

Provision of Meaningful Care at Diagnosis, Birth, and after Stillbirth: A Qualitative Synthesis of Parents' Experiences

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ABSTRACT: Background: The care provided to parents experiencing stillbirth can have significant and lasting impacts on their immediate and long-term psychological well being. The aim of this qualitative synthesis was to investigate parents' experiences of care received during and after stillbirth. **Methods:** Qualitative findings extracted from 20 included studies were pooled using a meta-aggregative approach. **Results:** Four meta-syntheses encompassing parents' experiences of care at diagnosis of stillbirth, induction and birth, immediately postbirth and onwards, revealed care strategies that parents appreciated and found helpful, and also actions and behaviors that were distressing. Helpful strategies included a warm and sensitive communication style, provision of clear and understandable information, shared decision making, and respect for individual needs and preferences. Parents appreciated guidance from health care professionals about seeing and holding, including being prepared for their baby's possible appearance, information on how to spend time with their baby, and collection of memorabilia. After stillbirth, offers of follow-up care, including referrals for professional support, were appreciated. **Conclusions:** Care received during and after stillbirth may have lasting impacts on parents' future well being. Health care professionals may aid in improving parents' well being after stillbirth by providing care that is cognizant of parents' emotional states. Care strategies arising from the findings of this review are suggested. (BIRTH 43:1 March 2016)

Key words: fetal death, meta-synthesis, psychosocial care, stillbirth, systematic review

Stillbirth is traumatic for parents and may lead to long-term psychological sequelae including depression, anxiety, and post-traumatic stress disorder (PTSD) (1). As many stillbirths occur in pregnancies that appear to be progressing normally (2), parents are rarely prepared. Compared with women who give birth to healthy babies, mothers of stillborn babies have higher levels

of anxiety and PTSD, and lower self-esteem (3,4). Fathers can also experience depression, anxiety, and PTSD after stillbirth (5).

Stillbirth is a relatively common occurrence; one in every 160 births, or nearly 24,000 stillbirths, occur in the United States every year (6). In Australia, approximately one in every 135 births is a stillbirth (7), and

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worldwide it was estimated that 2.64 million babies were stillborn in 2009 (8). Despite the high prevalence of stillbirth and the significant psychological impacts on parents, ambiguity remains about the most effective, meaningful and appropriate care that can be provided by health care professionals. For example, there is no clear consensus on whether or not parents should be encouraged to see or hold their stillborn baby. Some research suggests adverse effects in mothers who held their baby (4,9), however these results have been debated by other researchers (10) and by parents of stillborn babies (11), and more recent research indicates positive effects for parents who see and hold their stillborn baby (12–15).

What is clear from the available literature is that interactions with health care professionals at each point in the stillbirth experience can have significant and lasting impacts, either positive or negative, on parents (16–18). Care throughout the experience of stillbirth encompasses care received at the time of diagnosis and birth, care and support received immediately after the birth, and longer-term support that may be provided to parents weeks, months, or years after the event. Care involves interactions with a variety of health care providers, such as ultrasound technicians, midwives, nurses, and obstetricians, occurs in discrete settings, involves the provision of specific and sensitive information, and requires certain actions and decisions by parents. Understanding how parents and families perceive care received throughout the experience of stillbirth is crucial for the development of meaningful and appropriate evidence-based guidance to inform decision making.

The aim of this qualitative synthesis was to investigate parents' experiences of nonpharmacological interventions and care received at diagnosis of stillbirth, induction and birth, immediately postbirth and onwards.

Methods

This work formed part of a comprehensive systematic review that aimed to investigate the effectiveness, meaningfulness, and cultural appropriateness of care delivered to families experiencing stillbirth (19). The full comprehensive systematic review was conducted according to an a priori protocol (20). An expert advisory group aided in the development of the protocol and provided feedback on the results and conclusions of the full review.

Studies were eligible for inclusion if they described the experiences of families with interventions and care strategies implemented by health care professionals throughout the experience of stillbirth. For the purposes of this review, stillbirth was defined as the death of a

baby in utero at any time from 20 weeks until immediately before birth (21). Families included mothers, fathers, siblings, and/or grandparents from any cultural context or background. Studies that included families who had experienced neonatal death, perinatal death, miscarriage, and termination of pregnancy for nonmedical reasons were excluded if data pertaining to families who had experienced stillbirth could not be extracted separately. Qualitative research studies, including qualitative descriptive, phenomenological, ethnographic, and grounded theory studies were considered for inclusion.

PubMed, CINAHL (EBSCO Host), Embase, PsycINFO (Ovid SP interface), ClinicalTrials.gov (US National Library of Medicine), and metaRegister of Controlled Trials (mRCT) were searched for the full review. Grey literature sources included Stillbirth and Neonatal Death Charity (SANDS; www.uk-sands.org), International Stillbirth Alliance (ISA; www.stillbirthalliance.org), Perinatal Society of Australia and New Zealand (PSANZ; www.psanz.com.au), Australian and New Zealand Stillbirth Alliance (ANZSA; www.stillbirthalliance.org.au), SIDS and Kids (www.sidsandkids.org), Stillbirth and Neonatal Death Support Group (www.sands.org.au), Pregnancy Loss and Infant Death Alliance (www.plida.org), Australian Centre for Grief and Bereavement (www.grief.org.au), Pregnancy Loss Australia (www.teddyloveclub.org.au), Antenatal Results and Choices (www.arc-uk.org), and A Heart-breaking Choice (www.heartbreakingchoice.com). Only studies published in English were sought. All searches were conducted between February and April 2014 with no date restrictions (Data S1).

