

Parents' and healthcare professionals' experiences of care after stillbirth in low and middle-income countries: a systematic review and metasummary'

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Shortened running title (60 characters): Care after stillbirth in low and middle-income countries

Supplementary file 1: Search strategy

Supplementary file 2: Data extraction form

Supplementary file 3: Summary of studies

Supplementary file 4: Sample extracted findings

Supplementary file 5: Intensity effect sizes

Supplementary file 6: Quality assessment

Abstract:

Background: Stillbirth has a profound impact on women, families, and healthcare workers. The burden is highest in low and middle-income countries (LMICs). There is need for respectful and supportive care for women, partners, and families after bereavement.

Objective: To perform a qualitative metasummary of parents' and healthcare professionals' experiences of care after stillbirth in LMICs.

Search Strategy: Search terms were formulated by identifying all synonyms, thesaurus terms and variations for stillbirth. Databases searched were AMED, EMBASE, MEDLINE, PsychINFO, BNI, CINAHL.

Selection Criteria: Qualitative, quantitative, and mixed method studies that addressed parents' or healthcare professionals' experience of care after stillbirth in LMICs.

Data Collection and Analysis: Studies were screened and data extracted in duplicate. Data was analysed using the Sandelowski meta-summary technique that calculates frequency and intensity effect sizes (FES/IES).

Main Results: 118 full texts were screened and 34 studies from 17 countries were included. FES range was 15-68%. Most studies had IES 1.5-4.5. Women experience a broad range of manifestations of grief following stillbirth, which may not be recognised by healthcare workers, or in their communities. Lack of recognition exacerbates negative experiences of stigmatisation, blame, devaluation, and loss of social status. Adequately developed health systems, with trained and supported staff, are best equipped to provide the support and information that women want after stillbirth.

Conclusions: Basic interventions could have an immediate impact on the experiences of women and their families after stillbirth. Examples include public education to reduce stigma, promoting the respectful maternity care agenda, and investigating stillbirth appropriately.

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Keywords: Stillbirth, LMIC, global health, bereavement care, systematic review, qualitative metasummary

Tweetable abstract:

Reducing stigma, promoting respectful care and investigating stillbirth has a positive impact after stillbirth for women and families in LMICs.

Introduction

Stillbirths hold an increasingly important place in the global maternal and newborn health agenda. The loss of a baby has a profound impact on women, families, communities and healthcare workers(1). The burden is highest in low and middle income countries(LMICs) where an estimated 98% of the 2.6 million stillbirths worldwide occurred in 2015(2).

Efforts to provide effective antenatal and intrapartum care are essential for improving maternal health and preventing stillbirth in LMICs(3). Effective bereavement care is vital for preventing negative short and long term outcomes for families.(1) The 2016 Lancet Ending Preventable Stillbirth Series called for a 'global consensus on a package of care after a death in pregnancy or childbirth... for the affected family, community and caregiver'(4).

A systematic review in 2016(5) addressed experiences of care after stillbirth by parents and healthcare professionals in high-income countries (HICs). Parental findings included the desire for support in memory making, and for increased public awareness and prioritisation of stillbirth(5). It was noted that staff behaviours and actions have a memorable impact on parents(5), underlining the need for improved training and care pathways to support staff. In the UK, this evidence has been synthesised and already used to inform national care pathways (*nbcpathway.org.uk*).

No previous literature synthesis has focussed on evidence from LMICs, where most stillbirths occur. There is a lack of evidence-based recommendations about the care that should be provided to women, partners and families who experience bereavement in LMICs (4,6). Difficulty in providing bereavement care due to lack of support or training is a major source of stress and challenge for health care workers(1).

This systematic review identified studies from LMICs and assessed the available evidence to identify themes which are important to both parents and healthcare workers. The aim was to determine themes which could be used to inform training, guidelines, and a subsequent consensus on global bereavement care principles.

Methods

Objective

To systematically review and perform a qualitative metasummary of research surrounding parents' and healthcare professionals' experiences of care after stillbirth in LMICs.

