depth interviews with 21 mothers whose babies had died before to birth. Participants recruited through the Swedish	21 women	Investigating mothers' experiences of the time from the diagnosis of their unborn baby's death until induction of labor.

Table 2

Characteristics of Included Studies

			National Infant Foundation website.		
Meaney et al. 2014[58]	Ireland	Interpretive Phenomenological Analysis	Semi-structured interviews. Purposive sampling of 10 parents who either consented or declined autopsy from a large tertiary maternity hospital in Cork Ireland.	10 parents (6 mothers, 4 fathers)	Exploring decision-making process about perinatal autopsy among parents who experienced antepartum and intrapartum stillbirth.
Murphy 2012[59]	United Kingdom	Exploratory, grounded theory	In-depth interviews with parents who experienced a stillborn child. Recruited via Birth Trauma Association and SANDS websites. Inclusion criteria: stillbirth since 1993 and no less than 6 months prior to the interview.	32 parents (22 mothers, 10 fathers)	The effect of expectant motherhood discourses on parents who suffer a stillbirth
Murphy 2012[60]	United Kingdom	Grounded Theory	Interviews with couples and mothers who experienced stillbirth from 1992 to no less than six months before the interview took place. Recruited through support groups, pregnancy loss websites and personal contacts.	32 parents (22 mothers, 10 fathers)	Exploring empowerment as a means of overcoming the stigma of stillbirth.

Table 2

Characteristics of Included Studies

Murphy & Thomas 2013[61]	United Kingdom	Grounded Theory	Thirty-one in-depth interviews with parents of 22 stillborn babies. Joint interviews were held with 10 couples, of which five women and four men participated in individual interviews. An additional 12 women were interviewed individually, as their partners declined involvement.. Parents recruited through SANDS groups, national support groups and personal contacts.	22 women, 10 men, comprising 31 interviews	Exploring how parents respond to memories of their stillborn child over the years following their loss.
Norlund et al. 2012[62]	Sweden	Qualitative Content Analysis (thematic analysis)	Web survey questionnaire available on the Swedish National Infant Foundation's website. Survey available between 27 March 2008 and 1 April 2010. Eight-four of the 213 respondent completed the qualitative questions.	84 women	Exploring mothers' lived experiences following the death of a baby and the quality of their interactions with health professionals.
Nuzum et al. 2018[63]	Ireland	Interpretive Phenomenological Analysis	Semi-structured qualitative interviews with bereaved parents. Purposive sampling of bereaved parents from Cork University Maternity Hospital. Inclusion criteria: participants had to be cared for in the study hospital, not currently pregnant, over 18 years of age and had not previously indicated that they did not wish to be contacted by the hospital for research purposes.	17 (12 mothers and 5 fathers)	Exploring the personal impact of stillbirth on bereaved parents including researching the lived experience of parents who were told that their baby had died or would die before birth.

Table 2

Characteristics of Included Studies

Nuzum et al. 2017[64]	Ireland	Interpretive Phenomenological Analysis	Semi-structured qualitative interviews with bereaved parents. Purposive sampling of bereaved parents from Cork University Maternity Hospital. Inclusion criteria: participants had to be cared for in the study hospital, not currently pregnant, over 18 years of age and had not previously indicated that they did not wish to be contacted by the hospital for research purposes.	17 (12 mothers and 5 fathers)	Exploring bereaved parents' spiritual and theological struggle following stillbirth.
Nuzum et al. 2017[65]	Ireland	Interpretive Phenomenological Analysis	Semi-structured qualitative interviews with bereaved parents. Purposive sampling of bereaved parents from Cork University Maternity Hospital. Inclusion criteria: participants had to be cared for in the study hospital, not currently pregnant, over 18 years of age and had not previously indicated that they did not wish to be contacted by the hospital for research purposes.	17 (12 mothers and 5 fathers)	Exploring the impact of how bad news was provided to parents following diagnosis of stillbirth.
Osman et al. 2017[66]	Somaliland	Phenomenology	Qualitative interviews with 10 Somali women one to six months after stillbirth. Recruitment via Traditional Birth Attendants (TBAs) in eight villages of a Somaliland district. Inclusion criteria were married; non-pregnant women who had given	10 women	Describing the experience of Muslim Somali mothers whose babies died at birth.

Table 2

Characteristics of Included Studies

			birth in a health facility to a baby with no signs of life at or after 28 weeks of gestation within the six months prior to study.		
Pena 2009[67]	United States of America	Phenomenology	A convenience sample of six fathers who experienced perinatal loss (one stillbirth). Inclusion criteria: men whose partners have experienced a perinatal loss; that they are psychologically aware and possess the sufficient insight to clearly articulate their experience; may benefit from study participation.	6 men (1 who experienced stillbirth)	Investigating men's experience of perinatal loss.
Radestad et al. 2014[68]	Sweden	Qualitative Content Analysis (thematic analysis)	Semi-constructed questions during face-to-face interviews with mothers bereaved by stillbirth. Self-recruited participants recruited via information posted on the Swedish National Infant Foundation website. Inclusion criteria were that the mothers should have given birth to a dead child after 28 gestational weeks.	26 women	Exploring mothers' experiences of the confirmation of ultrasound examination results and how they were told that their baby had died in-utero.
Radestad et al. 2011[69]	Sweden	Qualitative inductive manifest content analysis	Retrospective cross-sectional study via questionnaire posted on the Swedish National Infant Foundation website between 27 March 2008 and and 1st April 2010. Participants self-selected. Inclusion criteria was	799 women	Describing mothers' gratitude for the actions of health professionals involved in the birth of their baby. Also examining whether the aspects of care for which women were grateful differed between

Table 2

Characteristics of Included Studies

			experiencing a stillbirth after the 22nd weeks of gestation, as well as stating the year the baby was born and answered an open question about gratitude.		mothers whose children died before and after 1990.
Roberts et al. 2012[70]	India (Central Rural)	Grounded Theory	Key informant interviews with 17 women who experienced stillbirth and two validation focus groups with health care providers and family members. Snowball sampling.	33 (17 women who experienced stillbirth; focus group 1 n= 6 women of reproductive age no stillbirth; focus group 2 n=10 older women, grandmothers, mother-in-law's and Dais of which 3 had experienced stillbirth	Exploring how poor, rural women in central India experience grief from stillbirth and how their social environment reacts to and influences their grief.
Ryninks et al. 2014[71]	United Kingdom	Interpretive Phenomenological Analysis	In depth interviews were conducted with mothers three months after stillbirth. Participants were recruited from nine National Health Service (NHS) hospitals in the UK. Inclusion criteria: women over 18 who had experienced a stillbirth at 24 weeks gestational aged or later and who were not pregnant again three months after stillbirth.	21 mothers	Investigatung how mothers describe their experience of spending time with their stillborn baby and how they felt retrospectively about the decision they made to see and hold their baby.

