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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.

Keywords: Stillbirth, Fetal death, Bereavement, Psychosocial care, Pregnancy, Review

24 **Introduction**

25 The stillbirth rate in Australia is around 3.5 per 1000 births.[1] Even with this relatively high
26 prevalence, there is a lack of clear evidence-based guidance available to support and inform
27 maternity care providers who provide care for families that experience stillbirth. The actions and
28 behaviours of maternity care providers from the point that a baby has been diagnosed as no longer
29 alive, and throughout the experience of stillbirth may be critical for the ability of families to cope
30 with stillbirth.[2] Perhaps as a result of being ill-equipped to appropriately work with families around
31 the time of stillbirth, the best standard of care and support may not be provided.[3] Parents who
32 experience stillbirth are at risk of potentially harmful psychosocial effects including grief, depression,
33 anxiety, and self-blame.[2,4-6] Between diagnosis and birth, mothers can suffer significantly.[7] Waiting
34 to give birth may even be more distressing that the birth itself.[8,9] For this reason, they need
35 supportive and sensitive care from maternity care providers from before confirmation that their
36 baby has died or will be stillborn.[7] Recent research has also focussed upon the impact that stillbirth
37 has on fathers and their experiences of care provided by maternity care providers.[10] Parents are
38 rarely prepared for the experience of stillbirth and may benefit from information provided by
39 maternity care providers in the antenatal period.[2,11] The negative effects of experiencing stillbirth
40 may be lessened by receiving care from care providers who are trained and prepared to help parents
41 cope with the tragic experience.[5-8,11-17] Research has found that parents' negative experiences and
42 outcomes may be compounded, or in some cases inadvertently caused, by interactions with
43 maternity care providers throughout the experience of stillbirth.[2] In some cases, maternity care
44 providers may not be adequately prepared or trained to provide the appropriate supportive and
45 sensitive care required.[3] Maternity care providers may be emotionally affected by stillbirth
46 themselves and this can influence their interaction with parents and the quality of care that is
47 provided.[5,12]

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

69 **Methods**

70 The systematic review was conducted according to an *a priori* systematic review protocol.[20] The
71 review's phenomenon of interest was the experiences of families with interventions and care
72 strategies implemented by maternity care providers throughout the experience of stillbirth; from the

73 time of diagnosis to any time in the weeks, months, and years that followed.. Family was defined as
74 mothers, fathers, siblings and/or grandparents. Stillbirth was defined as the death of a baby in utero
75 at any time from 20-weeks until immediately before birth. This is in line with the standard definition
76 used in Australia.[21] Papers that included families that had experienced perinatal death (after birth),
77 neonatal death, miscarriage, termination of pregnancy for non-medical reasons or pregnancy loss
78 before 20 weeks were excluded. Studies that investigated the death of a baby that matched the
79 definition of stillbirth used in the review were included if participant data and findings could be
80 disaggregated from those of ineligible participants.

81 A comprehensive search for published and grey literature was conducted during February to April
82 2014 across a number of databases including PubMed, CINAHL, EMBASE, PsycINFO, and selected
83 trial registries and stillbirth related websites. Initial keywords included: The initial keywords used
84 were: stillbirth; stillborn; fetal death; intrauterine death; perinatal death; psychosocial;
85 psychotherap*; bereave*; grief; emotion*; depressi*; guilt. Only English language publications were
86 considered for inclusion; publication date was not limited. The reference lists of included studies
87 were examined to identify additional studies. No grey literature was identified that met the
88 inclusion criteria for the review. Twenty four qualitative studies were assessed for methodological
89 quality by two independent reviewers prior to inclusion in the review using Joanna Briggs Institute
90 (JBI) critical appraisal tools.[22,23] Findings were extracted from papers included in the review using
91 standardised JBI data extraction instruments.[22,23] Meta-aggregative synthesis of the findings was
92 performed using JBI-QARI (Joanna Briggs Institute, Adelaide, Australia).[22] Common themes among
93 findings were identified and used to group findings into categories. Developed categories were
94 further brought together based upon similarity in meaning, to produce synthesised findings
95 intended to be reliable representations of the primary authors' findings and intent that may be used
96 as a basis for evidence-based guidance.[24,25] A more detailed discussion of the methodological
97 approach and methods used are detailed in a separate publication.[26]

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

119 **Findings**

120 Twenty two qualitative studies were included in the comprehensive systematic review. Overall, the
121 studies were of moderate to high methodological quality with only one study receiving three out of
122 ten possible negative responses to the critical appraisal criteria.[22,23] Two studies of low

