



## CASE STUDY

## Caring for families experiencing stillbirth: Evidence-based guidance for maternity care providers



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## ABSTRACT

**Background:** Evidence-based guidance is needed to inform care provided to mothers and families who experience stillbirth. This paper focuses upon how meaningful and culturally appropriate care can be provided to mothers and families from when they are informed that their baby will be stillborn to many years after the experience. Avoidable suffering may be occurring in the clinical setting.

**Aims:** To promote and inform meaningful and culturally appropriate evidence-informed practice amongst maternity care providers caring for mothers and families who experience stillbirth.

**Methods:** A comprehensive systematic review was conducted which primarily synthesised relevant qualitative research studies. An expert advisory group comprised of stillbirth researchers, clinicians, and parents who have experienced stillbirth provided guidance for the review and the development of implications for practice.

**Findings:** Grieving parents want staff to demonstrate sensitivity and empathy, validate their emotions, provide clear, information, and be aware that the timing of information may be distressing. Parents want support and guidance when making decisions about seeing and holding their baby. Sensitivity, respect, collaboration, and information are essential throughout the experience of stillbirth. Culturally appropriate care is important and may require staff to accommodate different cultural practices.

**Conclusion:** The findings of the review and expert consensus inform the provision of meaningful and culturally appropriate care for mothers and families that have experienced stillbirth. Evidence informed implications for practice are provided to guide the actions, communication, and behaviours of maternity care providers.

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## 1. Introduction

The stillbirth rate in Australia is around 3.5 per 1000 births.<sup>1</sup> Even with this relatively high prevalence, there is a lack of clear evidence-based guidance available to support and inform maternity care providers who provide care for families that experience stillbirth. The actions and behaviours of maternity care providers from the point that a baby has been diagnosed as no longer alive, and throughout the experience of stillbirth may be critical for the ability of families to cope with stillbirth.<sup>2</sup> Perhaps as a result of being ill-equipped to appropriately work with families around the time of stillbirth, the best standard of care and support may not be provided.<sup>3</sup> Parents who experience stillbirth are at risk of potentially harmful psychosocial effects including grief, depression, anxiety,

and self-blame.<sup>2,4–6</sup> Between diagnosis and birth, mothers can suffer significantly.<sup>7</sup> Waiting to give birth may even be more distressing than the birth itself.<sup>8,9</sup> For this reason, they need supportive and sensitive care from maternity care providers from before confirmation that their baby has died or will be stillborn.<sup>7</sup> Recent research has also focussed upon the impact that stillbirth has on fathers and their experiences of care provided by maternity care providers.<sup>10</sup> Parents are rarely prepared for the experience of stillbirth and may benefit from information provided by maternity care providers in the antenatal period.<sup>2,11</sup> The negative effects of experiencing stillbirth may be lessened by receiving care from care providers who are trained and prepared to help parents cope with the tragic experience.<sup>5–8,11–17</sup> Research has found that parents' negative experiences and outcomes may be compounded, or in some cases inadvertently caused, by interactions with maternity care providers throughout the experience of stillbirth.<sup>2</sup> In some cases, maternity care providers may not be adequately prepared or trained to provide the appropriate supportive and sensitive care required.<sup>3</sup> Maternity

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care providers may be emotionally affected by stillbirth themselves and this can influence their interaction with parents and the quality of care that is provided.<sup>5,12</sup>