Table 2

Characteristics of Included Studies

Schirmann et al. 2018[72]	Australia and New Zealand	Framework Analysis using the Decision Drivers Model	Analysis of open-ended questions from a multi-country online survey of parents' experience of stillbirth. Inclusion criteria: mothers residing in Australia or New Zealand who reported a stillbirth after 20 weeks' gestation.	460 mothers (416 Australian, 44 New Zealand)	Understanding the influences on parents' decisions about autopsy after stillbirth and to identify aspects of effective decision support that align with parents' needs. Male respondents (n=15) were excluded due to low response rates.
Sun et al. 2014[73]	Taiwan	Phenomenology	In-depth interviews with 12 couples who experienced stillbirth in maternity units in Taoyuan, Taiwan. Purposive sampling. Inclusion criteria: 20 years or older, the married, pregnant woman and her spouse accepted labor induction for stillbirth, able to communicate in Mandarin or Taiwanese, agreed to audio recordings of interviews.	24 (12 couples comprising 12 women, 12 men)	Understanding the essence and structure of parents' decision making and seeing phenomena during stillbirth of their child.
Sutan & Miskam 2012[74]	Malaysia	Exploratory Descriptive	Data collected via focus groups and in-depth unstructured interviews. Purposive sampling among Muslim women who attendee Universiti Kebangsaan Malaysia Medical Centre (UKMMC).	16 women	Exploring and describing the psychosocial impact of social support among Muslim women following perinatal loss.

Table 2

Characteristics of Included Studies

Thomadaki 2012[75]	United Kingdom	Interpretative Phenomenological Analysis	Eight semi-structured interviews with women who lost their firstborn baby perinatally. Only women that experienced a perinatal loss (death from 24th week of gestation until 28th day of life) were included. Sampling via SANDS website and a specialist midwife from the Kings College Hospital.	8 women	Exploring “how mothers experience personal growth after a perinatal loss”.
Tseng et al. 2018[76]	Taiwan	Qualitative Descriptive	A qualitative descriptive study of in-depth interviews with 16 Taiwanese women who experienced stillbirth. Purposive sampling from two teaching hospitals on southern Taiwan. Inclusion criteria: experienced stillbirth during 20-40 weeks’ pregnancy; had participated in rituals after diagnosed with a stillbirth; and consented to participate. Exclusion criteria: unmarried mothers and pregnant adolescent.	16 women	Exploring the meaning of rituals that women and their families perform after stillbirth.
Tseng et al. 2014[77]	Taiwan	Qualitative inductive content analysis	A qualitative descriptive study of in-depth interviews with 21 Taiwanese women who experienced stillbirth. Purposive sampling from two teaching hospitals on southern Taiwan. Inclusion criteria: experienced stillbirth during 20-40 weeks’	21 women	Portraying Taiwanese women’s’ recovery processes after stillbirth.

Table 2

Characteristics of Included Studies

			pregnancy in 2006-2008; pregnant married women were included; pregnant adolescents and pregnant unmarried women were excluded.		
Weaver-Hightower 2012[78]	United States of America	Auto-ethnography	Autoethnographic essay of a father's experience of his stillborn daughter.	1 man	Exploring stillbirth, grief, tactile contact with death and how these demonstrate the strictures and ruptures of masculinity in Western cultures. Counter-poses these realities against the political, economic and medical discourses of stillbirth to explore how social structures mediate and complicate parents experiences of their baby's death.
Yamazaki 2010[79]	Japan	Grounded theory (constant comparative analysis)	Interviews with 17 Japanese women. Non-probability convenience sampling from self-report groups for perinatal loss in three areas of Japan. Inclusion criteria: native Japanese speaker, sudden IUFD after 28 weeks' gestation, and at least one year after IUFD.	17 women	Describing the meaning of fetal death for Japanese women in a local community.

Participant Characteristics

After the removal of 154 duplicate participants, the total sample consisted of 2,773 participants ($N_{studies}$ = 51); 2,462 women and 311 men. Female participants were aged between 16 and 47 years (*M* = 30.83 years; *SD* = 9.48), based on 1,031 female participants ($N_{studies}$ = 5). The mean age of male participants could not be determined due to insufficient information. Overall, 2,691 stillborn babies were represented in this synthesis with a gestational age range of 20 to 44 weeks (*M* = 35.37 weeks; *SD* = 5.99), based on 183 stillborn babies ($N_{studies}$ = 2).

Synthesised Findings

The included studies presented 280 findings. Through a meta-aggregative approach, the synthesis of these findings resulted in six categories *Shock and Grief*; *Support Needs; Gender, Culture, Social Norms and Faith; Parenting a Child who has Died; Education and Information;* and *Mementoes and Rituals*, shown in Table 3. These categories are discussed below.

Table 3

Synthesised Findings and Categories of Men and Women’s Lived Experience of Stillbirth

Shock and Grief: Profound grief is experienced by men and women in response to stillbirth despite, but within the context of gender, culture, religion and social norms.
• Parents are shocked by stillbirth. Parents from developed countries do not expect their pregnancy to result in stillbirth due to perceived advances in medicine and obstetrics. • Women and men grieve with the same intensity for the loss of their stillborn child. • Men and women experience and display their grief within the context of social norms, gender roles, parental roles and religious beliefs. • Men and women grieve for a stillborn child like that of a child that lived; their grief continues for many years. • Women and men express their grief in different ways and have different needs.
Support Needs: Support needs commence on notification that the baby has died and continue through labour and delivery, post-natal care and beyond.
• Compassionate support has a positive impact on recovery for bereaved parents. • Men and women bereaved by stillbirth feel that health professionals alone cannot meet their support needs. • Women and men want health professionals who are trained in responding to stillbirth. • Bereaved parents respond positively to health professionals who display emotions; feeling this legitimises their loss. They are distressed by health professionals who are cold and distant, medicalise their loss and reassure them that they can have another child. • Parents want to be contacted by health professionals for follow-up care; they want access to skilled mental health professionals, grief counselling, pastoral care and community support. • Bereaved parents want their family, friends and colleagues to provide support with empathy and compassion. • Bereaved men and women benefit from support groups where they feel that their loss of a child and ongoing role as a parent is recognised and acknowledged. • Support groups offer bereaved parents the benefit of meeting people with a shared experience. They are able to witness that recovery from their loss is possible. Women engage in support groups more than men.
Gender, Culture, Social Norms and Faith: Men and women experience stillbirth as a profound loss. The expression, coping style and communication of that loss is influenced by gender roles, social roles and norms, culture and faith.
• Men and women display differences in how they express their grief. Women grieve more openly, within groups, sharing their emotions with their partner and family. Men prefer to grieve internally, privately, or with a trusted friend. • Men want to be recognised as grieving fathers, not as supportive partners. • Men are expected to return to their normal lives soon after stillbirth without consideration of their emotional, psychological or functional needs (e.g., return to work). • How men and women express, display and cope with their loss occurs in the context of social roles and expectations.