123 methodological quality were excluded. Full details regarding the methodological quality of the
124 included studies is presented in the systematic review report.[19] The included studies were conducted
125 in Australia (3)[13,27,28], the United States (5)[5,7,15,29,30], Sweden (5)[2,8,9,31,32], Canada (1)[33], Taiwan (3)[34-36],
126 the United Kingdom (2)[11,12], South Africa (1)[6], Japan (1)[17], and Norway (1)[16]. Most studies included
127 mothers aged between 18 to 41 years; one study included mothers up to the age of 62.[6] Some
128 studies included both fathers and mothers as a couple,[2,5,7,11,31,36] A small number of studies involved
129 fathers (aged between 28 and 54) only.[27,28,30,32,33]. The time since stillbirth reported in the included
130 studies most commonly ranged from two to three months,[12,13] up to six years,[2,8,15,17,29-35] and up to 22
131 years after stillbirth in one study.[31]

132 Early in the project, the expert advisory group emphasised the importance of the time since the
133 stillbirth on the experience of parents. The group also highlighted that the timing of events during
134 the experience of stillbirth was also important, as parents often interact with different maternity
135 care providers during different stages of the experience of stillbirth. Therefore to reflect this and to
136 provide pragmatic guidance for maternity care providers, the synthesis was constructed to be
137 relevant to the phenomenon of interest at different periods in the temporal sequence of the
138 experience of stillbirth. The included studies reported experiences of care that parents felt to be
139 positive and supportive, as well as those that were perceived to be negative and distressing. There
140 was a paucity of studies investigating the experiences of siblings and grandparents. The 22 included
141 studies contributed 210 findings that ultimately informed six synthesised findings following the
142 meta-aggregative process to qualitative synthesis.[24,25] All of the extracted qualitative findings are
143 available in the systematic review report. [19] The first synthesised finding was relevant to the overall
144 experience of stillbirth: from diagnosis to many years later. The second synthesised finding related
145 specifically to the period when parents of a stillborn infant are first informed of the diagnosis of
146 stillbirth. The third synthesised finding related to the period around the time of induction and birth.
147 The fourth synthesised finding was pertinent to the period immediately after birth when parents
148 may have the opportunity to see and hold their baby. The fifth synthesised finding related to any

149 time beyond the immediate post-birth period. The sixth and final synthesised finding was centred on
150 the provision of culturally appropriate care. In instances where the expert advisory group identified
151 an important issue regarding the provision of care to mothers and families with no available
152 evidence, the implications for practice have been informed by consensus amongst advisor group
153 members alone. Specific examples include guidance around support and training for health
154 professionals, and appropriate care for Aboriginal and Torres Strait Islander mothers and families.

155 Implications for practice

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

158 Implications for practice relevant throughout the stillbirth experience

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

164 *Providing sensitive, genuine and empathetic care*

165 Throughout the stillbirth experience, friends or family members may be sources of valuable support.
166 If possible, parents may appreciate when maternity care providers give them the option to have
167 friends or family members present to provide support while in hospital. Parents may appreciate it
168 when maternity care providers show emotion and empathy towards their experience. Parents
169 appreciate it when maternity care providers respect and validate their emotional experience and
170 reactions of being parents of a baby that has died shortly before or during birth. For many parents,
171 this recognition should endure, as their understanding of being a parent is not diminished by the
172 experience of stillbirth. Parents who experience stillbirth can be emotionally fragile and appreciate

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

182 ***Information provision and communication throughout the stillbirth experience***

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

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

191 ***Support and training for maternity care providers***

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

195 **The diagnosis of stillbirth**

196 Implications for practice derived from findings of experiences of healthcare provision at the time of
197 diagnosis similarly centre on three aspects of care. The findings revealed that communication at this

198 critical time, particularly the way the diagnosis of stillbirth is conveyed, is a key factor that can
199 impact upon parents' experience of care and their psychological well-being.

