

SPECIAL ARTICLE

The RESPECT Study for consensus on global bereavement care after stillbirth☆

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SYNOPSIS

A modified policy-Delphi process has been used to establish global consensus on eight principles for bereavement care after stillbirth.

★ The data have been presented as an oral presentation at the Royal College of Obstetricians and Gynaecology World Congress 2019, entitled 'Global bereavement care after stillbirth- towards consensus: The RESPECT Project' Reference 1976. 17-19 June 2019, London, UK.

ABSTRACT

Objective: To develop global consensus on a set of evidence-based core principles for bereavement care after stillbirth.

Methods: A modified policy-Delphi methodology was used to consult international stakeholders and healthcare workers with experience in stillbirth between September 2017 and October 2018. Five sequential rounds involved two expert stakeholder meetings and three internet-based surveys, including a global internet-based survey targeted at healthcare workers in a wide range of settings.

Results: Initially, 23 expert stakeholders considered 43 evidence-based themes derived from systematic reviews, identifying 10 core principles. The global survey received 236 responses from participants in 26 countries, after which nine principles met a priori criteria for inclusion. The final stakeholder meeting and internet-based survey of all participants confirmed consensus on eight core principles. Highest quality bereavement care should be enabled through training of healthcare staff to reduce stigma and establish respectful care, including acknowledgement and support for grief responses, and provision for physical and psychologic needs. Women and families should be supported to make informed choices, including those concerning their future reproductive health.

Conclusion: Consensus was established for eight principles for stillbirth bereavement care. Further work should explore implementation and involve the voices of women and families globally.

1 INTRODUCTION

An estimated 2.6 million stillbirths occurred worldwide in 2015 [1], leaving a lasting and profound impact on women, families, communities, and healthcare workers [2]. The care received by women and their families immediately after a stillbirth, and in the days and months that follow, is inconsistent and often deficient [3]. The 2016 *Lancet* series on ending preventable stillbirths called for a “global consensus on a package of care after a death in pregnancy or childbirth... for the affected family, community, and caregiver in all settings” [4].

Recent systematic reviews of care after stillbirth have identified many comparable findings across low-, middle-, and high-income settings in the experiences of women, their families, and healthcare workers [5, 6]. Women experience various effects of grief that may not be recognized by healthcare workers or their communities. This lack of recognition exacerbates the women’s psychologic symptoms and is associated with stigma, blame, devaluation, and loss of social status [2, 3]. Conversely, positive attitudes and support from healthcare workers, family, and communities can improve bereavement experience.

High-quality care can moderate both immediate and long-term negative outcomes [2]. National guidelines exist in some settings to guide healthcare workers and organizations responsible for providing care to bereaved women after stillbirth [7, 8]. However, evidence for best practice is limited in most settings, and particularly in low- and middle-income countries (LMIC), where the burden is greatest [1]. This lack of relevant evidence has hindered progress toward concerted global action. The same fatalism that has plagued stillbirth prevention for decades [1] seems to be also associated with a lack of recognition of loss, which has impeded agreement on bereavement care.

The aim of the present study was therefore to develop a global consensus on a set of feasible and evidence-based core principles for bereavement care after stillbirth in order to meet the milestones set by the *Lancet* in 2016.

2 MATERIALS AND METHODS

The present survey-based study was carried out from 21st September 2017 to 8th October 2018 among international stakeholders and healthcare workers with

experience in providing bereavement care. Ethics approval was gained from the Faculty of Health Sciences Research Ethics Committee, University of Bristol, Bristol, UK, on August 1, 2018 (ref. 67861).

A modified policy-Delphi methodology [9] was used to establish a global consensus on principles for a package of bereavement care. The opinions of participants were gathered over five sequential survey rounds. During the study period, two expert stakeholder meetings and three internet-based surveys were conducted (Figure 1).

2.1 Round 1

An expert stakeholder meeting was held by the research team at the International Stillbirth Alliance (ISA) conference, September 22–24, 2017 (Cork, Ireland). An international group of 23 clinical and academic experts was identified through the ISA global network and invited to join a pre-conference workshop. Participants were asked to discuss evidence-based themes extracted from two systematic reviews of care after stillbirth: one in high-income countries (HIC) [6], and one in LMIC [5] (Table 1).

Participants discussed the following four key topic areas derived from one of the systematic reviews in groups of 5–6: overarching principles; diagnosis, delivery, and postnatal care; follow-up and support; and healthcare workers (Supplementary File S1) [6]. A member of the research team facilitated each group. Discussions were documented in note form on the same day. Thematic analysis identified a list of core statements about care after stillbirth, which was used for the internet-based survey in round 2 (Table 2).