- Culture and faith influence whether and how a stillborn baby is recognised.
- In some cultures, fertility and motherhood are strongly associated with social status, value, worth and acceptance. In these cultures, parents grieve in silence to avoid stigmatisation. Women in these cultures risk loss of their social status and security as a result of stillbirth.
- Social taboo, stigma and silence are experienced as significant sources of distress for bereaved parents. In these cultures, bereaved parents feel unable to openly grieve or celebrate their child’s birth and death.
- In some cultures, stillbirth is seen as a failure of the role of mother, wife and daughter-in-law. This loss is not discussed, and grieving mothers cope by suppressing their emotions. The birth of a subsequent live baby is important to reinstate the mother’s identity and value within the family and society.
- In other cultures, bereaved parents were unable to, or feared to, see or hold their baby due to religious beliefs and practices. They feared violating the taboo to see or hold their child would affect the deceased, survivors and future pregnancies.
- Bereaved parents experience the death of their child as challenging their beliefs and faith. Some parents were able to draw strength and find meaning in their loss through their faith and connection to God/Allah.

Parenting a Child Who Has Died: Men and women want their stillborn baby to be treated by health professionals, family, friends and colleagues as a child who has died.

- Bereaved parents want their stillborn baby to be treated like a live baby who had died. They want to be treated as parents who have lost a child.
- Men and women form attachments to their child during pregnancy. Fathers connect to their child from the beginning of pregnancy.
- Women bereaved by stillbirth want the same acknowledgment of the challenges of labour and birth as women who deliver live babies. They want the emotional and psychological complexity of delivering a stillborn child acknowledged.
- Men and women are distressed when health professionals refer to their child in medical terms (e.g., foetus). Bereaved parents want their child to be referred to by their name.
- Legitimising the existence of a stillborn baby assists parents to process their loss.
- Men and women want their child to be acknowledged by their family and friends.
- Men and women want to be encouraged to see, hold and parent their stillborn child.
- Parents feel they have limited time to make memories with their stillborn child.
- Women report distress on leaving their stillborn child.
- Men and women continue to engage in behaviour that represents parenting their child for many years. Often this is done in the privacy of the home.

Education and Information: Bereaved men and women want information from the time of notification that their baby has died through to follow-up care and beyond.

- Parents need more education on what to expect, how to make memories and the support available to them.
- Information provided to bereaved parents should commence from the point of notification that their baby has died.
- Health professionals should use clear, empathic and unambiguous language in all encounters with bereaved parents.

- Bereaved parents find it difficult to retain information during acute distress, shock and grief. Therefore they want information repeated, clarified and provided in multiple formats.
- Bereaved parents want information on all options to see, hold, parent, ritualise, commemorate and remember their baby. They want to make their own choices based on unbiased information. They do not want to feel pressured to make decisions about their baby, nor feel they have limited time (while acknowledging that they do).
- Bereaved parents want information on what to expect and how to cope with their loss in the medium to long-term. They often feel alone in navigating their loss and unsure of where to access support.

Mementoes and Rituals: Bereaved parents cherish the mementoes of their stillborn child. Men and women engage in rituals to legitimise their baby, their loss, their role as parents and as a primary form of coping

- Parents are often not aware of the many options to memorialise their baby and create mementoes; they want health professionals to provide information and coordinate these practices.
- Parents of stillborn babies cherish mementoes. Loss of items is highly distressing, even years later. Rituals, memories and meaning-making are important factors for positive coping.
- Men and women participate in rituals to acknowledge the existence of their stillborn child, protect their baby and connect to their role as parents.
- Men and women practice rituals even when not socially or culturally acceptable or encouraged, in which case they are conducted in private.
- Men and women use rituals to recover from distress and process their grief. They want to include siblings and family in rituals to acknowledge the birth and death of their child.
- Religious practices and rituals assist bereaved parents to understand and accept their loss.

Shock and Grief

Men and women experience a profound sense of grief in response to stillbirth which persists for many years. Overwhelmingly, parents are shocked by stillbirth. Due to perceived advances in medicine and obstetrics, parents from western, developed countries do not expect their pregnancy to result in stillbirth. As one woman described: *"I had no clue. I had a textbook pregnancy and everything was perfect all the way to the end. You think that as long as you are getting medical care, they can take care of anything that is going to come up, or that there might be a warning.*[51(p3)] This synthesis identified that men experience grief with the same intensity as women. Both men and women grieve for their stillborn child like that of a child who had lived. Their grief is experienced and expressed within the complex constructs of gender, culture, social norms, parental roles and religious beliefs and values. It is these constructs and their complex interplay which result in differences seen in how men and women express and cope with their loss. One man explained: *"You can't say it was worse for Melissa because it was in her stomach; it is not. Obviously the baby was in there but the bond and therefore the loss is just as much".* [23(p253)]

Support Needs

Bereaved parents support needs commence immediately on notification that their child has died. This need continues through preparation for labour, delivery, post-partum care and well beyond the hospital encounter. One woman emphasised the need for immediate support on notification: *"the doctor did an ultrasound…he then leaned over and said 'I'm sorry, your baby is gone', and he walked out! He just walked out! I was alone in the room with my dead baby inside me".*[37(p28)] Men and women bereaved by stillbirth report that health professionals alone cannot meet their support needs. They express the need for family, community and pastoral support. Additionally, they discuss motivation to engage in skilled mental health support and grief counselling, although note they are often unsure of how or

where to access this. Men and women want health professionals to engage in proactive follow-up care rather than relying on bereaved parents to initiate such services.

Compassionate support from health professionals and family and friends have a positive impact on recovery for bereaved parents. Men and women want their treating health professionals to be trained in how to respond to stillbirth and have the emotional capacity and professional experience to do so. Bereaved parents appreciate health professionals who display emotions in response to the loss, noting this validates and acknowledges their experience. In addition, they expect health professionals to be compassionate, empathic and self-aware, noting that health professionals who are distant, unsympathetic, uncommunicative, medicalise their loss or inadvertently undermine their loss through assurances they can have another child exacerbate their distress. One woman highlighted the powerful words of an empathic midwife who recognised the birth of her daughter: *"Even though she wasn't breathing and she didn't open her eyes, she [the midwife] still said you've got a beautiful baby girl. It just meant the world"*.[42(p7)] Conversely, one woman emphasised the distress caused by a midwife who trivialised her loss: *"A midwife called my baby 'the miscarriage', despite the fact that the baby was born in week 25. She also said 'there are worse things'. It was horrible to hear her say that"*.[62(p782)] Both men and women have reported benefit from support groups. In these settings, they feel recognised as parents who have lost a child and can connect with others through shared experience. They also discuss that seeing others coping with such a profound loss has a positive impact on their own recovery. Despite the benefits, overwhelmingly, women engage in support groups more than men.