200 ***Emotional impact upon parents***

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

204 ***Telling parents their baby will be stillborn***

205 Prior to the confirmation of the death of their baby, parents may appreciate honest and transparent
206 news about their baby's status. Contradicting parents' instincts that something is wrong can cause
207 unnecessary distress for the parents. Parents may experience potentially avoidable or unexplained
208 delays in receiving information about the death of their baby negatively. Parents appreciate clear
209 and understandable language and communication when learning that their baby has died. Medical
210 terms and ambiguous descriptions may not be understood and can be distressing. Maternity care
211 providers may use language that parents do not understand or that is ambiguous and upsetting;
212 "…we had no idea what the doctor was talking about as we had never heard of it [anencephaly]. All I
213 remember the doctor say to us was NOT COMPATIBLE WITH LIFE" (emphasis in original)[13p.68]) After
214 learning that their baby has died, parents may appreciate maternity care providers asking them
215 whether they would like them to stay to provide support and answer questions, or if they would
216 rather be left alone. Parents may appreciate being provided with verbal, electronic, and written
217 information, and may require information and details to be repeated. Having a supportive
218 companion present can help alleviate distress and anxiety. Parents may appreciate time to discuss
219 their situation with maternity care providers. Not allowing time for this, for instance, by leaving a
220 room immediately after telling parents their baby has died or will be stillborn, may be distressing to
221 parents.

222 ***Continuity of care from diagnosis***

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

227 **Preparing parents for induction and birth**

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

233 ***Informed preparation for birth***

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

243 ***Timing between diagnosis and birth***

244 Involving parents in collaborative discussion and informed decision-making regarding the timing of
245 the induction of birth may be appreciated by parents. Parents may have differing needs and
246 individual preferences for the length of time between learning that their baby has died and
247 induction of birth. While some mothers may prefer to be induced and to give birth as soon as

248 possible, others may appreciate being able to discuss their options to go home first and return to
249 hospital when they have prepared themselves. If parents do return home, it is helpful to remind
250 them about things they might want to bring to the birth, such as cameras and clothes for their baby.
251 Parents may also wish to invite other family members. Where possible, both parents appreciate
252 being included in information provision and discussion. Exclusion of partners may cause feelings of
253 ostracism and blame for that parent and can also mean that both parents aren't equally informed of
254 what is happening to them and their baby.

255 ***Communicating with parents preparing for birth***

256 Parents may feel neglected or blamed by maternity care providers who seem insensitive or
257 judgemental regarding their emotions or actions. Maternity care providers can play a part in
258 validating the emotional experiences of parents at the time of birth. Mothers appreciate staff that
259 accept and respond to their feelings as they experience them rather than feeling as though they
260 were expected to feel or behave in a certain way. Maternity care providers who sympathetically
261 acknowledge mothers' sorrow and who are warm, attentive and caring are found to be sources of
262 great support at the time of birth; "I thought the staff who took care of us were fantastic. They were
263 people, not programmed machines in a huge organization. People who cared, who dared to cry with
264 us, who dared to stand by us in our pain and sorrow. Just totally fantastic."[16p.192]

265 ***The hospital environment leading up to birth***

266 Parents may be distressed when the birthing suite or delivery ward is not set up or equipped to
267 support parents during a stillbirth. In the time between learning that their baby has died and birth,
268 exposure to the cries of newborn babies and other parents can be highly distressing to parents.
269 Ideally, a designated private area away from newborn babies and parents within the delivery ward
270 and access to staff who are prepared to support parents of stillborn babies may better support
271 parents. Parents may not appreciate being moved outside the maternity ward if the staff there are
272 unaware of the parents' situation. Improved communication between staff can help to avoid parents
273 having to explain their story multiple times. Staff should be aware that it is important to respect

274 parents' privacy when talking about their situation in public areas of the hospital. This is especially
275 important in hospitals in small communities.

276 **During and immediately after birth**

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

284 ***Information about their baby***

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

290 ***Seeing and holding their baby***

291 Parents may make better personal decisions if maternity care providers provide information about
292 how other parents have chosen to meet their stillborn babies and how seeing their baby may affirm
293 the baby's existence and their parental identity, as well as allowing them to create important
294 memories. Parents appreciate gentle, personalised guidance when deciding on seeing their baby
295 that acknowledges their natural desire as parents to see and hold their baby after birth. Parents
296 appreciate when maternity care providers consider and ask about their wishes and feelings both as
297 individuals and as a couple. Some parents may decline to see or hold their baby at first. Closed-
298 ended questions for example; 'do you want to see your baby?' may unintentionally 'guide' parents

299 to decline. Open-ended questions can be more appropriate, for example asking parents when or
300 how they would like to see their baby. Parents may appreciate being informed that they can change
301 their minds any time and appreciate when their decisions are respected and supported. Parents who
302 do decline to see or hold their baby may still appreciate sensitive conversation about their baby and
303 their experience.