2.2 Round 2

The group of stakeholders who attended the consensus workshop, including the research team, were invited to complete an anonymous internet-based survey hosted by Survey Monkey [10] (Supplementary File S2). Respondents were asked to rank from 1 to 10 the importance of each statement generated in round 1. They were also asked to provide feedback and comments on the statements, to ensure that they accurately reflected the discussions from the initial workshop, and to help integrate similar themes. Mean scores were calculated for each statement.

2.3 Round 3

The principles resulting from round 2 were used as the basis for a global internet-based survey targeted at healthcare workers in a wide range of settings (Supplementary File S3). The online survey was managed by using Survey Monkey [10] and was distributed via an introductory email containing a link to the questionnaire. The intent was to distribute the survey to as wide a range of healthcare workers as possible using multiple avenues that included personal contacts, professional bodies, and mailing lists for formal and informal networks including the ISA, Healthy Newborn Network, and Health Information for All. Particular efforts were made to include LMIC respondents by targeting personal contacts in these settings. The survey was piloted by the research team to check usability. The survey remained open from April 1 to May 31, 2018.

Responses were analyzed by using descriptive statistics and histograms. Participants were asked to rank the importance of each principle using a 9-point Likert scale from 1 (not at all important) to 9 (critically important), and encouraged to leave comments on each principle, including barriers to implementation in their setting.

There are no routinely agreed criteria for establishing consensus in Delphi surveys, and a wide variation in methodology has been reported [11]. For this project, it was agreed in advance that consensus would be established for each principle if more than 70% of participants scored the principle as critical (score 7–9) and fewer than 15% scored the principle as unimportant (score 1–3). Conversely, principles would be excluded if 70% of participants scored the principle as unimportant (score 1–3) and fewer than 15% scored the principle as critical (score 7–9). These criteria have successfully been used in other consensus studies [12].

Barriers to implementation for each principle were analyzed with framework analysis based on the WHO Health Systems Framework [13]. Participants were also asked to select the top three principles that they felt were most important to help inform priorities for implementation.

2.4 Round 4

A second expert stakeholder meeting was held at the International Society for the Study and Prevention of Perinatal and Infant Death and ISA (ISPID-ISA) conference, June 7–9, 2018 (Glasgow, UK). The same international stakeholders from round 1 were invited to join a pre-conference workshop, along with other experts nominated during the previous three rounds.

The findings of the global survey were presented at the workshop. Participants worked in small groups to discuss the results of the survey and the wording of the principles. Two members of the research team were assigned to each group to facilitate and document discussions. After the workshop, the research team met to review the discussions and produce the final amended principles.

2.5 Round 5

The final round of the consensus involved an internet-based survey (Supplementary File S4) sent out to all participants of the global survey in round 3 and attendees of either bereavement consensus workshop. The purpose was to present the amended principles and gain consensus on the amendments made in round 4. Respondents were asked to rank each principle using a Likert scale, as in round 2, with the same criteria for establishing consensus. Three reminder emails were sent to email addresses voluntarily provided by participants in previous rounds of the consensus process.

2.6 Data analysis

Microsoft Excel was the only software used for simple descriptive statistics

3 RESULTS

3.1 Round 1

The expert stakeholder group (n=23) included obstetricians (n=6, 26%), midwives (n=4, 17%), researchers (n=10, 43%), a pathologist (n=1, 4%), neonatologist (n=1, 4%), and a chaplain (n=1, 4%), some of whom were also bereaved parents. In total, 43 evidence-based themes were considered by the group (Table 1). Ten statements were generated for round 2 (Table 2).

3.2 Round 2

Overall, 19 (83%) of the 23 participants responded to the internet-based survey. Scoring of the statements ranged from 8.4 to 9.8 out of 10, demonstrating that each was considered important by participants. No additional topic areas were suggested by the participants beyond the previously identified 10 statements.

Comments from respondents identified areas of ambiguity in wording and areas for clarification. The core statements were adjusted with minor wording changes in response to comments: for example, to reflect “parents” rather than “women.” In addition, the number of statements were reduced from 10 to 9 (Table 2) because two were reported by respondents as having complementary meaning that could be combined into one principle (i.e., “Healthcare workers should acknowledge the breadth of grief associated with stillbirth across all settings” and “Healthcare workers should acknowledge that grieving is a natural response to the loss of a baby and offer appropriate emotional support to all women”). General comments and responses informed the design of the global survey in the next round.

3.3. Round 3

The global survey received 236 responses from participants from 26 countries (Figure 2). Most respondents identified themselves as midwives (96, 40.6%), obstetrician/gynecologists (n=55, 23%), and nurses (n=20, 9%). The remaining respondents included psychologists, pathologists, public health specialists, researchers, and social workers.

More than half of the participants (n=130, 55%) had worked in their role within healthcare for longer than 20 years, and 26% (n=61) for 11–20 years. Most respondents were based in HIC (n=184 78%), and 22% (n=52) of respondents worked in LMIC. Participants in Australia contributed 57% (n=135) of the total responses.