The title and abstract of retrieved citations were assessed against the inclusion criteria by five reviewers (KL, MP, DR, ZJ, EA). Papers retrieved in full text were initially assessed against the review inclusion criteria by one reviewer (MP) and if necessary, study eligibility was determined by discussion.

Studies that met the inclusion criteria were assessed for methodological quality by two independent reviewers, using a standardized critical appraisal instrument (Joanna Briggs Institute Qualitative Assessment and Review Instrument [JBI-QARI]) (22,23). Studies that met seven to ten of the appraisal criteria were considered to be of high quality; studies that met four to six of the appraisal criteria were considered to be of moderate quality; studies that scored lower than four were considered to be of low methodological quality and were excluded. Study characteristics and relevant findings were extracted from included studies, using the standardized data extraction tool from JBI-QARI. Where possible, findings were extracted as themes identified by authors of the primary studies and extracted verbatim along with one or more illustrations to support each finding. Where identifiable themes were

not presented in the included studies, findings were extracted from the narrative in the form of definitive statements made by authors after discussion by three reviewers (KL, MP, DR). All findings were assigned a level of credibility according to the following criteria: unequivocal (U)—evidence beyond reasonable doubt, such as directly reported or observed findings clearly derived from qualitative data and not open to challenge; credible (C)—findings that were plausible interpretations, given the presented data and theoretical framework; and unsupported (Un)—findings that were not supported by the presented data (24). Only unequivocal and credible findings were included in the meta-syntheses (24). Data were synthesized using a meta-aggregative approach (25), where findings were grouped into categories based upon similarity of meaning. Categories were then aggregated, again according to similarity of meaning, to produce a set of synthesized findings used to inform evidence-based practice.

Results

Study Selection

The search for the comprehensive review (19) identified 10,177 records (Fig. 1). A total of 1,831 duplicate citations were removed and 8,346 records were screened by title and abstract. A total of 8,006 articles were excluded for either not meeting the review inclusion criteria ($n = 8,004$) or because the full text could not be retrieved ($n = 2$). The full texts of 340 studies were retrieved and assessed against the inclusion criteria; 24 qualitative studies were eligible for inclusion and assessed for methodological quality. After appraisal, 22 qualitative studies were included in the full comprehensive review, with 20 studies contributing findings to the meta-syntheses presented.

Methodological Quality

The 20 included studies were of moderate to high quality and met four or more out of 10 critical appraisal criteria (Table 1). Nine of the included studies (45%) did not report a specific philosophical perspective or specific qualitative methodology such as “interpretative” or “phenomenology,” respectively (Question 1); this item was marked “unclear” for these studies. Over half of the studies (almost 60%) did not include statements of the researchers’ personal values or experience with regard to stillbirth (Question 6), and almost 70 percent did not address the possible influence of the researcher on the study or the influence of the study on the researcher (Question 7). These omissions may represent

potential issues in terms of the impacts of the researcher on the interpretation or analysis of the data.

Description of Included Studies

The characteristics of the included studies are described in Table 2. Five studies were conducted in Sweden (26–30), five in the United States (18,31–34), three in Australia (35–37), two in the United Kingdom (38,39), and single studies in South Africa (40), Taiwan (41), Norway (42), Canada (43), and Japan (44). Time elapsed since the stillbirth varied widely both across and within studies, from 1 month to 22 years. Study participants were either mothers (nine studies) (27,28, 31,33,36,39,40,42,44) or fathers (five studies) (30,34, 35,37,43) of stillborn babies. Six studies included both parents (18,26,29,32,38,41). No studies were located that investigated the experiences of grandparents or siblings.

Findings of the Review

Diagnosis

The meta-synthesis of experiences with care provided at the time of diagnosis was derived from 30 findings that were grouped into six categories (Table 3), to provide the overall synthesized finding: “Sensitivity, validation of emotions and provision of clear understandable information at the appropriate times influence parents’ experience of being told that their baby has died or will be stillborn.”

Before the diagnosis, parents did not appreciate delays in receiving information or instances where health care professionals were seen as avoiding delivering the news. When the diagnosis was delivered, ambiguous, or technical language and unclear information contributed to parents’ distress, and also left parents feeling that health care professionals lacked empathy for their situation (28). Similarly, abrupt or blunt communication (“*He told me that sometimes these things just happen then left the room*” (18, p. 346)) left parents feeling unsupported or abandoned by health care staff.