Gender, Culture, Social Norms and Faith

Women and men display differences in how they express their grief. Women are noted to grieve more openly, within groups and benefit from sharing their emotions with their

partner and family. In the context of male gender roles and social expectations of male emotion processing, men describe a preference to grieve internally, privately or with a trusted friend. As one man described: *"I think it was because she (wife) wasn't there and I could lose it for a minute and not feel that I'm going to cause her to lose it even more. I felt like if I was with her and I lost it we would never recover".*[23(p258)] Another woman reflected with insight on the impact the loss of their son had on her husband: *"We don't normally talk about the son we lost. But when my sister-in-law had a baby and we celebrated the occasion, my husband said, 'let me hold the baby' and he cried. While watching him, I was struck for the first time by the thought, 'it must have been hard for him too'".*[79(p928)]

Both men and women note that how they cope and express their loss is impacted by social expectations and gender roles of wife/husband, mother/father, woman/man. Interestingly it was found that men want to be recognised as grieving fathers, not just as supportive partners to a grieving mother. Men also note the existence of social and cultural expectations to quickly resume their pre-loss lives often without consideration of their emotional, psychological or functional needs. One woman highlighted the impact of gender roles and social expectations when commenting on her husband's experience of stillbirth: *"Men are expected not to show emotions and also to support women. Besides, they need to go back to work immediately (while women are not necessarily expected to do the same)".*[79(p927)]

An individual's culture also has multiple influences on their lived experience of stillbirth. Firstly, culture was found to influence whether a stillborn baby is recognised and to what extent. In some cultures, social taboo, stigma and silence were common consequences of the stillbirth experience and resulted in marked distress for bereaved parents. As a result, these parents felt unable to openly grieve and celebrate the birth and death of their child despite their continued distress. In other cultures, fertility and motherhood were strongly

associated with social status, value, worth and acceptance. Parents in these cultures grieve in silence to avoid stigmatisation. As a result of stillbirth women in these cultures risk the loss of their social status and security with stillbirth seen as a failure of the role of mother, wife and daughter-in-law. The experience is of a loss ignored, and grieving women learn to cope by suppressing their emotions. For these women, the birth of a subsequent live baby is an important step in reinstating her identity and value within the family and society. A Taiwanese woman describes this complex interplay: *My mother-in-law made it very clear that my husband could not go into the delivery room, and could not see the baby. I really wanted to look but I couldn't, because they had already covered it up. She forbade me from mentioning anything related to the lost baby. But my thoughts just kept turning in my mind, making me cry. She did not want to hear about it; she rejected the baby in the same way she rejects disease and death. Because the baby died without even being born, she rejected him even more strongly; so the only thing I could not was suppress my feelings.*[77(p223)]

In some cultures, bereaved parents were unable to, or feared to, see or hold their baby due to religious beliefs and practices. They feared that by violating the taboo concerning seeing or holding their child, they would affect the deceased (prevent reincarnation, stuck in the spirit world), survivors and future pregnancies (result in future pregnancy loss). For some parents, the shocking loss of a child to stillbirth led them to question their faith and beliefs. For others, their faith provided a means of drawing strength to cope with their distress and find meaning in their loss. An Israeli Ultraorthodox Jewish woman emphasised the ability to draw strength from one's faith: *I caught myself and said, 'Wait a minute. This was a test from God'. God gave me strength, and there were worse things. I suddenly realized that we had an opportunity to sanctify God's name, and I turned to God and said 'Help me sanctify your name and get through this test with strength'. I then told my mother that this was from the*

Blessed Lord, and that there was a reason for the stillbirth. Once I realized that, I felt much better, and much stronger.[45(p926)]

Parenting a Child Who Has Died

Men and women form attachments with their child during pregnancy. Men noted connecting to their child from the beginning of pregnancy, with some highlighting advances in ultrasound technology intensified this connection. It was overwhelmingly apparent that bereaved parents want their stillborn baby to recognised, acknowledged and treated like a baby who has died. A woman emphasised the positive impact being recognised as a parent had on her experience of stillbirth: *"They told us that she was beautiful, and congratulated us that, in spite of everything, we had become parents to this wonderful little girl"*.[69(p649)] Another woman acknowledged the benefit of health professionals responding to the stillbirth of her baby the same as the death of a child who had lived: *"The staff on the delivery ward were wonderful. They cried and showed respect"*.[69(p649)] As such, men and women want to be treated as parents who have lost a child. They want this recognition not only from health professionals but also from family, friends and colleagues. Legitimising the existence of a stillborn baby assists parents to process their loss.

Women discussed the need to be treated the same as women who deliver live babies, with the same acknowledgment of the challenges of labour and birth. They also expressed a need for the psychological and emotional complexity of delivering and then later leaving a stillborn child to be recognised. One man demonstrated the importance of being treated the same as other parents who recently welcomed a baby: *"They really were there to help and always available to do so. I was just as pampered as my wife was. The staff made us feel as though we were exactly like all other couples having a baby"*.[8(p667)] In order to facilitate this recognition, bereaved parents want their child to be referred to by their name. Parents also have a strong desire to engage in parenting behaviours with their stillborn child. Where

siblings exist, they want to integrate them into these practices as a family. Parents feel they have limited time to make memories with their stillborn and want to be encouraged to see, hold, and parent their baby. It should be noted that parenting practices continue well beyond the hospital experience and when conducted, the funeral. Men and women continue to engage in behaviour that represents parenting their child for many years. Often this is done in the privacy of the home. One man described how he and his family continue to recognise their stillborn son: *"We usually as a family celebrate his birthday and have a birthday cake and we did this year. Yeah, we celebrate his birthday and go down to the grave at least a couple of times a year and if I'm ever walking around that way I usually go over".*[23(p257)] Another woman highlighted how their stillborn son continues to be recognised as a member of the family: *"He (the stillborn baby) is truly alive in our family. Elizabeth (the sibling) talks to him in the evening, so I feel that the siblings experience that they have a little brother, in a sort of way. I experience the farewell as a process*".[39(p154)]

Education and Information

It was very evident that parents need more education on what to expect, how to make memories and support services. Parents want information from the time they are notified that their baby has died. They also note that due to their shock, distress and grief, they need information to be repeated, clarified and provided in multiple formats (e.g., verbal and written). Parents discussed the need for health professionals to use clear, empathic and unambiguous language in all their interactions. One woman articulated the importance of language as follows: *"I'm really sorry, your baby has died. She [the Doctor] was very clear and precise with her words, as in I was able to understand her…I understood everything clearly and I felt there was no stone unturned".*[65(p509)]

Information of particular importance to bereaved parents included all available options to see, hold, parent, ritualise, commemorate and remember their baby. Parents

expressed a desire to make their own choices based on comprehensive and unbiased information. They do not want to feel pressured to make decisions about their baby, nor feel they have limited time (while acknowledging that they do). Parents also discussed the importance of having information about what to expect and how to cope beyond the hospital experience. They reported often feeling alone in navigating their loss and being unsure of where to access support. One woman emphasised: *"I was feeling so bad and I was so upset that I forgot everything the doctor taught me. I even lost the information brochures. I think it was the duty of the prenatal care provider to follow-up and ask why I had not referred for healthcare"*.[36(p468)] Another woman highlighted the lack of support beyond the hospital encounter: *"I was allowed to stay for three days…any assistance after that was pretty thin on the ground. There was no follow-up"*.[43(p335)]

Mementoes and Rituals

In their state of shock and grief, men and women are often unaware of the options they have to create memories and memorialise their child. Overwhelmingly, they want health professionals to provide information and assist in coordinating these practices. The importance of extra guidance was emphasised by one woman: *"I now realise that extra guidance about what I could do with my baby would've been appreciated, for example, bathe/dress her, walk with her in the garden, take more photos, have hand/foot casts taken, open her eyes etc! These are the little things chronically grieving parents do not think to do – they need guidance"*.[7(p189)]

Parents discussed the high value placed on mementoes of their child, noting the loss of an item was highly distressing. Regardless of culture, men and women participate in rituals as a means of acknowledging the existence of their stillborn child, connecting to their role as parents and protecting their baby. They also express the desire to engage siblings and family in these practices. When bereaved parents' culture or religion did not support rituals, any

rituals were often conducted in private or isolation. Bereaved men and women found that religious practices and rituals assisted them to make sense of and accept their loss. One woman described the key roles chaplaincy played in memorialising her stillborn son: *"Chaplaincy staff were absolutely brilliant and held a baptism for our son, which was one of the most important things that we did, officially recognising and naming him"*.[16(p154)] Overall, rituals, mementoes and memory making practices were found to be an important part of positive coping for parents bereaved by stillbirth.