All nine principles met the previously agreed criteria for inclusion in the consensus (Table 3). All principles were scored by more than 75% of participants as critical (score 7–9) and less than 2% of participants scored any of the principles as unimportant (score 1–3). All principles remained eligible for inclusion when the scores were analyzed separately by HIC and by LMIC.

Among all principles, the score for public education about stillbirth scored the lowest in both HIC and LMIC, but still met the criteria for inclusion in the consensus.

Respondents commented that this principle should be more specific to stillbirth bereavement care, rather than to education about stillbirth in general. This was taken into account in round 4 when the principles were revised.

Overall, the principles were rated very similarly by participants in LMIC and HIC (Table 3). As compared with respondents from LMIC, those from HIC rated respectful care and emotional support, information about management options and delivery, and investigation of cause of stillbirth higher. By contrast, respondents from LMIC rated postnatal care and follow-up, and information about future reproductive health more highly.

When respondents were asked to rank their top three priorities (Figure 3), training of healthcare staff in the care of bereaved parents was considered the most important in both LMIC and HIC, and was included in the top three principles by 65.2% (n=146) of respondents overall (LMIC, 61.7% [n=29]; HIC, 66.1% [n=117]). This was followed by investigation to provide an explanation to parents for the loss of their baby (overall, 43.8% [n=98; LMIC, 42.6% [n=20]; HIC, 44.1% [n=78]). Public education about stillbirth, although having the lowest importance score, was the fourth most likely principle to be ranked as a top priority, supporting the need to revise the wording of this principle rather than omit it.

There was more variation in the prioritization of other principles. For example, provision of respectful maternity care was included by 59.6% (n=28) of respondents in LMIC, but only 34.5% (n=61) of those in HIC. Conversely, provision of information on management options and delivery was included by 35.6% (n=63) of HIC respondents, but only 12.8% (n=6) of LMIC respondents. Information about future pregnancy was considered important by 21.3% (n=10) of LMIC respondents, but only 6.2% (n=11) of HIC respondents, giving it the lowest score overall.

With regard to barriers to implementation (Table 4), respondents from HIC reported fewer barriers overall and were more likely to comment “no barriers” or “this is

already done in my healthcare facility.” Both HIC and LMIC respondents identified barriers in each of the six areas, many of which represented similar themes: for example, lack of funding and resources for staff training, cultural issues including taboo and stigma, and the need for clear clinical guidelines.

Round 4

The second consensus workshop at the 2018 ISPID-ISA conference in Glasgow was attended by 30 participants, including obstetricians (n=10, 33%), midwives (n=5, 17%), researchers (n=11, 37%), representatives of charitable organizations (n=3, 10%), and a neonatologist (n=1, 4%), some of whom were also bereaved parents. Of the nine countries represented, two were LMIC (Ghana and Georgia). The results of the global survey from round 3 were presented and discussed.

Two principles concerning postnatal care and follow-up were combined because they were considered by the workshop participants to have significant overlap (i.e., “All parents should be offered appropriate postnatal care addressing physical and psychologic needs” and “Bereaved parents should be given adequate information before discharge from healthcare setting, including a lead professional contact in the follow-up period”). Wording was adjusted to be inclusive of women, partners, their families, and the stillborn baby. The workshop produced eight final principles that retain the sense and importance of the statements included in the global survey of round 3, with improved wording and more concise meaning, including active verbs to prompt action in response to the *Lancet* call (Box 1).

Round 5

The response rate for this round was 54% (143/267). No objections were raised by participants to any of the eight principles, all of which fulfilled the criteria for inclusion in the final list (Box 1).

4 DISCUSSION

Widespread recognition of the need for quality bereavement care after stillbirth to reduce stigma and preventable harm to parents, their families, and their communities made this consensus process a timely study to meet the milestones set by the *Lancet* [4]. Rounds 1 and 2 of the policy-Delphi process used the results of

systematic reviews in LMIC and HIC, together with the experience of expert stakeholders, to develop evidence-based principles for bereavement care. These were revised and refined throughout the multi-round consensus process with input from healthcare workers and other professionals involved in stillbirth care worldwide. The response to the global survey, involving 236 participants from 26 countries, demonstrates the wide reach and level of interest in this topic. The enthusiastic response rate from Australia may reflect significant recent stillbirth awareness work through a nationally funded program [14]. Encouragingly, overall almost one in four responses were from LMIC, representing 18 different countries. There is a continuing need to understand the challenges to quality bereavement care in low-resource settings, where the majority of stillbirths occur globally [1, 15].

In some HIC, such as the United Kingdom [7] and Ireland [8], national guidelines for bereavement care after stillbirth do exist, but may be too resource-intensive to be implemented in other settings. A comprehensive review of evidence for respectful and supportive bereavement care by the Perinatal Society of Australia and New Zealand, and the Australian Stillbirth Centre of Research Excellence [14] describes many themes that are similar to the principles developed in the present study, while acknowledging that evidence for best practice is limited particularly in LMIC. The RESPECT consensus study has combined this limited evidence with intelligence from global experts and interested healthcare workers to advance current understanding.