Parents often remembered the behavior and words of health care professionals at the time diagnosis. Sensitivity and validation of the parents’ emotions were experienced positively, and the provision of clear and understandable information at appropriate times appeared to be particularly important. Parents appreciated clear explanations using sensitively worded, lay language rather than medical terminology, which was not always understood. Owing to their emotional state, parents were not always able to immediately process infor-

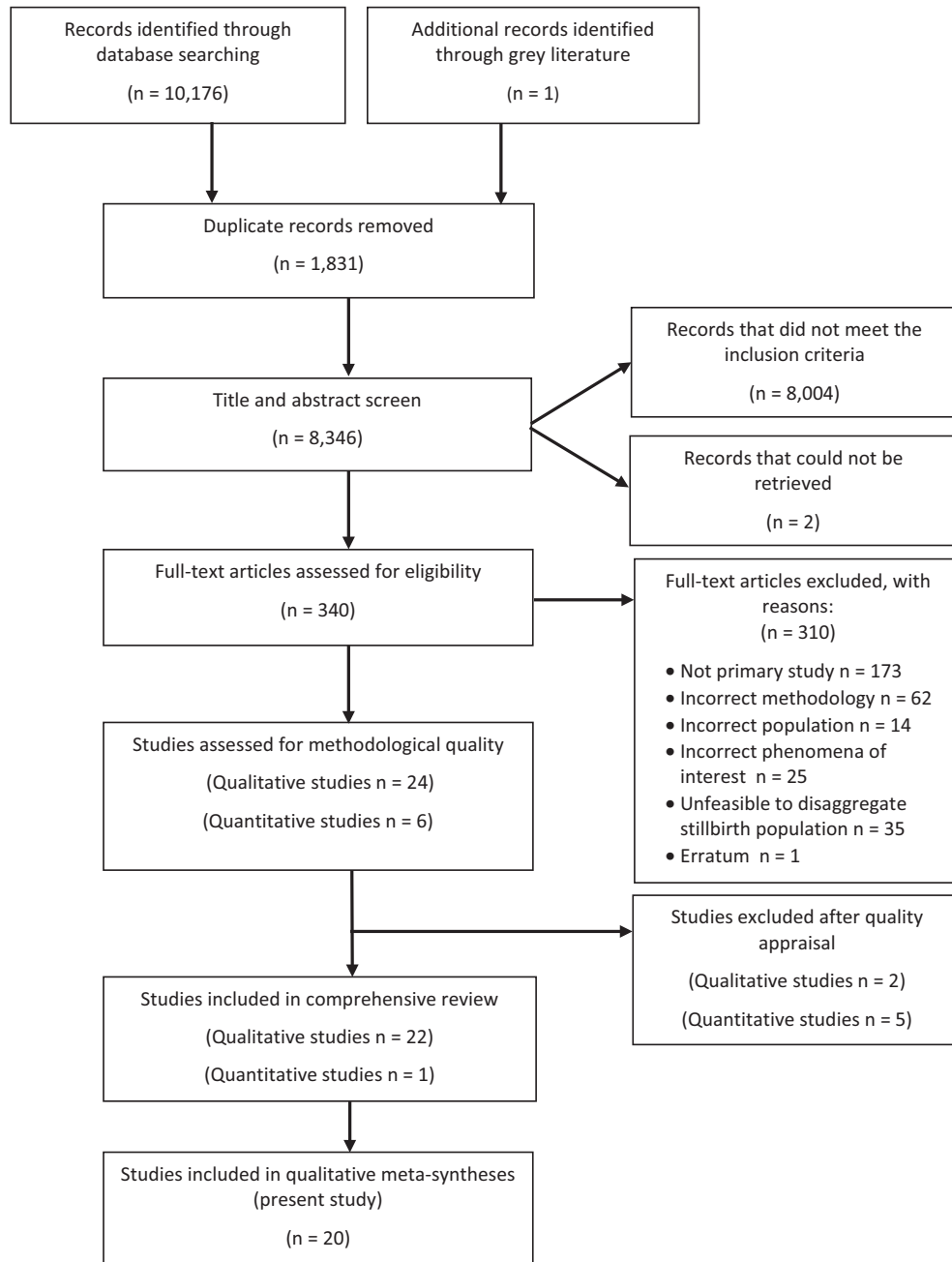


Fig. 1. Search and study selection process for the comprehensive systematic review (19). A subset of 20 studies informed the meta-syntheses presented in this paper.

mation; as one mother stated: “You don’t really understand what they’ve told you, even though you know the worst has happened. It’s unreal...that whole time...I don’t know...it’s like I can’t remember it, can’t describe my feelings. It was like being in a straitjacket” (42, p. 191). Having time and space to absorb the news was often appreciated. Some parents wished to go home, while others needed or wanted to remain in the hospital. Parents wished to be informed of the next steps, particularly about what they could expect leading up to and dur-

ing birth. Parents often appreciated being included in decision making around the different options available for the birth and advice about how they could prepare for the arrival of their baby, such as by bringing a camera or clothes for the baby from home (27).

Some parents desired continuity of care from the same health care professionals from the point of diagnosis through to the delivery, and cited that this could provide a greater sense of security and support (33,42).