Discussion

This study aimed to explore the lived experience of men and women bereaved by stillbirth and to utilise these findings to inform grief and support guidelines. The meta-synthesis of fifty-one studies resulted in 280 findings which were aggregated into six categories. These categories encompassed men and women's lived experience of grief, support, parenting, gender, social norms, culture and faith in response to stillbirth. Insights were also gained into the role of rituals and mementoes and the importance of education and information.

The findings of this study were consistent with, and build upon, previous meta-syntheses in the stillbirth literature.[80,10,29] Profound grief was found to be a universal experience for men and women bereaved by stillbirth regardless of ethnicity, culture, religion, faith or social role or status. This study supports previous research which identifies stillbirth-related grief occurs in the context of stigma, gender, parenting roles and attachment.[16,17] Bereaved men and women yearned for their baby to be recognised as a child who had died and to have their role of parent legitimised by the healthcare system, family, friends and colleagues. Regardless of gender, culture or faith men and women bereaved by stillbirth found compassionate, empathic, humanistic support promoted their coping and recovery.

A new finding identified from this study is that men and woman were aware of discrepancies between their feelings of grief and distress and the gender, cultural and social expectations of emotional expression and coping. Building on what is known in the literature, this study also found that for many a stillborn child was a silent loss.[11,13,14] This study found that the volume of silence was mediated by the society and culture within which bereaved parents live. Bereaved men and woman craved information about their loss, how to recognise and remember their child, and how to learn to cope over time. The provision of this information was inconsistent. Mementoes and rituals played a crucial role in recognising the birth and death of a stillborn baby, continuing to integrate the baby into the family construct, and fulfilling the needs of bereaved men and women to parent their child and to process their grief.

This study presented four hypotheses. The findings of the meta-synthesis support the first hypothesis that social and cultural factors impact men and women's lived experience of stillbirth. It also supports the proposal that cultural norms associated with gender, parenting and relationship roles result in differences in the lived experience of stillbirth between men and women. This study also identified support for the second hypothesis that differences will be found in the experience of grief between men and women in response to stillbirth as a result of cultural and social factors. Building on the work of Hennegan et al.[22] and McCarthy[18] this study found men and women express, and cope with, their grief differently, with men preferring to grieve in private and internally and women preferring sharing their emotions and grieving within groups.

This meta-synthesis in part supported the third hypothesis that social norms associated with male gender, fatherhood and what it means to be a spouse lead to suppressed or delayed expression of grief for men when compared to women. While grief suppression was prevalent for some men in this study, it was not found to be a universal experience of men bereaved by

stillbirth. Interestingly, this study found that grief suppression was influenced by culture and faith and as such, was also reported by some bereaved women. Overwhelmingly this meta-synthesis identified that men bereaved by stillbirth experience grief with the same intensity as women; often without any personal sense of suppression.

Grief suppression can then be argued to occur as a consequence of assumptions by the support network of bereaved men that their loss experience is not as painful, intense or challenging as bereaved women and therefore is somehow suppressed. Interestingly, the notion of grief suppression feeds into Western social and cultural expectations of how men are expected to cope and express their emotions. Delayed grief amongst men was also not found to be a universal experience. While found in this study to be used as a coping strategy by some men, often to facilitate supporting their distraught spouse, other men reported no delay in their experience or processing of grief, facing the same emotional challenges as women. This finding challenges previous assumptions made about the male experience of stillbirth and broadens understanding of the lived experience of men. It also highlights that much remains to be learnt about the role culture, gender and social norms play in the lived experience of stillbirth.

The findings of this study support the final hypothesis that the grief and support needs of men and women bereaved by stillbirth will extend beyond the hospital encounter and outside the clinical care team. Overwhelmingly bereaved parents wanted the support of a multidisciplinary team, their family and community, both in recognising the birth and death of their child and in processing their loss in the short- and long-term. This study identified that bereaved men and women seek support for many years after their loss and find meaning in sharing their lived experience with those who can relate.

In response to the results of this study, grief and support guidelines that extend beyond the hospital setting for men and women bereaved by stillbirth have been developed (Table 4). These guidelines also propose research informed training and governance needs.

Table 4

Grief and Support Guidelines for Men and Women Bereaved by Stillbirth

Grief
• Parents should be provided with basic information during the ante-natal period on what to expect in the tragic event that their child is stillborn. This advice should be tailored to the hospital in which they plan to deliver their child.
• Treating health professionals should determine the cultural, spiritual and religious needs of bereaved parents and integrate this into their care plan.
• Psycho-social and grief interventions should be culturally sensitive and consider the ethnic and spiritual meaning of the loss for bereaved parents.
• Parental shock and grief should be acknowledged and normalised by treating health professionals.
• Parents should be provided with information on common grief reactions to stillbirth.
• On the notification of stillbirth, health professionals should acknowledge the commencement of grief.
• Health professionals should address the emotional needs during labour and delivery of parents experiencing antepartum stillbirth.
• Parents should be given information and referrals for grief counselling (if desired).
Support
• All expectant parents should receive education about stillbirth during the antenatal period. Information should include evidence-based risk reduction practices.
• Mothers should be encouraged to monitor fetal movements and trust their instincts.
• Mothers should be educated on when to seek medical review and be aware of their rights to be examined.
• Stillbirth should be managed by a multidisciplinary team comprising medical practitioner, midwife, social worker, psychologist and chaplain (or equivalent).
• Multidisciplinary teams should determine what family, social, community or religious support bereaved parents need and facilitate engagement.
• Parents should not be left alone following notification of the death of their child unless they specifically request for this to occur.

- From time of notification through to hospital discharge, parents should be consulted regularly to clarify information and provide opportunities for questions.
- Multidisciplinary teams should consider the differing information and support needs of antepartum and intrapartum stillbirth.
- Parents should be offered the opportunity to involve the stillborn baby's siblings, grandparents and other family members in rituals and memory making practices.
- Follow-up must include at a minimum both parents. This should include an assessment of each parent's psycho-social needs. Where relevant the family system may require follow-up (e.g., siblings, grandparents). Follow-up should be initiated by the healthcare system and referrals facilitated where the need is identified.
- Information on the referral pathways for mental health support, grief counselling, social work, chaplaincy and support groups should be provided and referrals arranged.
- Parents should be provided with information on what to expect on returning home without their baby.
- Parents should be provided with information on adaptive means of coping and self-care practices.