The final eight bereavement care principles all met predefined criteria for inclusion in the consensus, with a high level of concurrence between HIC and LMIC in round 3. The differences that were evident between HIC and LMIC may reflect priorities for implementation or the standards of care that are already in place in each setting, in addition to sociocultural and health system differences. Using the WHO framework to explore barriers provided context to the scoring and prioritization results [13]. For example, provision of respectful maternity care was ranked as a top priority by more than half of respondents in LMIC, but only one in three of those in HIC. Many respondents in HIC commented in the barriers section of the global survey that this principle was routinely enacted in their setting. This apparent disparity between

settings is therefore likely to reflect a difference in perceptions about the health systems rather than the importance of the principle itself.

In addition to the development of the final list of principles, the multi-stage consensus process itself was useful for understanding different contexts and the way that they impact on provision of bereavement care. This understanding will help tailor implementation approaches to various settings and country-specific action plans. For example, the principle concerning future reproductive health and family planning had low ranking in round 3 as compared with the other principles. It also represented one of the biggest differences between LMIC and HIC in both the scoring and prioritization exercises of round 3. This is concordant with the findings from a systematic review of care after stillbirth in LMIC, where desire for more information on future pregnancy was mentioned often by women and their partners [5]. In a systematic review in HIC, the need for more information about future reproductive health did not feature in the narratives by bereaved parents, possibly because in such settings it is commonly addressed at medical follow-up [6]. To address this disparity, more information may need to be imparted in the immediate postpartum period in low-resource settings, where follow-up is difficult to arrange. These two examples are important reminders that it is necessary to capture perspectives and opinions from specific settings in both LMIC and HIC before prioritizing any interventions for global implementation.

The barriers and facilitators captured by the consensus process provide additional insight into implementation of the bereavement care principles. Many comments were similar across settings, despite different baselines of care provision. Staff training and a desire for clear localized guidelines were major factors in all settings. Implementation may need to start with more general efforts to reduce stigma, train healthcare workers in emotional care, and provide respectful care to all women accessing maternity services. Other targeted aspects of best practice will need to follow, such as improving stillbirth investigation and offering delivery options including analgesia. Conversely, initially targeting specific initiatives to high-risk groups, such as families who have experienced a previous loss or women with poor social support, might make the best use of resources in some settings; more general expansion would then follow as resources become available.

The major strength of the present study is the size, breadth, and depth of response to the global survey. There were multiple rounds involving international experts in the overall process, with ample opportunity for objections, refinements, and identification of barriers and facilitators. There are some limitations, including the spread of settings of participants in the global survey. South America, francophone Africa, and the Middle East were underrepresented, whereas Australia was overrepresented. The experts attending the workshops were predominantly female, white, and from HIC. The survey was not translated into languages other than English. Ongoing efforts are needed to engage healthcare workers from all settings to achieve an even wider consensus.

The present study sought to develop global consensus on a set of feasible, evidence-based, core principles from a healthcare perspective. Some participants including researchers and workshop participants, however, had had personal or family experience of stillbirth or neonatal death. Their personal experience adds another dimension to the results of the consensus process, because it is important for the principles to be parent-centered. A next important step will be to incorporate the voice of bereaved parents from around the world both formally and widely. This might be facilitated by communicating the findings from the present study; the challenge will be to elicit opinions from LMIC communities that may be more difficult to reach with methods such as online surveys.

Even though the consensus process was based on systematic reviews that captured published research from both LMIC and HIC, there remains an urgent need for further primary research in LMIC settings to ensure that recommendations are appropriate for each setting worldwide. This should also include well-documented pilot studies and implementation research to improve the evidence base for the design of bereavement care packages in different contexts. Establishing a community of practice, particularly for those in LMIC settings, may be highly beneficial.

For successful implementation, it is essential that stillbirth bereavement care is incorporated into the normative guidelines of global agencies such as the WHO and

UNICEF, who are responsible for setting standards of care for LMIC, as well as into other relevant initiatives, such as the Every Newborn Action Plan [16], in order to gain political momentum to improve bereavement care. Each LMIC can adapt guidance and tools from these sources for their own context.

Finally, it is important to acknowledge the impact of all perinatal loss on a global scale and the need for bereavement care not limited to those experiencing stillbirth. Although the present study was focused on stillbirth, it would be useful to consider how these principles may overlap and be applicable to other aspects of perinatal bereavement care, including neonatal death.