Table 1. Methodological Quality of Included Studies

References	Critical appraisal criteria									
	Question 1	Question 2	Question 3	Question 4	Question 5	Question 6	Question 7	Question 8	Question 9	Question 10
Avelin et al 2011 (26)	U	Y	Y	Y	Y	N	N	Y	Y	Y
Bonnette and Broom 2012 (35)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Corbet-Owen and Kruger 2001 (40)	Y	Y	Y	Y	Y	Y	N	Y	U	Y
Downe et al 2013 (38)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Dyson and While 1998 (39)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Huberty et al 2014 (31)	U	Y	Y	Y	Y	N	U	Y	Y	Y
Kelley and Trinidad 2012 (32)	U	Y	Y	Y	Y	N	Y	Y	Y	Y
Lee 2012 (36)	U	Y	Y	Y	Y	N	N	Y	U	Y
Malm et al 2011 (27)	U	Y	Y	Y	Y	N	Y	Y	Y	Y
O'Neill 1998 (37)	U	U	U	U	U	Y	Y	Y	N/A	Y
Pullen et al 2012 (18)	Y	Y	Y	Y	Y	Y	U	U	U	Y
Radestad et al 2013 (28)	U	Y	Y	Y	Y	N	N	Y	Y	Y
Säftund et al (29)	U	Y	Y	Y	Y	N	U	Y	Y	Y
Samuelsson et al 2001 (30)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Sanchez 2001 (33)	U	Y	Y	N	Y	Y	N	N	Y	U
Sun et al 2013 (41)	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Trulsson and Radestad 2004 (42)	U	Y	Y	Y	Y	Y	Y	Y	Y	Y
Weaver-Hightower 2012 (34)	Y	Y	Y	Y	Y	Y	Y	Y	N/A	Y
Worth 1997 (43)	U	Y	Y	Y	Y	N	N	Y	Y	Y
Yamazaki 2010 (44)	Y	Y	Y	Y	Y	U	N	Y	Y	Y
%	50	95	95	91	95	41	32	77	85	95

Percentages indicate proportion of questions answered Yes (Y), Y = Yes; N = No; U = Unclear; N/A = Not applicable. Critical appraisal criteria for qualitative studies: Is there congruency between: 1) the stated philosophical perspective and the research methodology? 2) the research methodology and the research question or objectives? 3) the methods used to collect data? 4) the representation and analysis of data? 5) the interpretation of results? 6) Is there a statement locating the researcher culturally or theoretically? 7) Is the influence of the researcher on the research and vice versa addressed? 8) Are participants, and their voices, adequately represented? 9) Is the research ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body? 10) Do the conclusions drawn in the research report appear to flow from the analysis or interpretation of the data?

Table 2. Characteristics of Included Studies

<i>Study/country</i>	<i>Methodology</i>	<i>Methods</i>	<i>Participants</i>	<i>Phenomena of interest</i>
Avelin et al 2011 (26)/ Sweden	Qualitative content analysis (thematic analysis)	Participants recruited by way of the Swedish National Infant Foundation website. Focus groups.	25 parents representing 22 families; 20 mothers and 5 fathers (ages not specified), stillbirth experienced between 1 and 22 years earlier (average 6 years).	Parenthood and the needs of siblings after stillbirth from the parents' perspective.
Bonnette and Broom 2012 (35)/Australia	Interpretive/exploratory qualitative (otherwise unspecified)	Purposive and snowball sampling using posters placed on community notice boards, in libraries, community centers, pharmacies, and shops. Interviews.	12 men (28–54 years) who had experienced a stillbirth (time since loss unspecified).	How men engaged with their unborn and stillborn child as fathers and the perceived legitimacy of male grief.
Corbet-Owen and Kruger 2001 (40)/ South Africa	Constructionist grounded theory	Purposive sampling. Participants were referred to study by health care professionals or contacted the researcher after hearing about the study by word of mouth. Interviews.	8 women (32–62 years; age at stillbirth 18–30 years). 4 women experienced multiple losses. 2 women experienced single losses at 12 and 5 weeks; data pertaining to these participants was excluded where possible.	To understand mothers' experiences and needs after pregnancy loss and how the medical system can best support them.
Downe et al 2013 (38)/ U.K.	Grounded theory (constant comparative analysis)	Purposive sample of participants who had previously completed a web-based questionnaire via the Stillbirth and Neonatal Death Society (SANDS) website. Interviews.	19 mothers and 3 mother/father couples. Mothers' ages at stillbirth 18–44 years. Gestational age 24–27 weeks (2 participants) and 32–42 weeks (20 participants).	To obtain the views of parents of a stillborn baby about their interactions with health care staff just before or during labor.
Dyson and While 1998 (39)/U.K.	Phenomenology	Recruitment methods not stated. Interviews.	8 mothers (18–39 years) of stillborn infants (gestational age 24–40 weeks) 6 weeks to 14 years after stillbirth. Mothers had experienced between 1 and 5 stillbirths.	How mothers experienced and felt about stillbirth.
Huberty et al 2014 (31)/U.S.	Qualitative exploratory	Participants purposively recruited nationally via: prior participation in a survey; advertisements in clinics and research and education foundations; online social networks; word of mouth. Semi-structured interviews.	24 mothers (mean age 33 ± 3.68 years) of stillborn infants (gestational age ≥ 20 weeks). Mean time since stillbirth 6.33 ± 3.06 months.	Women's beliefs about physical activity after a stillbirth.
Kelley and Trinidad 2012 (32)/U.S.	Qualitative discourse analysis	Purposive and snowball samples through parent hospital guild groups. Semi-structured focus groups with mothers and/or fathers.	12 mothers and 2 fathers of stillborn infants (ages not given).	Parents' and physicians' experiences and beliefs surrounding stillbirth during the clinical encounter.