Search strategy

The search strategy (inception to May 2017) used text word variations and thesaurus terms for stillbirth, families, healthcare professionals, personal experience, and LMICs (Supplementary file 1). LMICs were defined by December 2016 World Bank classification(7). The databases searched were AMED, EMBASE, MEDLINE, PsychINFO, BNI, CINAHL. Conference abstracts from the International Stillbirth Alliance and First Candle conferences were hand-searched for eligibility. There were no date or language limits for the search.

Eligibility criteria

Qualitative, quantitative, and mixed method studies that addressed parents or healthcare professionals experience of care after stillbirth in LMICs were included. Many papers included a

combination of miscarriage, stillbirth and early neonatal death. In many LMICs it is difficult to accurately define gestational age at stillbirth, and definitions vary internationally. Therefore, to avoid losing useful and relevant data, only studies explicitly addressing miscarriage, fetal anomaly, and neonatal death alone were excluded. In studies with results divided by type of loss, findings specific to stillbirth were extracted.

No language restrictions were applied. Dissertations and conference abstracts were included but none contributed to the final review. Review articles, opinion pieces and books were excluded but hand searched for relevant references.

Study selection

Two reviewers screened all abstracts using Covidence software(8), an online platform for systematic review collaboration. Disagreements were resolved by discussion with a third author.

Quality assessment

Study quality and risk of bias was assessed using standard checklists for observational(9) and qualitative(10) studies. The overall quality assessment was synthesised using the Gough weight of evidence framework(11) to take into account the appropriateness of the study method as well as the relevance of each study to answer the review question. Studies were not excluded on basis of quality as the Sandelowski metasummary method allows for inclusion of all potentially useful findings.

Data extraction

Data was independently extracted from included studies in duplicate by two authors (CSh, DB) using a standardised data extraction form (Supplementary file 2). The data extraction form was piloted before use and no changes made.

Data analysis

Sandelowski's metasummary approach(12,13) was used for quantitative aggregation of qualitative and quantitative findings. Firstly, data was extracted from each paper, regarding the events or experiences investigated. Similar findings were then grouped into topics, enabling identification of recurring findings whilst preserving the breadth and complexity of the data. Concise but comprehensive thematic sentences were then derived. The core research team (CSh, DB, AM, RB, ML, CSt, DS) reviewed and discussed all the extracted findings and developed thematic sentences.

Finally, effect sizes were calculated to add a quantitative 'weight' to each finding and to each study(12,13). The frequency effect size (FES) reflects the relative magnitude of an abstracted finding within the included studies, by answering the question 'in how many studies does this finding appear?' ('number of studies with the finding' divided by 'total number of studies'). The intensity effect size (IES) reflects the impact of each study and how much it contributed to the final set of findings by defining the number of findings within it ('number of findings within the study' divided by 'total number of findings'). This helps identify findings only presented in weaker studies, as well as studies which contributed findings with a large FES.

Results

Study selection

Electronic searches revealed 2491 records, and an additional 13 were identified from handsearching conference abstracts and review references. After duplication and eligibility screening, 118 full texts were obtained. Of these, 34 were eligible for inclusion (Figure 1- Prisma diagram).

Description of included studies.

Over half of the included studies used qualitative study designs (19, 56%), with quantitative (7, 21%) and mixed method (8, 24%) study designs playing a smaller role (Figure 2). A summary of the studies in the review is included as Supplementary file 3.

The 34 studies were conducted in 17 countries across 5 regions (Figure 2), by 26 different research groups. All but 5 were conducted in middle income countries (85%), with an equal number of studies in upper middle income countries (South Africa [5]; Brazil [3]; Iran [3]; Malaysia [2]; and one each in China [Hong Kong and Singapore findings excluded] and Russia) and in lower middle income countries (India [6 studies]; Nigeria [3]; Ghana [2]; and one each in Bangladesh, Indonesia and Uganda). Studies were conducted in the following low income countries: Benin; Ethiopia; Malawi; Somalia; Tanzania.