In summary, the consensus process has produced eight core principles for bereavement care after stillbirth based on contributions from a wide range of experts and healthcare workers actively involved in frontline care. More work is needed to involve the voices of parents globally and explore the best way to implement care packages for each principle in various settings. Women and their families continue to experience stillbirth every day: it is time to recognize the need for basic bereavement care and start ameliorating the impact of stillbirth now.

AUTHOR CONTRIBUTIONS

DS and CSh conceived the study. DS is lead author and guarantor of data. All authors contributed to the study design and interpretation of findings. CSh, AM, DB, ML, CSt, and DS organized and implemented the workshops and surveys. The RESPECT group contributed to workshops. CSh, AM, and DS analyzed the data. CSh was responsible for writing the first draft and all authors contributed to finalizing the manuscript.

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CONFLICTS OF INTEREST

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REFERENCES

- 1 Lawn JE, Blencowe H, Waiswa P, *et al*. Stillbirths : rates, risk factors, and acceleration towards 2030. *Lancet* 2015; **387**: 587–603.
- 2 Heazell AEP, Siassakos D, Blencowe H, *et al*. Stillbirths: Economic and psychosocial consequences. *Lancet* 2016; **387**: 604–16.
- 3 Burden C, Bradley S, Storey C, *et al*. From grief, guilt pain and stigma to hope and pride – a systematic review and meta-analysis of mixed-method research of the psychosocial impact of stillbirth. *BMC Pregnancy Childbirth* 2016; **16**: 9.
- 4 Bernis L De, Kinney M V, Stones W, *et al*. Stillbirths : ending preventable deaths by 2030. *Lancet* 2016; **387**: 703–16.

- 5 Shakespeare C, Merriel A, Bakhbakhi D, *et al.* Parents' and healthcare professionals' experiences of care after stillbirth in low- and middle-income countries: a systematic review and meta-summary. *BJOG An Int J Obstet Gynaecol* 2019; **126**: 12–21.
- 6 Ellis A, Chebsey C, Storey C, *et al.* Systematic review to understand and improve care after stillbirth : a review of parents ' and healthcare professionals ' experiences. *BMC Pregnancy Childbirth* 2016; **16**: 1–19.
- 7 National Bereavement Care Pathway for pregnancy and baby loss. Bereavement Care Standards. 2018.
http://www.nbcpathway.org.uk/file/bereavement_care_standards.pdf (accessed Jan 10, 2019).
- 8 Health Service Executive. National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death. 2016
<https://www.hse.ie/eng/services/list/3/maternity/bereavementcare/national-standards-for-bereavement-care-following-pregnancy-loss-and-perinataldeath.pdf>.
- 9 Linstone Harold A., Turoff M. The Delphi Method: Techniques and Applications. 2002.
- 10 Survey Monkey. www.surveymonkey.com.
- 11 Junger S, Payne S, Brine J, Radbruch L, Brearley S. Guidance on Conducting and REporting DELphi Studies (CREDES) in palliative care: Recommendations based on a methodological systematic review. *Palliat Med* 2017; **31**: 684–706.
- 12 Bakhbakhi D, Siassakos D, Storey C, *et al.* PARENTS 2 study protocol: pilot of Parents' Active Role and ENGagement in the review of Their Stillbirth/perinatal death. *BMJ Open* 2018; **8**. DOI:10.1136/bmjopen-2017-020164.
- 13 WHO. The WHO Health Systems Framework.
http://www.wpro.who.int/health_services/health_systems_framework/en/.
- 14 Boyle F, Horey D, Middleton P, Flenady V. Clinical practice guidelines for perinatal bereavement care: an overview. *Women and birth* 2019; **In press**.
- 15 Blencowe H, Cousens S, Jassir F, *et al.* National, regional, and worldwide estimates of stillbirth rates in 2015, with trends from 2000: a systematic analysis. *Lancet Glob Heal* 2016; **4**: e98– 108.
- 16 WHO: Every Newborn Action Plan.
https://www.who.int/maternal_child_adolescent/newborns/every-newborn/en/.

FIGURE LEGENDS

Figure 1 Flow chart showing the rounds involved in the modified policy-Delphi process.

Figure 2 Distribution of responses to the global survey.

Figure 3 Prioritization of principles as determined by respondents selecting their top three priorities.

SUPPORTING MATERIALS LEGENDS

Supplementary File S1 Round 1 topic guide.

Supplementary File S2 Round 2 survey.

Supplementary File S3 Round 3 survey.

Supplementary File S4 Round 5 survey.

Table 1 Themes from systematic reviews of care after stillbirth in LMIC and HIC settings.

Specificity of themes	Thematic sentences from systematic reviews	
	LMIC [5]	HIC [6]
Common to both	Across all settings, women experience multiple manifestations of grief, which the healthcare community and wider society often fail to recognize.	Parents have a range of emotions and reactions because stillbirth is a life-changing event. Emotional support and acknowledgement of the birth and death of a baby is an important part of

Positive community support, as opposed to stigmatization and blame, can improve bereavement experience.