A recent Cochrane systematic review sought to assess the effectiveness of support strategies for mothers, fathers, and families after perinatal death, including stillbirth.<sup>18</sup> This review sought randomised trials that assessed any form of support aimed at encouraging acceptance of loss, bereavement counselling, or specialised psychotherapy or counselling for parents and families who had experienced perinatal death. The review was not able to include any studies because of the high loss of participants at follow-up. The authors concluded that practical guidance for the support for families affected by perinatal death could not be provided from an examination of trials and experimental evidence alone.<sup>18</sup> There is a pressing need for a systematic review of the current evidence on this topic to be conducted that encompasses more than randomised trials, and seeks the best available evidence from other types of research including quantitative research. A comprehensive systematic review, which provided the evidence base for the development of the implications for practice presented in this paper, was undertaken to investigate the effectiveness, meaningfulness, and cultural appropriateness of non-pharmacological, psychosocial supportive care interventions and care strategies for families to improve their psychological well-being throughout the experience of stillbirth.<sup>19</sup> In order to capture the range of experiences of care that parents may have during a stillbirth, this review considered language studies conducted in developed countries that are applicable to inform guidance for Australian maternity care providers who provide care to parents and families from a range of cultural backgrounds. This paper presents the implications for practice relevant to the care of mothers and families that have been developed from the synthesised findings of the comprehensive review and input of an expert advisory group of stillbirth researchers, clinical staff, and parents who have experienced stillbirth.

## 2. Methods

The systematic review was conducted according to an a priori systematic review protocol.<sup>20</sup> The review's phenomenon of interest was the experiences of families with interventions and care strategies implemented by maternity care providers throughout the experience of stillbirth; from the time of diagnosis to any time in the weeks, months, and years that followed. Family was defined as mothers, fathers, siblings and/or grandparents. Stillbirth was defined as the death of a baby in utero at any time from 20-weeks until immediately before birth. This is in line with the standard definition used in Australia.<sup>21</sup> Papers that included families that had experienced perinatal death (after birth), neonatal death, miscarriage, termination of pregnancy for non-medical reasons or pregnancy loss before 20 weeks were excluded. Studies that investigated the death of a baby that matched the definition of stillbirth used in the review were included if participant data and findings could be disaggregated from those of ineligible participants.

A comprehensive search for published and grey literature was conducted during February to April 2014 across a number of databases including PubMed, CINAHL, EMBASE, PsycINFO, and selected trial registries and stillbirth related websites. Initial keywords included: the initial keywords used were: stillbirth; stillborn; foetal death; intrauterine death; perinatal death; psychosocial; psychotherap\*; bereave\*; grief; emotion\*; depressi\*; guilt. Only English language publications were considered for inclusion; publication date was not limited. The reference lists of included studies were examined to identify additional studies. No grey literature was identified that met the inclusion criteria for the

review. Twenty four qualitative studies were assessed for methodological quality by two independent reviewers prior to inclusion in the review using Joanna Briggs Institute (JBI) critical appraisal tools.<sup>22,23</sup> Findings were extracted from papers included in the review using standardised JBI data extraction instruments.<sup>22,23</sup> Meta-aggregative synthesis of the findings was performed using JBI-QARI (Joanna Briggs Institute, Adelaide, Australia).<sup>22</sup> Common themes among findings were identified and used to group findings into categories. Developed categories were further brought together based upon similarity in meaning, to produce synthesised findings intended to be reliable representations of the primary authors' findings and intent that may be used as a basis for evidence-based guidance.<sup>24,25</sup> A more detailed discussion of the methodological approach and methods used are detailed in a separate publication.<sup>26</sup>

Members of the expert advisory group provided input throughout the project via three, face to face meetings, teleconferences and email correspondence with the research team. Advisory group members were asked to draw upon their professional knowledge and expertise, as well as their personal experiences as maternity care providers, clinicians, and parents of stillborn babies to provide advice. The role of the expert advisory group was to fulfil three main objectives; firstly, to provide guidance and feedback on the conduct of the systematic review to ensure that it located relevant evidence, secondly, to provide insight on the synthesis and interpretation of the findings of the review, and finally, to assist in the development of the implications for practice from the findings of the review to ensure that they would be suitable and practical in real-world practice and be appropriate for maternity care providers, mothers and families. Draft copies of the protocol and review were circulated to members of the group prior to meetings and members were invited to provide comment, critique, and guidance. Details of the protocol and the proposed conduct of the review were considered at the first face to face meeting while the full review report was considered in detail at the second face to face meeting of the advisory group and research team. To develop the implications for practice reported on in this paper, the results and conclusions of the systematic review were discussed in depth and members provided detailed feedback on what the implications for practice were and how they should be presented. Draft implications for practice were provided to the expert advisory group for input and comment and were further refined through detailed discussion at the final, face to face meeting. The advisory group provided additional depth and detail pertinent to the provision of care for mothers and families that was used to enrich and supplement the review findings.