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

315 ***Respect for their baby***

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

320 ***Involving other family members at the birth***

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

324 **Collecting and storing mementos**

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

332 **Follow-up care for stillbirth**

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

341 ***Providing care following birth***

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

346 Parents appreciate being cared for by maternity care providers who are familiar with their situation
347 rather than unfamiliar staff, which may occur if parents are moved to a different ward. A subtle way
348 to make other hospital staff aware of the parents' situation is important; obvious door stickers/signs
349 may distress some parents. Parents may wish to remain in hospital for a time, or want to go home

350 sooner after birth. Parents appreciate being involved in these decisions. The mothers' clinical
351 condition is also an important consideration. Parents and other family members, such as siblings and
352 grandparents, can be affected by stillbirth for many years and may benefit from ongoing care and
353 referrals to other supportive services and groups such as local or online support groups. Unique,
354 individual experiences of grief, loss and other emotions such as anger can be acknowledged as valid
355 and natural by maternity care providers.

356 ***Individualised follow-up information***

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

373 ***Providing support in subsequent pregnancies***

374 Pregnancy following stillbirth is likely be stressful for many parents. Leading up to and during
375 subsequent pregnancies, parents may appreciate the choice to receive care from familiar maternity

376 care providers who cared for them during the stillbirth experience and know their personal history.
377 It is important that parents be able to access advice and care when needed. During subsequent
378 pregnancy, parents may appreciate care and additional support especially around the time that they
379 experienced the stillbirth.

380 **Providing culturally appropriate care**

381 Some cultural groups have particular beliefs and practices around death which may affect their
382 preferences for care. Parents appreciate maternity care providers to be aware of this when
383 providing care. Parents from culturally diverse backgrounds appreciate maternity care providers who
384 acknowledge, and are inclusive of spiritual, religious and cultural beliefs that may be different from
385 their own. Parents may have particular needs such as speaking to their baby in their own language
386 or performing important cultural, spiritual or religious rituals while in the maternity care setting.
387 Parents may have individual preferences for care that do not necessarily match the preferences of
388 their cultural, spiritual or religious group. Parents' individual preferences should be heard and
389 acknowledged as parents may not want the same care as other parents with a similar background.
390 Parents may appreciate assistance with contacting their preferred spiritual, religious and/or cultural
391 support and services while in hospital.

392 Aboriginal and Torres Strait Islander people may wish to have family members, elders and/or
393 community leaders present to support them through their experience. Staff may be able to contact
394 specialist services such as Aboriginal healthcare workers and Aboriginal and Maternal Infant Care
395 (AMIC) workers from outside their local healthcare service and area for information and advice
396 when caring for Aboriginal and Torres Strait Islander people. Staff attending to Aboriginal and Torres
397 Strait Islander people should be aware of and acknowledge that kinship and family structure is of
398 particular cultural significance. Parents may want family members and/or elders to be there for
399 them to provide support. For many Aboriginal and Torres Strait Islander people, mothers assign the
400 'birth order' to their children. Understanding that a stillborn baby may have a particular place in this

401 birth order and for example may be the mothers' 'firstborn' is important. Maternity care
402 professionals attending to parents of stillborn babies may be better able to provide culturally
403 appropriate care if they are provided with training and support to develop their knowledge and skills
404 to acknowledge and understand different cultural groups' needs and preferences for care.

405 **Discussion**

406 As far as the authors are aware, this is the first collection of evidence-based guidance for the care of
407 mothers and parents who have experienced stillbirth. Guidelines do exist for clinicians supporting
408 parents who experience perinatal death including stillbirth.[37-40]

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

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

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

425 and found the action meaningful and helpful to validate their experience and grief.[6,12,16,36] It is
426 important for many parents that they are supported by maternity care providers and other staff to
427 collect mementos, such as photographs, hand and footprints and other tangible items.[2,5,11,13,30,32]
428 Ultimately, it is likely that parents should be offered the choice as well all the information they need
429 to make the best decision for them.

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

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

447 While it is hoped that the implications for practice presented in this paper will inform clinical
448 practice, it is acknowledged that uptake of research findings relies on implementation strategies and
449 health professional buy-in to support change.[43] The expert advisory group suggested that maternity

450 care providers may benefit from training that teaches the specifics of how to deliver sensitive care
451 and support to parents who have experienced stillbirth. Likewise, hospital protocols and policies
452 should ensure that maternity care providers are aware of grief and compassion fatigue symptoms
453 and are equipped with techniques that can help them manage or minimise this.[44,45]

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

469 **Conclusion**

470 The implications for practice presented in this paper have been derived from a systematic review of
471 the available qualitative evidence as well as consensus amongst experts regarding how maternity
472 care providers can offer and engage in meaningful and culturally appropriate supportive care
473 strategies to improve mothers and families psychological well-being throughout the experience of
474 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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