Women and staff believe that specialized bereavement care is important.

Understanding the causes of stillbirth and supporting proper investigation will help to reduce stigma.

Women value supportive family presence throughout care.

Awareness of and support for different coping mechanisms, as culturally and individually appropriate, can assist with the grieving process.

Availability of timely and culturally appropriate psychologic support is desired.

Knowledge and information about stillbirth will empower women to take control of their own health.

Women value follow-up care and advice to help them return to health.

Adequately developed health systems are best equipped to provide respectful

bereavement care.

Parents wish for increased awareness and acknowledgement of stillbirth.

Parents with a baby who died in utero may feel that their care is not appropriately prioritized by staff.

Long delays and inconclusive results can cause distress to parents.

Many factors influence the parents' decision regarding whether to have a postmortem.

Parents want privacy not abandonment.

Spending time and making memories with their baby should be an option that is supported and offered more than once.

Support groups are helpful for many parents.

Support and information from staff may help parents who feel emotionally unprepared for a vaginal birth. To be involved in decision-making, parents appreciate being given options and the time to consider them.

Pain-relief options should be fully discussed with parents.

Staff should support parents to express their concerns.

Clear, easily understandable and structured information given sensitively at appropriate times, helps parents through their experience.

Continuity of care and carer is important to parents. Continuity of care is important to staff.

Parents should be supplied with information about what to expect postnatally.

A debriefing and follow-up appointment can help resolve uncertainty.

Parents would appreciate a healthcare system ready to provide emotional support following birth and

	care.	discharge from hospital. There are challenges that may prevent staff from providing effective bereavement care: emotional, and knowledge- and system-based.
	Comprehensive staff training and support systems for staff are prerequisite to improving care.	Behaviors and actions of staff can have a memorable impact on parents. Staff want improved training and a supportive working environment. Research and multi-professional training are important for all staff to improve standards of bereavement care. Parents want improved training so that staff can provide tailored discussions and written information to help them make informed decisions about postmortem and funeral arrangements. Verbal and non-verbal communication skills are important. Experience and knowledge may ease the provision of bereavement care but can increase the emotional burden felt by staff.
LMIC only	Cultural differences and beliefs can lead to devaluation and stigmatization of women and babies. Women want information, advice and individualized discussions about future pregnancies.	
HIC-only		Fathers may have different needs to mothers; they want to be involved in decision-making and often focus on practical tasks. Parents may regret certain decisions made regarding postmortem and funeral arrangements. Clear care pathways are required at the interface between primary and secondary care. Providing parents with information, enabling them to be actively involved in decision-making, is a staff priority.

Abbreviations: HIC, high-income countries; LMIC, low- and middle-income countries.

Table 2 Iterations of principles through rounds 1–5.

Round 1	Rounds 2 and 3	Rounds 4 and 5
Public education about stillbirth should be promoted to raise awareness.	Public education about stillbirth should be promoted to raise awareness.	Reduce stigma experienced by bereaved women and families by increasing awareness of stillbirth within communities.
Staff should provide respectful care to bereaved women, in accordance with the WHO statement on respectful maternity care.	Staff should provide respectful care to bereaved women, in accordance with the WHO statement on respectful maternity care.	Provide respectful maternity care to bereaved women, their families, and their babies.
Parents should be provided with clear and understandable information about management options and delivery	Parents should be provided with clear and understandable information about management options and delivery	Support women and families to make shared, informed, and supported decisions about birth options.
An effort should be made to investigate and provide an explanation to parents for the loss of their baby, within the resources available.	Every effort should be made to investigate and provide an explanation to parents for the loss of their baby, within the resources available.	Make every effort to investigate and identify contributory factors, to provide an acceptable explanation to women and families for the death of their baby.
Healthcare workers should acknowledge the breadth of grief associated with stillbirth across all settings.	Healthcare workers should acknowledge the breadth of grief associated with stillbirth and offer appropriate emotional support.	Acknowledge the depth and variety of normal grief responses associated with stillbirth and offer appropriate emotional support in a supportive environment.
Healthcare workers should acknowledge that grieving is a natural response to the loss of a baby and offer appropriate emotional support to all women.		
All parents need appropriate postnatal care addressing physical and psychologic needs, and follow-up encounters to provide information and assess wellbeing.	All parents should be offered appropriate postnatal care addressing physical and psychologic needs.	Offer appropriate information and postnatal care to address physical, practical, and psychologic needs, including a point of contact for ongoing support.
Bereaved parents should be given adequate information before	Bereaved parents should be given adequate information before	

discharge from the healthcare setting, including a single point of contact in the follow-up period.	discharge from healthcare setting, including a lead professional contact in the follow-up period.	
Women should receive adequate information about their future reproductive health, including family planning if desired.	Parents should receive information about their future reproductive health, including family planning if desired.	Provide information for women and their families about future pregnancy planning and reproductive health at appropriate time points throughout their care and follow-up.
Healthcare staff should be offered basic training in the care of bereaved parents, including evidence-based principles of care and management, and communication skills, and should be aware of processes/guidelines in their own unit.	Healthcare staff should be offered basic training in the care of bereaved parents, including evidence-based principles of care and management, and communication skills, and should be aware of processes/guidelines in their own unit.	Enable the highest quality bereavement care by providing comprehensive and ongoing training and support to all members of the healthcare team.