Training and Governance

- All midwives and obstetricians should be trained in how to sensitively and respectfully respond to stillbirth.
- Hospital settings should have multidisciplinary teams trained in best practice responses to stillbirth.
- Hospitals should have established referral pathways for psychologists, social workers and chaplains experienced in supporting those bereaved by stillbirth.
- Hospitals should have facilities purposely designed to meet the needs of parents bereaved by stillbirth. These facilities should be designed to support health professionals in providing evidence-based care.
- Employers should have policies and practices in place to meet the psycho-social needs of their employees responding to and experiencing stillbirth.
- Health professionals not trained in how to respond to stillbirth should seek the professional supervision of skilled peers.

These grief and support guidelines emphasise the importance of a multidisciplinary approach to responding to stillbirth where bereaved parents are acknowledged to live within a broader social, cultural, ethnic, familial and religious/spiritual structure. Grief response should focus on attending to the basic needs of bereaved men and women, normalising their grief, and providing empathic care focussed on reinstating a sense of control and agency in their time of crisis. Grief should be attended to by a multidisciplinary team with a priority to integrate the family and community to assist with immediate and longer-term support. These guidelines also reinforce that stillbirth needs to be viewed as a crisis of loss, not simplified to a medical problem that requires resolution during the hospital encounter.

Increased education and awareness concerning stillbirth needs to be provided in the antenatal period. This education should include the communication of evidence-based strategies to reduce the risk of stillbirth. Follow-up of men and women bereaved by stillbirth needs to improve. Follow-up should be routine and should encompass the wider family system. Noting that bereaved men experience stillbirth with the same intensity as women, considerably more needs to be done to ensure their needs are addressed.

Limitations and Future Research

The findings of this study must be considered in light of possible limitations. First, despite a rigorous search strategy, it is possible that not all relevant studies have been included in this study. Also, studies not published in English were excluded. Second, the stillbirth literature is known to markedly underrepresent the experience of bereaved men, therefore impacting on the representation of men in the findings of this study. The stillbirth literature has even fewer studies which examine the impact of culture, gender and social roles on the lived experience of bereaved men and women. Another limitation was the majority of studies (n = 37) in this synthesis were from Western, developed countries, therefore making it difficult to generalise results beyond these settings. Where other cultures were represented,

these were small in number. These limitations were in part balanced by the methodological strengths of this study which include the use of a predetermined, standardised search strategy, quality assessment tool and systematic synthesis of findings.

This study identified the need for further research investigating the grief and support needs of men bereaved by stillbirth. Studies which investigate the impact of gender, social expectations and parenting roles on men's experience of stillbirth would also be valuable. Specific studies which consider the cultural and spiritual needs of men and women bereaved by stillbirth are also significantly lacking. Valuable information could also be gleaned from studies which explore the role of family, community, chaplaincy and allied health professionals in meeting the medium- to long-term grief and support needs of bereaved men and women. Examining the needs of men and women bereaved by stillbirth beyond the hospital encounter is an area of research that requires additional attention.

The findings of this study make an important contribution to improving our understanding of the lived experience of men and women bereaved by stillbirth. This study presents important grief and support guidelines for those responding to bereaved men and women. It is hoped that with the application of these guidelines and continued research, men and women bereaved stillbirth can be better supported with the life-long consequences of this tragic loss.

Reflexive Paragraph

During this study, the primary researcher (NR) experienced a planned second pregnancy and consequent missed-miscarriage at ten weeks. This occurred after quality appraisal and before data extraction. This was the primary researcher's first experience of pregnancy loss. It is acknowledged that this experience has potentially influenced the interpretation of findings and research as a whole. This risk was moderated by regular consultation during all stages of extraction, interpretation and presentation of findings with

the secondary researcher (MO) who was aware of the primary researcher's pregnancy and subsequent loss. Important to limiting the impact on the interpretation of findings, and ensuring her own wellbeing, the primary researcher took a break until she felt emotionally and psychologically ready to continue with the study. In the spirit of this study, the primary researcher offers a narrative of her experience of pregnancy loss (Appendix B).

Conclusion

Stillbirth is a tragic loss which has far-reaching implications for those bereaved and the family, community, health and social systems within which they live. Support and grief interventions should be culturally sensitive and consider the ethnic and spiritual meaning of the loss for bereaved men and women. Responding to stillbirth needs to encompass the family system ensuring the grief and support needs of both men and women are addressed. More needs to be done to reduce the silence around stillbirth and improve understanding of the experience in the context of social norms, parenting roles and gender.

Conflict of Interest

The author declares no conflict of interest.

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Appendix A: Search Grids

PubMed

Stillbirth	Parents	Qualitative
"abortion, spontaneous"[mh] OR spontaneous abortion*[tiab] OR "stillbirth"[mh] OR stillbirth*[tiab] OR still birth*[tiab] OR stillborn*[tiab] OR still born*[tiab] OR "fetal death"[mh] OR fetal death*[tiab] OR foetal death*[tiab] OR fetus death*[tiab] OR foetus death*[tiab] OR pregnancy loss*[tiab] OR miscarriage*[tiab] OR "perinatal death"[mh] OR perinatal death*[tiab] OR peri natal death*[tiab] OR perinatal loss*[tiab] OR peri natal loss*[tiab] OR "perinatal mortality"[mh] OR perinatal mortalit*[tiab] OR peri natal mortalit*[tiab] OR "infant mortality"[mh] OR infant mortalit*[tiab] OR "infant death"[mh] OR infant death*[tiab] OR neonatal mortalit*[tiab] OR neo natal mortalit*[tiab] OR neonatal death*[tiab] OR neo natal death*[tiab] OR baby death*[tiab] OR baby's death*[tiab]	"parents" [mh] OR parent*[tiab] OR "women"[mh] OR "mothers"[mh] OR "female"[mh] OR women*[tiab] OR mother*[tiab] OR woman*[tiab] OR maternal*[tiab] OR female*[tiab] OR wife*[tiab] OR wives*[tiab] OR "men"[mh] or "fathers"[mh] OR "male"[mh] OR male[tiab] OR men[tiab] OR men's[tiab] OR father*[tiab] OR man[tiab] OR man's[tiab] OR paternal*[tiab] OR husband*[tiab]	"qualitative research"[mh:noexp] qualitative*[tiab] OR "focus groups"[mh] OR focus group*[tiab] OR interview*[tiab] OR thematic analys*[tiab] OR content analys*[tiab] OR discourse analys*[tiab] OR lived experience*[tiab] OR personal experience*[tiab] OR interpretative phenomenological analys*[tiab] OR ethnograph*[tiab] OR case stud*[tiab] OR narrative*[tiab]