(continued)

Table 2 (continued)

<i>Study/country</i>	<i>Methodology</i>	<i>Methods</i>	<i>Participants</i>	<i>Phenomena of interest</i>
Lee 2012 (36)/ Australia	Qualitative descriptive	Purposive sampling of respondents to the 2010 Having A Baby in Queensland survey. Participants were identified by matching birth and death notifications. Qualitative web-based survey containing open-ended questions.	14 mothers (23–39 years) of stillborn infants gestational age 20–24 weeks (9 women); 25 weeks (2 women); 36 weeks (1 woman); 37 weeks (1 woman); unknown (1 woman). Time since stillbirth: 3–4 months.	To describe Australian women's experience of late pregnancy loss, with a particular emphasis on their experiences with the health care system.
Malm et al 2011 (27)/ Sweden	Qualitative inductive content analysis	Participants recruited by way of the Swedish National Infant Foundation website. In-depth, qualitative interviews including two open-ended questions.	26 mothers (20–41 years) of stillborn infants (gestational age 30–42 weeks). Time since stillbirth 1–80 months.	To investigate mothers' experiences of the time from diagnosis of stillbirth to induction of labor.
O'Neill 1998 (37)/Australia	Personal retrospective account	Retrospective account and analysis of personal experience in the style of an autoethnography.	1 father of a stillborn infant of 7 months gestational age.	Retrospective account of hospital and posthospital experiences.
Pullen et al 2012 (18)/U.S.	Grounded theory	Respondents to a web-based survey. Parents who had experienced stillbirth, stated exact recall of words used by health care provider to deliver death notification, and either strongly agreed or disagreed that "the way I found out about the diagnosis negatively impacted my grieving process," were included. Web-based survey that included open-ended and closed-ended qualitative items.	90 mothers and fathers of stillborn infants with a gestational age or 20 weeks or longer.	Stillbirth notification messages recalled by parents who strongly agreed and strongly disagreed that the way news about the death of their infant was delivered negatively impacted their grieving process.
Radestad et al 2013 (28)/ Sweden	Exploratory, inductive qualitative content analysis	Participants recruited by way of the Swedish National Infant Foundation website. In-depth interviews.	26 mothers of stillborn infants (gestational age 28+ weeks). Time since stillbirth 1–6 years (18 mothers), < 1 year (8 mothers).	Mothers' experiences of the confirmation of ultrasound examination results and how they were told that their baby had died in-utero.
Säflund et al 2004 (29)/ Sweden	Qualitative content analysis	Convenience sample of parents from two regional hospitals. One or two semi-structured interviews.	48 parents of stillborn infants (gestational age \geq 28 weeks). Time since stillbirth 4–6 years. Age of mothers was 22–42 years.	Caregivers' support as revealed by the parents' experiences.
Samuelsson et al 2001 (30)/Sweden	Phenomenology	Purposive sample of fathers of stillborn infants. Face-to-face interviews.	11 fathers aged between 31 and 46 years of stillborn infants (gestational age 32–42 weeks). Time since stillbirth 5–27 months.	To describe how fathers experienced losing a child as a result of stillbirth.

(continued)

Table 2 (continued)

<i>Study/country</i>	<i>Methodology</i>	<i>Methods</i>	<i>Participants</i>	<i>Phenomena of interest</i>
Sanchez 2001 (33)/U.S.	Qualitative (further details unspecified)	Sample from university hospital records with some stratification for type of loss and time since loss. In-depth, semi-structured interviews.	12 mothers (30–44 years) of stillborn infants (gestational age 24–41 weeks).	Mothers' perceived extent of recovery from stillbirth and the perceived influence on that recovery by a university hospital's perinatal loss support program.
Sun et al 2013 (41)/Taiwan	Descriptive phenomenology	Purposive sample of parents who terminated their pregnancies after diagnosis of fetal death in maternity units at a teaching hospital. Participant observation and in-depth interviews.	12 couples (24 participants; aged 23–42 years) who had experienced stillbirth. Gestational age 22–35 weeks.	To explore the situational or cultural meanings of Taiwanese parents' decisions to see their stillborn infants.
Trulsson and Rødestad 2004 (42)/Norway	Phenomenology	Mothers recruited after giving birth at Ullevål University Hospital. Interviews.	12 mothers (ages not reported). Gestational age > 24 weeks. Time since stillbirth 6–18 months.	Women's experiences before and during the diagnosis of the baby's death, the birth, and the time shortly after birth.
Weaver-Hightower 2012 (34)/U.S.	Autoethnography	A personal narrative and essay on the experience of stillbirth using autoethnographic methods.	One father (age not reported) of a stillborn baby (gestational age approximately 38 weeks). Time since stillbirth around 6 months (inferred).	The author's experience of his daughter Matilda's stillbirth and to illuminate larger sociocultural phenomena, particularly grief, masculinity, and father's roles.
Worth 1997 (43)/Canada	Exploratory descriptive. Constant comparison content analysis (grounded theory—unstated)	Convenience sample with participants recruited by way of newspaper advertisement, contacts with a perinatal support group, and personal contacts. Unstructured face-to-face or telephone interviews.	8 fathers (age not reported). Gestational age 26–41 weeks. Time since stillbirth 2 months to 5 years.	To identify and describe the reactions of fathers to a stillborn child.
Yamazaki 2010 (44)/Japan	Qualitative methodology based on grounded theory	Participants were recruited by way of invitation letters sent to self-support groups. In-depth, semi-structured interviews.	17 mothers (28–38 years) of stillborn infants (gestational age > 28 weeks). Time since stillbirth 1–6 years.	To describe the meaning of fetal death in the lives of Japanese women.