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TABLE 3 Principle statements in round 3, demonstrating consensus criteria ^a.

Principle	Overall			LMIC			HIC		
	1–3	4–6	7–9	1–3	4–6	7–9	1–3	4–6	7–9
All parents should be offered appropriate postnatal care addressing physical and psychologic needs.	0 (0)	10 (4.5)	214 (95.5)	0 (0)	1 (2.1)	46 (97.9)	0 (0)	9 (5.1)	168 (94.9)
Healthcare staff should be offered basic training in the care of bereaved parents, including evidence-based principles of care and management, and communication skills, and should be aware of processes/guidelines in their own unit.	0 (0)	12 (5.4)	212 (94.6)	0 (0)	3 (6.4)	44 (93.6)	0 (0)	9 (5.1)	168 (94.9)
Parents should be provided with clear and understandable information about management options and delivery.	2 (0.9)	11 (4.9)	211 (94.2)	0 (0)	4 (8.5)	43 (91.5)	2 (1.1)	7 (4.0)	168 (94.9)
Healthcare workers should acknowledge the breadth of grief associated with stillbirth and offer appropriate emotional support.	0 (0)	13 (5.8)	211 (94.2)	0 (0)	5 (10.6)	42 (89.4)	0 (0)	8 (4.5)	169 (95.5)
Staff should provide respectful care to bereaved women, in accordance with the WHO statement on respectful maternity care.	0 (0)	14 (6.3)	210 (93.8)	0 (0)	6 (12.8)	41 (87.2)	0 (0)	8 (4.5)	169 (95.5)
Bereaved parents should be given adequate information before discharge from the healthcare setting, including a lead professional contact in	2 (0.9)	14 (6.3)	208 (92.9)	0 (0)	3 (6.4)	44 (93.6)	2 (1.1)	10 (5.6)	165 (93.2)

the follow-up period.

Every effort should be made to investigate and provide an explanation to parents for the loss of their baby, within the resources available.	1 (0.5)	18 (8.0)	205 (91.5)	0 (0)	5 (10.6)	42 (89.4)	1 (0.6)	13 (7.3)	163 (92.1)
Parents should receive information about their future reproductive health, including family planning if desired.	1 (0.5)	21 (9.4)	202 (90.2)	0 (0)	2 (4.3)	45 (95.7)	1 (0.6)	19 (10.7)	157 (88.7)
Public education about stillbirth should be promoted to raise awareness.	3 (1.3)	50 (22.2)	171 (76.3)	0 (0)	9 (19.1)	38 (80.9)	3 (1.7)	41 (23.2)	133 (75.1)

Abbreviations: HIC, high-income countries; LMIC, low- and middle-income countries.

^a Scores of 1–3 were considered unimportant; those of 7–9 were considered critical. Participants' scores are summarized as number (percentage).

Table 4 Barriers and facilitators to implementation of care based on the nine principles in round 3.

Barrier/facilitator	LMIC	HIC
Barrier		
Leadership and governance	Lack of supervision of healthcare workers to ensure quality of care provided.	Lack of consensus among care providers, leading to inconsistency. Lack of guidance on monitoring of the quality of care provided.
Healthcare financing	Costs of care provision and shortage of resources for separate facilities or postmortem. Lack of funding and resources for training.	Cost of investigations including postmortem for cause of death. Lack of funding for training. Lack of funding for specialist bereavement teams.
Health workforce	Inadequate numbers of healthcare workers. Lack of workforce skills and knowledge; need for training. Staff demotivation. Resistance of healthcare workers to change. Lack of support for healthcare workers. Burnout from high perinatal mortality rates.	High levels of stress and workload among healthcare workers. Limited awareness and recognition of importance of mental health issues. Lack of training opportunities for staff, including communication skills.
Medical products, technologies	Appropriate information for families unavailable in local languages. No access to postmortem.	Limited availability of appropriate written information for families. Limited resources for investigation and postmortem in some settings.
Information and research	Community myths and misconceptions about stillbirth. Lack of public knowledge about stillbirth. Need for appropriate localized management guidelines.	Fear of provoking anxiety in women by public education about stillbirth. Lack of evidence base to support training or on the impact of interventions.
Service delivery	High volume of workload including emergencies and	Busy clinical areas and wards, limited time for patient care.