PsychINFO

Stillbirth	Parents	Qualitative
spontaneous abortion.sh OR spontaneous abortion*.tw. OR pregnancy outcomes.sh OR stillbirth*.tw. OR still birth*.tw. OR stillborn*.tw. OR still born*.tw. OR fetal death*.tw. OR foetal death*.tw. OR fetus death*.tw. OR foetus death*.tw. OR pregnancy loss*.tw. OR miscarriage*.tw. OR perinatal	parents.sh. OR parent*.tw. OR mothers.sh OR women*.tw. OR mother*.tw. OR woman*.tw. OR female*.tw. OR maternal*.tw. OR wife*.tw. OR wives*.tw. OR men.sh OR men.tw. OR male*.tw. OR father*.tw. OR man.tw. OR paternal*.tw. OR husband*.tw.	qualitative research.tw. OR qualitative*.tw. OR focus group*.tw. OR interview*.tw. OR thematic analys*.tw. OR content analys*.tw. OR discourse analys*.tw. OR lived experience*.tw. OR personal experience*.tw.

death*.tw. OR peri natal death*.tw. OR perinatal loss*.tw. OR peri natal loss*.tw. OR perinatal mortalit*.tw. OR peri natal mortalit*.tw. OR infant mortalit*.tw. OR infant death*.tw. OR neonatal mortalit*.tw. OR neo natal mortalit*.tw. OR neonatal death*.tw. OR neo natal death*.tw. OR baby* death*.tw.		OR interpretative phenomenological analys*.tw. OR ethnograph*.tw. OR case stud*.tw. OR narrative*.tw.

Web of Science

Stillbirth	Parents	Qualitative
TS=(“spontaneous abortion” OR stillbirth* OR “still birth*” OR stillborn* OR “still born*” OR “fetal death*” OR “foetal death*” OR “fetus death*” OR “foetus death*” OR “pregnancy loss*” OR miscarriage* OR “perinatal death*” OR “peri natal death*” OR “perinatal loss*” OR “peri natal loss*” OR “perinatal mortalit*” OR “peri natal mortalit*” OR “infant mortalit*” OR “infant death*” OR “neonatal mortalit*” OR “neo natal mortalit*” OR “neonatal death*” OR “neo natal death*” OR “baby’s death” OR “baby death*”)	TS=(parent* OR women* OR mother* OR woman* OR female* OR maternal* OR wife* OR wives* OR men OR male* OR father* OR man OR paternal* OR husband*)	TS=(“qualitative research” OR qualitative* OR “focus group*” OR interview* OR “thematic analys*” OR “content analys*” OR “discourse analys*” OR “lived experience*” OR “personal experience*” OR “interpretative phenomenological analys*” OR ethnograph* OR “case stud*” OR narrative*)

CINAHL – TI /AB

Stillbirth	Parents	Qualitative
MH “perinatal death” OR MH “pregnancy outcomes” OR TI stillbirth* OR AB stillbirth* OR TI “still birth*” OR AB “still birth*” OR TI stillborn* OR AB stillborn* OR TI “still born*” OR AB “still born*” OR MH “abortion, spontaneous” OR TI “spontaneous abortion*” OR AB “spontaneous abortion*” OR TI “fetal death*” OR AB “fetal death*” OR TI “foetal death*”	MH parents OR TI women* OR AB women* OR TI woman* OR AB woman* OR MH mothers* OR TI mother* OR AB mother* OR TI female* OR AB female* OR TI maternal* OR AB maternal* OR TI wife* OR AB wife* OR TI wives* OR AB wives* OR TI men OR AB men OR MH fathers* OR TI father* OR AB father* OR TI	MH “qualitative studies” OR TI qualitative* OR AB qualitative* OR MH “focus groups” OR TI “focus group*” AB “focus group*” OR MH interviews OR TI interview* OR AB interview* OR MH “thematic analys*” OR TI “thematic analys*”

OR AB “foetal death*” OR TI “fetus death*” OR AB “fetus death*” OR TI “foetus death*” OR AB “foetus death*” OR TI “pregnancy loss*” OR AB “pregnancy loss*” OR TI miscarriage* OR AB miscarriage* OR TI “perinatal death*” OR AB “perinatal death*” OR TI “peri natal death*” OR AB “peri natal death*” OR TI “perinatal loss*” OR AB “perinatal loss*” OR TI “peri natal loss*” OR AB “peri natal loss*”OR TI “perinatal mortalit*” OR AB “perinatal mortalit*” OR TI “peri natal mortalit*” OR AB “peri natal mortalit*” OR TI “infant mortalit*” OR AB “infant mortalit*” OR MH “infant death” OR TI “infant death*” OR AB “infant death*” OR TI “neonatal mortalit*” OR AB “neonatal mortalit*” OR TI “neo natal mortalit*” OR AB “neo natal mortalit*” OR TI “neonatal death*” OR AB “neonatal death*” OR TI “neo natal death*” OR AB “neo natal death*” OR TI “baby death*” OR AB “baby death*” OR TI “baby’s death*” OR AB “baby’s death*”	male* OR AB male* OR TI men OR AB men OR TI man OR AB man OR TI paternal* OR AB paternal* OR TI husband* OR AB husband*	OR AB “thematic analys*” OR MH “content analys*” OR TI “content analys*” OR MH “discourse analys*” OR TI “discourse analys*” OR AB “discourse analys*” OR MH “life experiences” OR TI “lived experience*” OR AB “lived experience*” OR TI “personal experience*” OR AB “personal experience*” OR TI “interpretative phenomenological analys*” OR AB “interpretative phenomenological analys*”

Embase

Stillbirth	Parents	Qualitative
“fetus death”/de OR stillbirth*:ti,ab OR “still birth*”:ti,ab OR stillborn*:ti,ab OR “still born*”:ti,ab OR “spontaneous abortion”/de OR “spontaneous abortion*”:ti,ab OR “fetal death*”:ti,ab OR “foetal death*”:ti,ab OR “fetus death*”:ti,ab OR “foetus death*”:ti,ab OR “pregnancy loss*”:ti,ab OR miscarriage*:ti,ab OR “perinatal	parent/de OR parent*:ti,ab OR mother/de or mother*:ti,ab OR female/de OR women*:ti,ab OR mother*:ti,ab OR woman*:ti,ab OR female*:ti,ab OR maternal*:ti,ab OR wife*:ti,ab OR wives*:ti,ab OR male/de OR male:ti,ab OR men:ti,ab OR father/de OR father*:ti,ab OR man:ti,ab OR paternal*:ti,ab OR husband*:ti,ab	qualitative/de OR qualitative*:ti,ab OR focus group*:ti,ab OR interview/de OR interview*:ti,ab OR “thematic analys*”/de OR “thematic analys*”:ti,ab OR “content analys*”/de OR “content analys*”:ti,ab OR “discourse analys*”/de

death*":ti,ab OR "perinatal mortalit*":ti,ab "peri natal death*":ti,ab OR "peri natal mortalit*":ti,ab OR "perinatal loss*":ti,ab "peri natal loss*":ti,ab OR "infant mortalit*":ti,ab OR "infant death*":ti,ab OR "neonatal mortalit*":ti,ab OR "neonatal death*":ti,ab OR "neo natal mortalit*":ti,ab OR "neo natal death*":ti,ab OR "baby death*":ti,ab OR "baby's death*":ti,ab		OR "discourse analys*":ti,ab OR "personal experience*"/de OR "lived experience*":ti,ab OR "interpretative phenomenological analys*":ti,ab OR ethnograph*:ti,ab OR "case stud*":ti,ab OR narrative*:ti,ab