Induction and Birth

This meta-synthesis was informed by 23 findings grouped into eight categories (Table 3) to produce the overall synthesized finding: “Sensitivity, the importance of preparing parents for the birth through clear and comprehensive explanation, preferences about timing of the birth and time to process information impact upon parents’ experiences at the time of induction and birth of their stillborn baby.”

As with each stage of stillbirth, it was important that health care providers were sensitive to parents’ emotional states and treated parents with respect and kindness before and throughout the birth. Depending on the circumstances of the loss, certain medical terminology, such as “termination” was perceived negatively. It was important for parents to be able to express their feelings and not be expected to behave in a certain way (39).

Parents appreciated clear and incremental information and options about the birth. Often, mothers did not know what to expect and may not necessarily realize that they may still need to go through labor. Parents had different preferences around the mode of birth and associated pain relief, and also for the length of time between diagnosis of stillbirth and induction. Parents appreciated when health care professionals were cognizant of these individual preferences and needs. Some parents wished to delay the birth and have time to come to terms with the death of their baby (“*Then they gave us the choice if we wanted to go home and spend the night at home or if we wanted to stay there on the delivery ward but we decided to go home and come back the next day. It was really important for us, at least we’ve noticed afterwards, that we got to go home, got to be alone together and...digest it, you might say*” [42, p. 191]), whereas other parents wanted to proceed with the birth immediately (“*I was not in a position to say what I wanted or did not want, the only thing I knew was that I did not want to wait any longer, I just wanted it over and done with*” [27, p. 53]). It was important for many parents to be included in collaborative care and decision making.

Organizational and practical issues that affected parents included the hospital environment. Providing a suitable environment for parents for the birth was perceived to be important, as parents sometimes found the sights and sounds of babies and other mothers in maternity wards distressing.

Immediately Postbirth

The meta-synthesis of parent experiences immediately postbirth was developed from 55 findings that were organized into 13 categories (Table 3) and the overall synthesized finding: “Health care professionals should

be respectful of the baby, and should tailor support with respect to parental decision making on whether or not to see and/or hold their stillborn baby to individuals. Personal preferences, being prepared, and having tangible memorabilia are important.”

How health care professionals interacted with the baby immediately after birth was very important and often had a lasting influence on parents. Parents were upset when their baby was treated disrespectfully, such as when the baby was placed in a bucket or laid out on a metal table. Parents appreciated when babies were treated with care and tenderness (“*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.*” [38, p. 5]), and referred to by name.

Immediately after the birth, parents may have the opportunity to meet their baby. Parents expressed that seeing or spending time with their baby validated their baby’s existence and provided visual evidence of their baby’s birth and life. As one father recounted, “*That was absolutely an amazing time because I’ll always look back at it as one of the most valuable short pieces of time I’ve ever had in my life, that I got to spend with her. That time was the most valuable time in my life, I could probably pinpoint at that hour, the most special time in my life, over our wedding, over anything*” (35, p. 256).

Parents had differing preferences about seeing or holding their baby and required different levels of guidance from health care professionals; some parents indicated that after the birth, they appreciated that professionals were “forceful” in their assertions to see the baby (“*After my daughter was born and they told me she was dead, I didn’t want to see her. I didn’t want to see what a dead baby looked like. They basically, for lack of a better word, forced me to do it. I had nurses in there. I was hysterical. They said, ‘You have to hold her and say goodbye to her while she is still warm. Don’t wait for her to be put in the refrigerator. Don’t go on 10 years and look back and say you never held her, you never saw her.’ I was so angry with them. I was yelling, but then I look back, that was the crucial event that they did to not only preserve future memories but for me to get through it...They were right*” [32, p. 7]).

Parents did not always know if they wished to see their baby, what actions to take, or how long they could spend with their baby (“*We were together with the baby and caressed him for a couple of hours. Afterwards I regret that we did not have him longer, and I also regret that we did not have him in the room when we were sleeping. What influenced me was that I did not know for how long the staff thought it was OK to be with the baby, and I was also afraid that the body would change*”

Table 3. Synthesized Findings and Component Categories of Parents' Experiences of Care Provided by Health Care Professionals at Diagnosis of Stillbirth, Induction and Birth, Immediately Postbirth and Onwards

Diagnosis: Sensitivity, clarity, validation of emotions, provision of understandable information and timing impact upon parents' experience of being told that their baby has died or will be stillborn

- Inconsiderate delays, avoidance and lack of transparency in the provision of information about the confirmation of a diagnosis of stillbirth
- Sensitive, appropriate, and reassuring information provision by health care professionals about informing parents of the diagnosis of stillbirth
- Clear explanation and information around the diagnosis of stillbirth and following the steps in care
- Validation of emotions around the experience of stillbirth diagnosis
- Having time and space to absorb information relating to the diagnosis of stillbirth: health care professional consideration for emotional state
- Continuity of care from the point of stillbirth diagnosis to the induction of labor

Induction and birth: sensitivity, the importance of preparing parents for the birth through clear and comprehensive explanation, preferences about timing of the birth and time to process information, and the influence on parents' experiences at the time of induction and birth of their stillborn baby