Facilitator

overcrowded healthcare facilities, leading to prioritization of physical over psychologic wellbeing.

Sociocultural issues and beliefs about stillbirth (e.g., death not discussed, unborn baby not recognized).

Stigma and societal negative attitudes.

Facilities including space and confidentiality.

Lack of access to prenatal care.

Public education on stillbirth via social media, radio, and TV.

Use of community health workers and village health communities, including opinion leaders or religious leaders.

Incorporation of education on stillbirth into prenatal care.

Inclusion in “minimum service delivery standards for maternal and newborn care,” and/or neonatal death audits.

Training for all healthcare staff.

Development of care pathways or flow charts for easy reference.

Women’s groups and peer support groups for emotional support from other bereaved mothers.

Cultural issues—not wanting to talk about loss, religious beliefs, taboos.

Stigma.

Medicalization may increase intervention rates and neglect psychologic care.

Lack of facilities (e.g., separate bereavement suite).

Lack of access to psychologic services. Lack of clinical pathways or local guidelines

Public education to reduce stigma via conventional and social media.

Inclusion in prenatal care and birth classes.

Linking with primary care, including postnatal home visits.

Provision of bereavement suites, with designated team, space and outreach professionals.

Training for all healthcare staff.

Development of clear care package.

Individualization of care—no “one size fits all.”

Support groups (e.g., SANDS in the United Kingdom) and peer support for emotional wellbeing.

Abbreviations: HIC, high-income countries; LMIC, low- and middle-income countries; SANDS, Stillbirth and Neonatal Death Society.

Box 1 Final principles for consensus on global bereavement care after stillbirth.

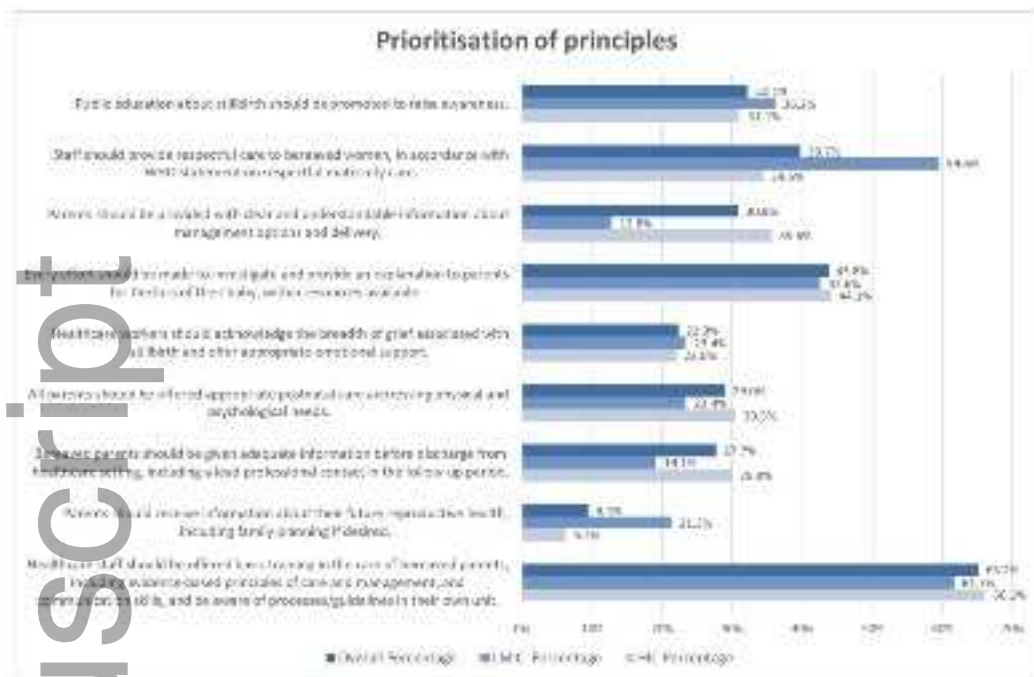
- 1 Reduce stigma experienced by bereaved women and families by increasing awareness of stillbirth within communities.
 - 2 Provide respectful maternity care to bereaved women, their families, and their babies.
 - 3 Support women and families to make shared, informed, and supported decisions about birth options.
 - 4 Make every effort to investigate and identify contributory factors to provide an acceptable explanation to women and families for the death of their baby.
 - 5 Acknowledge the depth and variety of normal grief responses associated with stillbirth and offer appropriate emotional support in a supportive environment.
 - 6 Offer appropriate information and postnatal care to address physical, practical, and psychologic needs, including a point of contact for ongoing support.
 - 7 Provide information for women and their families about future pregnancy planning and reproductive health at appropriate time points throughout their care and follow-up.
 - 8 Enable the highest quality bereavement care by providing comprehensive and ongoing training and support to all members of the healthcare team.
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(*Note: some participants did not participate in every stage)

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