Scopus

Stillbirth	Parents	Qualitative
TITLE-ABS-KEY("spontaneous abortion" OR stillbirth* OR "still birth*" OR stillborn* OR "still born*" "fetal death*" OR "foetal death*" OR "fetus death*" OR "foetus death*" OR "pregnancy loss" OR miscarriage* OR "perinatal death*" OR "peri natal death*" OR "perinatal loss*" OR "peri natal loss*" OR "perinatal mortalit*" OR "peri natal mortalit*" OR "infant mortalit*" OR "infant death*" OR "neonatal mortalit*" OR "neo natal mortalit*" OR "neonatal death*" OR "neo natal death*" OR "baby's death*" OR "baby death*")	TITLE-ABS-KEY(parent* OR women* OR mother* OR woman* OR female* OR maternal* OR wife* OR wives* OR men OR male OR father* OR man OR paternal* OR husband*)	TITLE-ABS-KEY("qualitative research" OR qualitative* OR "focus group*" OR interview* OR "thematic analys*" OR "content analys*" OR "discourse analys*" OR "lived experience*" OR "personal experience*" OR "interpretative phenomenological analys*" OR ethnograph* OR "case stud*" OR narrative*)

Sociological Abstracts

Stillbirth	Parents	Qualitative
NOFT("spontaneous abortion" OR stillbirth* OR "still birth*" OR stillborn* OR "still born*" OR "fetal death*" OR "foetal death*" OR "fetus death*" OR "foetus death*" OR "pregnancy loss*" OR miscarriage* OR	NOFT(parent* OR women* OR mother* OR woman* OR female* OR maternal* OR wife* OR wives* OR men OR male OR father* OR man OR paternal* OR husband*)	NOFT("qualitative research" OR qualitative* OR "focus group*" OR interview* OR "thematic analys*" OR "content analys*" OR "discourse

"perinatal death*" OR "peri natal death*" OR "perinatal loss*" OR "peri natal loss*" OR "perinatal mortalit*" OR "peri natal mortalit*" OR "infant mortalit*" OR "infant death*" OR "neonatal mortalit*" OR "neo natal mortalit*" OR "neonatal death*" OR "neo natal death*" OR "baby's death*" OR "baby death*")		analys*" OR "lived experience*" OR "personal experience*" OR "interpretative phenomenological analys*" OR ethnograph* OR "case stud*" OR narrative*)

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Stillbirth	Parents	Qualitative
NOFT("spontaneous abortion" OR stillbirth* OR "still birth*" OR stillborn* OR "still born*" OR "fetal death*" OR "foetal death*" OR "fetus death*" OR "foetus death*" OR "pregnancy loss*" OR miscarriage* OR "perinatal death*" OR "peri natal death*" OR "perinatal loss*" OR "peri natal loss*" OR "perinatal mortalit*" OR "peri natal mortalit*" OR "infant mortalit*" OR "infant death*" OR "neonatal mortalit*" OR "neo natal mortalit*" OR "neonatal death*" OR "neo natal death*" OR "baby's death*" OR "baby death*")	NOFT(parent* OR women* OR mother* OR woman* OR female* OR maternal* OR wife* OR wives* OR men OR male OR father* OR man OR paternal* OR husband*)	NOFT("qualitative research" OR qualitative* OR "focus group*" OR interview* OR "thematic analys*" OR "content analys*" OR "discourse analys*" OR "lived experience*" OR "personal experience*" OR "interpretative phenomenological analys*" OR ethnograph* OR "case stud*" OR narrative*)

Appendix B: Primary Researcher Pregnancy Loss Narrative

With no history of fertility or pregnancy complications, my pregnancy loss came as a shock. My husband, son and I were excited to grow our family. We were living away from family for work and had told a few family and friends of our pregnancy, earlier than most would. I felt very pregnant and we were excited for our first appointment with our obstetrician.

On viewing the ultrasound screen I could clearly make out our baby. Small, but clearly our baby. Our obstetrician stated, "I'm sorry, this is not a good pregnancy". I briefly thought she was joking whilst acutely aware that obstetrician's do not joke about such things. She followed up, "Your baby had stopped growing, there is no heartbeat". I cried. Unbeknownst to me, my husband did not hear what she had said. He connected the dots. We both cried.

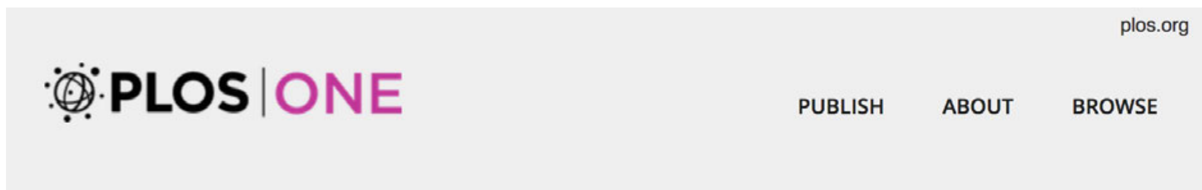
In my state of shock our obstetrician asked, "What would you like to do". I found the capacity to ask logical questions about options and risks, ultimately seeking her specialist advice on the best way forward. I agreed to think about undergoing a D&C. We left the obstetrician's office and found a partially private area to sob, as a family. I said "sorry" to my husband. He cried and reassured me I had nothing to be sorry for. The afternoon was a blur of tears. My husband returned to work, he cried. I rang the obstetrician and scheduled the D&C. I noticed how pregnant I still felt. I cried for my dead baby, for our loss and what could have been.

The following day my grief was raw but primarily as a means to cope I started noting a few things: people knew about our baby and were sorry for our loss; we didn't have to experience our grief in silence; our family of friends created a community of support around us; male colleagues of my husband shared their pregnancy loss experiences with him, legitimising his loss; his boss told him he didn't need to be at work.

With time I reflected on what I was grateful for: having our son; the positive impact my research has had on my loss experience; having a marriage that strengthens in times of loss; having an empathic healthcare team; having my grief acknowledged; having the loss of our baby recognised by family, friends and colleagues; the steadfast support of my supervisor during this research; the opportunity to try for another baby; the capacity to continue this meaningful research.

Two months on I profoundly feel that we lost a baby. A baby I now wish I had some proof of its existence beyond a health record entry (like the print out of the ultrasound screen). A baby that was loved. A baby that had a list of names waiting to pick just the right one. A baby whose four-year-old brother misses what might have been. A baby I continue to grieve for. A baby I had said goodbye to before I got to say hello. But this experience also has me feeling overwhelmingly grateful for what I do have and knowing I am not alone in my loss.

Appendix C: PlosONE Instructions to Authors



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