- Sensitivity, respect, kindness, inclusiveness, and professionalism for both parents during labor
- Clear and incremental information and explanation about the birthing process while recognizing the emotional state of parents
- The length of time between diagnosis of stillbirth and birth induction can be experienced differently for individual parents
- Preparing mothers for the birth: knowing what to expect and having time to process information provided by health care professionals
- Collaborative care between health care professionals and mothers can reduce mothers' distress and confusion about the birth
- Personal, individual preferences about the length of time between diagnosis and the induction of labor and birthing can be considered
- General maternity/birth wards may not provide suitable environments for parents of stillborn infants in the time before induction and birth. Similarly, other wards may be experienced as isolating and distressing
- Definitions of medical procedures and medical language used in hospital processes at birth can be traumatic

Immediately postbirth: Several factors exist around parental decision making about whether or not to see and/or hold their stillborn baby and how meeting or not meeting the baby is experienced and remembered. Personal preferences, being prepared, and having tangible memorabilia are important

- The extent of health care professional support with decision making about whether or not to meet their stillborn baby depends on the personal preferences and needs of parents
- Supporting the needs and preferences of patients as individuals in meeting their stillborn baby. Parents may have individual or shared preferences
- Preparing parents to meet their stillborn baby if they choose to: giving helpful information and time to understand
- Seeing the stillborn baby is validation and evidence of their baby's birth, existence, and death. Not seeing may cause regret for some people
- Memorabilia is valuable: tangible evidence is helpful and received with gratitude
- The choice to see or not see the baby may be to avoid unwanted and distressing emotions
- Evidence and acknowledgment of the reality of the experience of losing a baby
- Hospital systems and protocols around seeing, recognizing, holding, and saying goodbye to the stillborn baby can have a positive or negative effect
- Respect for the baby by health care professionals
- Sensitivity and compassion from health care professionals to support meeting and parting from their baby
- Guiding or taking the lead in supporting parents to see their stillborn baby
- Structured, well-timed information from health care professionals helps parents to make decisions about seeing and spending time with their baby
- Never enough time with the baby

Postbirth and onwards: Health care professionals should be aware that the need for support may continue into the postpartum period and beyond, and may influence care needs for any subsequent pregnancies

- The needs of mothers may continue beyond the initial health care context. Information provided by health care professionals can support mothers into the future
 - Differing preferences and experiences of the timing of practicalities and support
 - Health care protocols and processes may be experienced differently by parents. Sensitivity to individual preferences after birth could be amenable to these differing preferences
 - The reality of stillbirth may continue long after the pregnancy. Subsequent pregnancies may be concerning for mothers as they can be worried about another stillbirth. Information and support from health professionals can help mothers approaching and during their next pregnancy
 - Follow-up and continued contact with health care professionals
-

[29, p. 134]). Parents described receiving information about what to expect of seeing their baby, and cited that this was helpful in either allaying their fears of seeing an “abnormal” baby, or a baby that may have deteriorated. Specific actions taken with the baby, such as bathing and dressing the baby, were also remembered as important. Some parents regretted specific actions that they had not taken, such as not “exploring” the baby (39), and some parents felt that the amount of time spent with the baby was never enough (29). Mothers who chose not to see their babies often did so to avoid unwanted or distressing emotions, fearing that seeing their babies would increase feelings of guilt over the loss (41).

Collecting memorabilia was very important. Memorabilia ranged from photographs, locks of hair and foot and handprints, to hospital wrist bands and “cot cards.” Parents did not always think of collecting these items themselves and appreciated when health care staff made suggestions (“*It’s good that somebody thinks of taking pictures; you are very thankful afterwards*” [30, p. 127]).

Postbirth and Onwards

The meta-synthesis of 20 findings pertaining to care after stillbirth contained five categories (Table 3) and the synthesized finding: “Health care professionals should be aware that the need for support may continue into the postpartum period and beyond, and may impact on care needs for any subsequent pregnancies.”

The needs of parents were found to continue beyond the immediate experience of stillbirth. Mothers sometimes desired information about referrals for further psychosocial support offered by psychologists, social workers, and counsellors (36). Some mothers also desired specific information, for example, as to how to register the baby’s birth and arrange a funeral, how to provide support to their other children, and for information about engaging in physical activity to improve coping, manage depressive symptoms, and improve emotional health (31,36).

For any subsequent pregnancies, some mothers experienced increased anxiety and fear that their baby would die, either during pregnancy, labor, or in the postpartum period. As stated by one mother “*...the end (of the pregnancy) was very, very difficult, with her...and everyday was a battle really to...not get swamped up with the idea that she could die*” (39, p. 437). Parents appreciated when, after being made aware of a previous stillbirth, health care professionals showed understanding of their potential fears, uncertainties, and need of additional support. Mothers found it particularly valuable to receive additional care in a subsequent pregnancy at the equivalent time of their previous loss.

Discussion

The included studies contributed 128 findings which were aggregated into 32 categories and four synthesized findings related to parents’ experiences of care provided by health care professionals at diagnosis of stillbirth, induction and birth, immediately postbirth and onwards (Table 3). Strategies for health care professionals specific to diagnosis of stillbirth, induction and birth, immediately after birth and onwards were derived (Table 4).