## 3. Findings

Twenty two qualitative studies were included in the comprehensive systematic review. Overall, the studies were of moderate to high methodological quality with only one study receiving three out of ten possible negative responses to the critical appraisal criteria.<sup>22,23</sup> Two studies of low methodological quality were excluded. Full details regarding the methodological quality of the included studies is presented in the systematic review report.<sup>19</sup> The included studies were conducted in Australia (3),<sup>13,27,28</sup> the United States (5),<sup>5,7,15,29,30</sup> Sweden (5),<sup>2,8,9,31,32</sup> Canada (1),<sup>33</sup> Taiwan (3),<sup>34–36</sup> the United Kingdom (2),<sup>11,12</sup> South Africa (1),<sup>6</sup> Japan (1),<sup>17</sup> and Norway (1).<sup>16</sup> Most studies included mothers aged between 18 and 41 years; one study included mothers up to the age of 62.<sup>6</sup> Some studies included both fathers and mothers as a couple,<sup>2,5,7,11,31,36</sup> A small number of studies involved fathers (aged between 28 and 54) only.<sup>27,28,30,32,33</sup> The time since stillbirth reported in the included studies most commonly ranged from two

to three months,<sup>12,13</sup> up to six years,<sup>2,8,15,17,29–35</sup> and up to 22 years after stillbirth in one study.<sup>31</sup>

Early in the project, the expert advisory group emphasised the importance of the time since the stillbirth on the experience of parents. The group also highlighted that the timing of events during the experience of stillbirth was also important, as parents often interact with different maternity care providers during different stages of the experience of stillbirth. Therefore to reflect this and to provide pragmatic guidance for maternity care providers, the synthesis was constructed to be relevant to the phenomenon of interest at different periods in the temporal sequence of the experience of stillbirth. The included studies reported experiences of care that parents felt to be positive and supportive, as well as those that were perceived to be negative and distressing. There was a paucity of studies investigating the experiences of siblings and grandparents. The 22 included studies contributed 210 findings that ultimately informed six synthesised findings following the meta-aggregative process to qualitative synthesis.<sup>24,25</sup> All of the extracted qualitative findings are available in the systematic review report.<sup>19</sup> The first synthesised finding was relevant to the overall experience of stillbirth: from diagnosis to many years later. The second synthesised finding related specifically to the period when parents of a stillborn infant are first informed of the diagnosis of stillbirth. The third synthesised finding related to the period around the time of induction and birth. The fourth synthesised finding was pertinent to the period immediately after birth when parents may have the opportunity to see and hold their baby. The fifth synthesised finding related to any time beyond the immediate post-birth period. The sixth and final synthesised finding was centred on the provision of culturally appropriate care. In instances where the expert advisory group identified an important issue regarding the provision of care to mothers and families with no available evidence, the implications for practice have been informed by consensus amongst advisor group members alone. Specific examples include guidance around support and training for health professionals, and appropriate care for Aboriginal and Torres Strait Islander mothers and families.

#### 4. Implications for practice

The implications for practice developed and presented here align directly with the six synthesised findings.

##### 4.1. Implications for practice relevant throughout the stillbirth experience

The implications for practice relevant to the overall experience of stillbirth, including from the time of diagnosis up until many years later highlight three fundamental aspects of provision of care to mothers and parents. Parents require sensitive and genuinely empathetic care from maternity care providers as well as clear, carefully worded information and guidance. Maternity care providers may benefit from training to help develop skills to provide care for parents experiencing stillbirth.

###### 4.1.1. Providing sensitive, genuine and empathetic care

Throughout the stillbirth experience, friends or family members may be sources of valuable support. If possible, parents may appreciate when maternity care providers give them the option to have friends or family members present to provide support while in hospital. Parents may appreciate it when maternity care providers show emotion and empathy towards their experience. Parents appreciate it when maternity care providers respect and validate their emotional experience and reactions of being parents of a baby that has died shortly before or during birth. For many parents, this recognition should endure, as their understanding of

being a parent is not diminished by the experience of stillbirth. Parents who experience stillbirth can be emotionally fragile and appreciate empathy and support from maternity care providers and other healthcare professionals' from the time when they suspect that something is wrong with their pregnancy until many years after the immediate experience. The impact of stillbirth can be ongoing, and indeed never ceases for many parents. Parents often appreciate genuine and sincere engagement with maternity care providers. Individualised and personal care is valued by most parents, who appreciate when staff are aware of and attentive to their particular circumstances and experiences. Parents experience stillbirth as the death of their baby not as a medical event. As such, parents whose baby dies at a time that does not specifically align with the definition of stillbirth from 20 weeks gestation onwards should be treated with the same sensitivity and care.

##### 4.1.2. Information provision and communication throughout the stillbirth experience

Parents may be further distressed by maternity care providers who appear disengaged or do not take time to provide information, support and empathetic care. Parents should be given honest, forthcoming and step-by-step information in advance of each event and procedure. Dismissive, blunt, cold or inconsiderately worded communication distresses parents. Even small comforting gestures, such as a reassuring touch and simple words of sympathy and assurance can help parents feel supported.

Parents may wish to understand the cause of their baby's death. Parents making decisions about whether they would like investigations performed or post-mortem examinations conducted.

##### 4.1.3. Support and training for maternity care providers

Maternity care providers who attend to parents of stillborn babies may be better able to provide meaningful and appropriate care if training and support is available to develop their knowledge and skills to perform their role as well as to cope with their own emotional reactions.

#### 4.2. The diagnosis of stillbirth

Implications for practice derived from findings of experiences of healthcare provision at the time of diagnosis similarly centre on three aspects of care. The findings revealed that communication at this critical time, particularly the way the diagnosis of stillbirth is conveyed, is a key factor that can impact upon parents' experience of care and their psychological well-being.

##### 4.2.1. Emotional impact upon parents

Parents may have a potentially compromised ability to take in and process information due to the emotional impact of stillbirth. Maternity care providers can use cues from parents regarding their emotional state when deciding how best to time the delivery of information.

##### 4.2.2. Telling parents their baby will be stillborn

Prior to the confirmation of the death of their baby, parents may appreciate honest and transparent news about their baby's status. Contradicting parents' instincts that something is wrong can cause unnecessary distress for the parents. Parents may experience potentially avoidable or unexplained delays in receiving information about the death of their baby negatively. Parents appreciate clear and understandable language and communication when learning that their baby has died. Medical terms and ambiguous descriptions may not be understood and can be distressing. Maternity care providers may use language that parents do not understand or that is ambiguous and upsetting; "...we had no idea

what the doctor was talking about as we had never heard of it [anencephaly]. All I remember the doctor say to us was NOT COMPATIBLE WITH LIFE” (emphasis in original).<sup>13(p68)</sup> After learning that their baby has died, parents may appreciate maternity care providers asking them whether they would like them to stay to provide support and answer questions, or if they would rather be left alone. Parents may appreciate being provided with verbal, electronic, and written information, and may require information and details to be repeated. Having a supportive companion present can help alleviate distress and anxiety. Parents may appreciate time to discuss their situation with maternity care providers. Not allowing time for this, for instance, by leaving a room immediately after telling parents their baby has died or will be stillborn, may be distressing to parents.

#### 4.2.3. Continuity of care from diagnosis

Where possible, parents may appreciate receiving care from the same maternity care providers beyond the initial diagnosis of stillbirth. Mothers often wish to continue to see the same health care professionals after the initial diagnosis and have the same staff involved at induction of labour as those at the time that stillbirth was diagnosed.

### 4.3. Preparing parents for induction and birth

Implications for practice highlight four key elements of care to consider at the time when mothers are being prepared for induction and the birth of their stillborn baby. The provision of clear information and shared decision making about the lead up to and process of birth is very important. At this time sensitivity and respect on the part of the maternity care provider and provision of emotional and psychological support are also key elements.