Sensitive and genuine communication is important at all times, as is the provision of clear and understandable information in lay language. Parents are likely to be experiencing acute distress and their ability to absorb information may be impaired; it is important that health care professionals recognize these aspects and provide clear and complete information that may need to be repeated. Where possible, individual preferences should be considered and both parents partake in making decisions with respect to their care during and after birth.

Care strategies relevant to specific points in the stillbirth experience are also suggested (Table 4). At diagnosis, health care professionals should seek to avoid or minimize delays in communicating the stillbirth diagnosis to parents, and use clear and simple language to avoid confusion. Parents should be included in decision making about the birth, and preparing parents for the arrival of their baby by suggesting the option to bring clothes from home to dress the baby may be useful. After the birth, health care professionals may suggest and assist with collection of memorabilia as such items are often highly valued by parents well into the future.

About seeing and holding the stillborn baby, this review suggests that when parents were reticent or fearful about seeing their baby, in retrospect they often appreciated instances where health care professionals encouraged and guided them in making the decision to see their baby (32,38,42). While there were examples from the included studies of parents feeling apprehensive about seeing their baby (39) or unsure of exactly what actions to take, there were no findings that indicated that any parent regretted the decision to see their baby. Parents who had not seen their baby often expressed regret at not having done so or not having done more with their babies (36,39,42,43). This result concurs with the findings of a recent review that focused on evidence of benefit and harm for parents after seeing and holding their stillborn baby, and concluded that contact with the baby may be beneficial for parents’ well being after stillbirth (14). The findings of this review suggest that the manner in which health care professionals approach and provide care for parents experiencing stillbirth may be remembered by parents well into the future and may have a lasting impact on parents’ grief and subsequent well being. This is in agreement with previous research (15,16,45,46) and

highlights the importance of clear evidence-based guidance for health care professionals and health services about care during and after stillbirth to achieve the best possible outcomes for parents and other family members. The findings of this review have, with consultation from an expert advisory group, informed the creation of evidence-based guidance for health care professionals on the provision of meaningful care strategies for parents who experience stillbirth (19,47).

Limitations of the Review

Although a rigorous and comprehensive search strategy was utilized, it is possible that potentially relevant studies may have been missed, including papers published in languages other than English that were not searched for. Despite this review, seeking to examine the experiences of other family members in addition to mothers and fathers, no studies investigating the experiences of these

participants were found, identifying a significant gap in the available literature. As the included studies were conducted in a range of countries and included participants from a variety of cultural backgrounds, the findings and implications for practice arising from the review may not necessarily be acceptable or appropriate for all parents. The cultural appropriateness of care for parents experiencing stillbirth was one of the aims of the full systematic review; however, few studies were located that examined this phenomena (19). As no studies were found that investigated the experiences of other family members such as grandparents, the findings of this review pertains only to parents' experiences of care.

Conclusion

Stillbirth is a traumatic event for parents and the care received during this time may have a lasting impact on parents' well being. This synthesis suggests that health

Table 4. Strategies for Health Care Professionals Caring for Parents Experiencing Stillbirth at Diagnosis of Stillbirth, Induction and Birth, Immediately Postbirth and Onwards

Diagnosis

- Warm, sensitive, and genuine communication
- Clear and understandable information in lay language that may need to be repeated
- Minimization of avoidable delays or ambiguity in delivering the diagnosis
- Awareness and respect for parents' individual emotional states
- The option for continuity of care

Induction and birth

- Warm, supportive and genuine communication
- Avoidance of confusing or confronting medical terminology
- Inclusion and support for fathers/partners
- Clear verbal and written information about induction and birth, including explanation of available options and what parents can expect
- Respect for individual preferences about the length of time between diagnosis and induction of birth
- Collaborative decision making about birth and birthing options
- Consideration of the environment in which birth occurs

Immediately postbirth

- Respectful treatment of the baby
- Individual level of guidance and encouragement about seeing and holding the baby
- Respect for individual preferences about seeing and holding the baby and support and information provision to both parents
- Clear and descriptive information about the expected physical condition of the baby
- Suggestions of actions that can be taken with the baby
- Information on how long parents can spend with their baby
- Collection memorabilia (e.g., photographs, hand and foot prints, locks of hair, hospital wristbands)
- Guidance on including other family members in seeing and holding the stillborn baby

Postbirth and onwards

- Collaborative decision making about preferred ward environment
 - Written information about referrals to psychologists, social workers, counsellors, and other support organizations that can be taken up if and when desired.
 - Information about practical issues, such registration of the birth and funeral preparation, given at an appropriate time
 - Practical necessities, such as signing paperwork, raised at an appropriate time
 - Respect for individual preferences over strict adherence to service protocols and processes
 - Consideration of parents' preferences around whether to go home sooner after birth or remain in the hospital
 - Written or verbal information about physical considerations, such as lactation, that is tailored for mothers who have experienced a stillbirth, rather than providing usual postnatal information
 - Storage of memorabilia of baby for collection at a later date
 - Extra support during any subsequent pregnancy, particularly around time of previous loss
-

care professionals provide care that seeks to reduce parents' immediate and long-term experiences of distress, anxiety, and grief. Helpful strategies include a warm and sensitive communication style, provision of clear and understandable information, shared decision making, respect for individual needs and preferences, guidance on seeing and holding the baby, and suggestions for the collection of memorabilia.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Data S1. Search Strategy.