#### 4.3.1. Informed preparation for birth

Mothers appreciate clear, step-by-step information of the induction and birthing process so as to know how to prepare themselves and what to expect. Verbal, electronic and written information may be appreciated. Specific information around how to prepare for birth can be useful, such as informing parents that they can bring a camera and clothes for the baby back to the hospital if they are going home before the birth. At this time, parents may be distressed by medical terminology or language used by staff to explain what is about to happen, for example, hearing their baby referred to as a ‘product of conception’ may upset parents. The timing of particular hospital processes may distress parents. Maternity care providers may use cues from parents to determine when might be most appropriate to provide parents with things like paperwork to complete.

#### 4.3.2. Timing between diagnosis and birth

Involving parents in collaborative discussion and informed decision-making regarding the timing of the induction of birth may be appreciated by parents. Parents may have differing needs and individual preferences for the length of time between learning that their baby has died and induction of birth. While some mothers may prefer to be induced and to give birth as soon as possible, others may appreciate being able to discuss their options to go home first and return to hospital when they have prepared themselves. If parents do return home, it is helpful to remind them about things they might want to bring to the birth, such as cameras and clothes for their baby. Parents may also wish to invite other family members. Where possible, both parents appreciate being included in information provision and discussion. Exclusion of partners may cause feelings of ostracism and blame for that parent and can also mean that both parents are not equally informed of what is happening to them and their baby.

#### 4.3.3. Communicating with parents preparing for birth

Parents may feel neglected or blamed by maternity care providers who seem insensitive or judgemental regarding their emotions or actions. Maternity care providers can play a part in validating the emotional experiences of parents at the time of birth. Mothers appreciate staff that accept and respond to their feelings as they experience them rather than feeling as though they were expected to feel or behave in a certain way. Maternity care providers who sympathetically acknowledge mothers’ sorrow and who are warm, attentive and caring are found to be sources of great support at the time of birth; “I thought the staff who took care of us were fantastic. They were people, not programmed machines in a huge organisation. People who cared, who dared to cry with us, who dared to stand by us in our pain and sorrow. Just totally fantastic.”<sup>16(p192)</sup>

#### 4.3.4. The hospital environment leading up to birth

Parents may be distressed when the birthing suite or delivery ward is not set up or equipped to support parents during a stillbirth. In the time between learning that their baby has died and birth, exposure to the cries of newborn babies and other parents can be highly distressing to parents. Ideally, a designated private area away from newborn babies and parents within the delivery ward and access to staff who are prepared to support parents of stillborn babies may better support parents. Parents may not appreciate being moved outside the maternity ward if the staff there are unaware of the parents’ situation. Improved communication between staff can help to avoid parents having to explain their story multiple times. Staff should be aware that it is important to respect parents’ privacy when talking about their situation in public areas of the hospital. This is especially important in hospitals in small communities.

### 4.4. During and immediately after birth

Implications for practice informed by experiences of maternity care provision during and immediately after birth focus on five important aspects of care. The findings revealed a number of critical factors centred around ensuring that parents are sensitively and supportively informed and prepared to make decisions about seeing and holding their baby. If parents do decide to see their baby, maternity care staff can provide valuable advice and guidance to support parents in deciding how they would like to spend time with their baby, what they might like to do and especially if they would like to collect any mementos.

#### 4.4.1. Information about their baby

Parents may want information about what their baby is likely to look like when it is born, to prepare themselves for seeing the baby. This may include what the baby will look like in terms of gestational age and development, known physical abnormalities as well as potential injuries such as peeling skin. Confronting descriptions can distress parents and impact on their decisions around seeing their baby, so providing speculative information may not be appropriate.

#### 4.4.2. Seeing and holding their baby

Parents may make better personal decisions if maternity care providers provide information about how other parents have chosen to meet their stillborn babies and how seeing their baby may affirm the baby’s existence and their parental identity, as well as allowing them to create important memories. Parents appreciate gentle, personalised guidance when deciding on seeing their baby that acknowledges their natural desire as parents to see and hold their baby after birth. Parents appreciate when maternity care providers consider and ask about their wishes and feelings both as

individuals and as a couple. Some parents may decline to see or hold their baby at first. Closed-ended questions for example; 'do you want to see your baby?' may unintentionally 'guide' parents to decline. Open-ended questions can be more appropriate, for example asking parents when or how they would like to see their baby. Parents may appreciate being informed that they can change their minds any time and appreciate when their decisions are respected and supported. Parents who do decline to see or hold their baby may still appreciate sensitive conversation about their baby and their experience.

Parents have different preferences for when and how long they would like to spend with their baby and may appreciate discussing their preferences and options. Parents appreciate being told that they will be supported to spend as much time as they want with their baby. Being offered the option to take their baby home or to see and spend time with their baby on more than one occasion can also be valued. Information about what might physically happen to the baby over time, such as nose bleeds, for example, can be helpful for those who want to spend time with their baby. Parents may not know how to act or what to do with their baby and may appreciate supportive suggestions and guidance. Parents can be encouraged to bathe, dress and participate in other parenting activities with their baby and appreciate when these activities are respected as normal desires. For most parents, no length of time with their baby is 'long enough'; parents appreciate consideration that parting from their baby may be devastating.

#### 4.4.3. *Respect for their baby*

Parents appreciate when maternity care providers speak about and to, touch, and hold their baby with the same tenderness and respect afforded to any baby. This may involve cuddling and speaking gently to the baby. For parents, such activities can normalise spending time with their baby and help to validate their feelings.

#### 4.4.4. *Involving other family members at the birth*

Parents appreciate information and assistance around involving other family members and loved ones, such as the baby's older siblings and grandparents, in meeting and holding their baby. This information should be provided prior to birth so parents are able to plan accordingly.

#### 4.4.5. *Collecting and storing mementos*

Parents may appreciate support and encouragement to collecting tangible mementos including photographs, ultrasound images, locks of hair, blankets, items of clothing, and hand and foot prints. For some items, such as ultrasound images, parents may need special information regarding safe storage and preservation. Parents may not think of collecting mementos themselves and appreciate being told that it is okay and being helped with suggestions regarding what they might like to keep. Parents, including those who have decided not to see or hold their baby, may still appreciate tangible mementos being collected and stored by the hospital.

#### 4.5. *Follow-up care for stillbirth*

Three categories of Implications for practice corresponding to the time after birth when parents are still within the hospital environment as well as when they return home centre on three key aspects of care. The impact of stillbirth can last for many years and maternity care providers should be mindful that parents' needs for sensitivity, empathy, emotional validation, provision of clear, understandable information, and consideration of the timing of this information does not diminish. Critical factors centre on guaranteeing that parents are provided with information about follow-up care if and when they choose, as well as considerations

for providing extra care for parents during subsequent pregnancies, especially at the time they had experienced the stillbirth.

#### 4.5.1. *Providing care following birth*

Parents appreciate being asked about their preferences around how close they wish to be located to other babies and parents in the hospital following stillbirth; for some parents being near other babies and parents may be distressing, and for others unfamiliar areas of the hospital may be isolating.

Parents appreciate being cared for by maternity care providers who are familiar with their situation rather than unfamiliar staff, which may occur if parents are moved to a different ward. A subtle way to make other hospital staff aware of the parents' situation is important; obvious door stickers/signs may distress some parents. Parents may wish to remain in hospital for a time, or want to go home sooner after birth. Parents appreciate being involved in these decisions. The mothers' clinical condition is also an important consideration. Parents and other family members, such as siblings and grandparents, can be affected by stillbirth for many years and may benefit from ongoing care and referrals to other supportive services and groups such as local or online support groups. Unique, individual experiences of grief, loss and other emotions such as anger can be acknowledged as valid and natural by maternity care providers.

#### 4.5.2. *Individualised follow-up information*

All information can be provided in verbal, electronic and written forms. Information to take home and appropriately timed follow-up contact may also be appreciated. Referrals to follow-up care and support from psychologists, social workers, counsellors and peer support organisations may be appreciated by parents. Parents may however not desire to take up referrals or offers of support immediately. Parents may benefit from information and support with practical issues such as how to register their baby's birth and how to arrange for a funeral. Having information and support about how to support and talk to their other children and family members can also be important. Sensitively delivered information about the emotional, psychological, social, and relationship issues they may experience following stillbirth can be valuable. Parents may appreciate follow-up contact with the attending maternity care providers to ask further questions and to talk about their experiences. Clear and respectfully worded information that is especially for parents who have experienced stillbirth regarding any physical issues they may encounter following stillbirth, for example, physical changes, lactation, sex and contraception is very important. Generic information for new mothers may be distressing and inappropriate for mothers of stillborn babies. Mothers also may appreciate guidance regarding recommencing physical activity which can also improve self-management of grief following stillbirth.

#### 4.5.3. *Providing support in subsequent pregnancies*

Pregnancy following stillbirth is likely be stressful for many parents. Leading up to and during subsequent pregnancies, parents may appreciate the choice to receive care from familiar maternity care providers who cared for them during the stillbirth experience and know their personal history. It is important that parents be able to access advice and care when needed. During subsequent pregnancy, parents may appreciate care and additional support especially around the time that they experienced the stillbirth.

#### 4.6. *Providing culturally appropriate care*

Some cultural groups have particular beliefs and practices around death which may affect their preferences for care. Parents appreciate maternity care providers to be aware of this when providing care. Parents from culturally diverse backgrounds

appreciate maternity care providers who acknowledge, and are inclusive of spiritual, religious and cultural beliefs that may be different from their own. Parents may have particular needs such as speaking to their baby in their own language or performing important cultural, spiritual or religious rituals while in the maternity care setting. Parents may have individual preferences for care that do not necessarily match the preferences of their cultural, spiritual or religious group. Parents' individual preferences should be heard and acknowledged as parents may not want the same care as other parents with a similar background. Parents may appreciate assistance with contacting their preferred spiritual, religious and/or cultural support and services while in hospital.

Aboriginal and Torres Strait Islander people may wish to have family members, elders and/or community leaders present to support them through their experience. Staff may be able to contact specialist services such as Aboriginal healthcare workers and Aboriginal and Maternal Infant Care (AMIC) workers from outside their local healthcare service and area for information and advice when caring for Aboriginal and Torres Strait Islander people. Staff attending to Aboriginal and Torres Strait Islander people should be aware of and acknowledge that kinship and family structure is of particular cultural significance. Parents may want family members and/or elders to be there for them to provide support. For many Aboriginal and Torres Strait Islander people, mothers assign the 'birth order' to their children. Understanding that a stillborn baby may have a particular place in this birth order and for example may be the mothers' 'firstborn' is important. Maternity care professionals attending to parents of stillborn babies may be better able to provide culturally appropriate care if they are provided with training and support to develop their knowledge and skills to acknowledge and understand different cultural groups' needs and preferences for care.

## 5. Discussion

As far as the authors are aware, this is the first collection of evidence-based guidance for the care of mothers and parents who have experienced stillbirth. Guidelines do exist for clinicians supporting parents who experience perinatal death including stillbirth.<sup>37–40</sup>

The results of the systematic review combined with the input of the expert advisory group indicate that delivery of sensitive and competent care is meaningful to mothers and parents and may lessen the psychological suffering of those who have experienced stillbirth.

Parents are rarely prepared for the experience of stillbirth and provision of information is critical.<sup>7,8,11</sup> The expert advisory group recommended that any information – verbal, electronic and written – should be provided in clear, understandable language and in a step-by-step manner so that parents can take in the information. Cues from parents, their families and companions can be used to help identify the most appropriate times to provide information and guidance. Parents should be consulted to establish preferences and desires using collaborative decision making.<sup>7</sup>

One of the most important times during the experience of stillbirth when maternity care providers can provide compassionate support and information is when parents are making decisions around seeing their baby.<sup>12,16,30,36</sup> It is unclear whether seeing and holding a dead baby after birth is beneficial or harmful for mothers and parents.<sup>41</sup> Despite Hughes and colleagues' reports that seeing and holding a stillborn infant can have adverse consequences for some women,<sup>42</sup> our review and the advice from the expert group suggests that even when parents are reticent or fearful about seeing their stillborn baby, in retrospect they may appreciate that maternity care providers supported them and found the action meaningful and helpful to validate their experience and

grief.<sup>6,12,16,36</sup> It is important for many parents that they are supported by maternity care providers and other staff to collect mementos, such as photographs, hand and footprints and other tangible items.<sup>2,5,11,13,30,32</sup> Ultimately, it is likely that parents should be offered the choice as well all the information they need to make the best decision for them.

Sensitivity, empathy and validation of parents' emotions are important throughout the ongoing care of parents affected by stillbirth.<sup>11–13,28</sup> Mothers and parents should be consulted on their preferences regarding if and where they would like to be located within the hospital. Some mothers and parents may be distressed by being located near other parents and their babies and may want a private room.<sup>5,11</sup> Upon discharge from hospital, parents should be provided with information to take home as well as referrals to support and additional information to access if and when they choose.<sup>15,29</sup> Also, additional care for parents during any subsequent pregnancies, especially at the time they had experienced a stillbirth is valuable.<sup>2,12</sup> The expert advisory group emphasised that the impact of stillbirth on mothers and parents can last for many years and may never end and some may require long-term supportive care.

The implications for practice around culturally appropriate care were derived from the perspectives of a limited number of cultural groups; however discussion with the expert advisory group supported the view that these implications may be relevant for people from diverse cultural backgrounds as well as Aboriginal and Torres Strait Islander people. Maternity care providers must be aware that there is no 'one size fits all' approach to providing culturally appropriate care. Members of the expert advisory group highlighted that lack of respect and acknowledgement of parents' cultural heritage and beliefs can result in parents losing trust in the healthcare service.

While it is hoped that the implications for practice presented in this paper will inform clinical practice, it is acknowledged that uptake of research findings relies on implementation strategies and health professional buy-in to support change.<sup>43</sup> The expert advisory group suggested that maternity care providers may benefit from training that teaches the specifics of how to deliver sensitive care and support to parents who have experienced stillbirth. Likewise, hospital protocols and policies should ensure that maternity care providers are aware of grief and compassion fatigue symptoms and are equipped with techniques that can help them manage or minimise this.<sup>44,45</sup>

There are a number of limitations in the existing evidence regarding care for mothers and families who have experienced stillbirth. No studies were located that clearly addressed the experiences of care and support of other family members such as grandparents and other children. While recent research is beginning to investigate needs of these other family members also,<sup>31,46,47</sup> only one study touching upon this met the inclusion criteria for our review.<sup>31</sup> This study however did not report on the perspectives of siblings, only that of parents providing support to them. As none meet the criteria for our review, no research was located that investigated the components or the effectiveness of education or support programmes for maternity care providers about care for mothers and parents who have experienced stillbirth. This would be worthwhile for future research. Also, further investigation is needed that evaluates the translation and implementation of evidence-based guidance within the field of stillbirth in order to determine the impact on processes in healthcare and on the psychosocial outcomes of parents and families. Further primary research studies are also needed to establish the effects of care interventions and strategies as well as how these are experienced by grandparents, siblings, other family members, culturally and linguistically diverse people and Indigenous peoples.

## 6. Conclusion

The implications for practice presented in this paper have been derived from a systematic review of the available qualitative evidence as well as consensus amongst experts regarding how maternity care providers can offer and engage in meaningful and culturally appropriate supportive care strategies to improve mothers and families psychological well-being throughout the experience of stillbirth. Important factors centred around sensitivity, empathy, validation of parents' emotions, provision of clear, understandable information and consideration of the timing of information provided can all influence parents' experience of being told that their baby has died or will be stillborn. Implications for practice also address the importance of communication, specifically preparing parents for birth with clear and collaborative explanations, parents' preferences regarding the timing of birth and allowing parents enough time to process information. The implications for practice presented by this paper are intended as a guide to inform clinical decision-making combined with maternity care providers' understanding and experience of their own unique contexts, the preference of their clients and their own expert clinical judgement.

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