Overall the studies involved 2934 participants, including 1128 women who had experienced some form of perinatal loss; 300 were specifically identified as experiencing stillbirth. One study focussed on 33 men whose wife had had a stillbirth(14). Most studies (27, 79%) related to women's experiences of stillbirth or perinatal loss. Four studies included 259 health professionals with professional experience of stillbirth(15–18) .

Findings

The analysis identified 372 individual 'findings' (Supplementary file 4). From these, 13 thematic sentences were agreed which are represented schematically in Figure 3. These were used for calculation of FES (Figure 4).

Thematic sentences

Positive community support, as opposed to stigmatisation and blame, can improve bereavement experience.(14,19–40) (FES 68%): Women who experienced emotional and material support from society, including family, friends, religious and peer support groups reported lower perinatal grief and depression scores. Negative experiences on the other hand, included stigma, blame, loss of social status, social isolation, relationship difficulties, denial of motherhood and disenfranchised grief.

Women's' experience of grief has multiple manifestations often unrecognised by the healthcare community and wider society.(14,19,20,23–26,28–38,41–44) (FES 65%): Women across all cultures experienced grief that manifested as physical symptoms such as fatigue and pain, and emotionally, in the form of sadness, anxiety, guilt, confusion, and anger. Women wanted recognition of their baby, and of their own loss and bereavement. Fathers also experienced grief and sadness but this was likely to be suppressed. The healthcare community, however, often failed to recognise and acknowledge grief, understand its context, or identify women's need for additional support.

Awareness of, and support for, appropriate coping mechanisms can assist grieving .(14,15,21–25,28–33,36–38,40–43,45,46) (FES 65%): A range of coping mechanisms that women found

beneficial were reported including religion and faith, distraction, family support, peer groups, self-medication, and traditional remedies. Other strategies, commonly used in high income countries, were not universally supported, for example, making memories by taking pictures or seeing and holding the baby was not always culturally appropriate or desired. Some women, particularly those with no living children, mentioned pursuing a future pregnancy as a coping mechanism, or to enable them to regain social status. A few women took positivity from their experience, felt gratitude for their own survival, and were motivated to provide support for others in similar situations.

Access to timely and culturally appropriate psychological support is valued.(14,15,19–24,28,29,31,34,35,39,42–47) (FES 59%): Culturally and language appropriate psychological support, offered at an appropriate time, was effective in reducing anxiety, depression, and grief and may facilitate recovery for women. Women wanted healthcare workers to provide support, counselling, and good communication throughout their care. Access to appropriate support was limited however, by lack of trained or experienced staff, cost, and failure of referral by healthcare workers. The support needs of men may be overlooked.

Women want information, advice and individualised discussions about future pregnancies.(14,19–21,23–25,28,29,31,33,35,36,38–40,42,47) (FES 53%): Women reported mixed experiences of future pregnancy including fear of further loss, desire for another pregnancy and feeling pressure to conceive again soon. For some the thought of future pregnancy was helpful, although it was often acknowledged that it would not be replacement for the loss. Women desired information, psychological support, and individualised discussions about future pregnancies.

Addressing health system barriers is important for provision of respectful care.(14,15,17,18,20,22–24,29,31,33,36,39,40,42–45) (FES 53%): Many women expressed dissatisfaction with the quality of care they received, including neglect, insensitivity, poor attitudes, and poor communication from healthcare workers. Staff, meanwhile, reported lack of sufficient resources, including facilities, equipment, and staff-shortages as barriers to providing good care. These factors contributed to delays in accessing care, along with lack of knowledge, female disempowerment and male or mother-in-law dominated decision making.

Women may experience devaluation and stigmatization as a result of cultural practices and beliefs.(14,22,23,27–33,36–38,40,41,43) (FES 47%): In the included LMIC studies, progressive social attitudes and empowerment of women was associated with ability to express and manage grief, whereas negative social perceptions of stillbirth, culture with male or mother-in-law decision making, expectation of a woman's role as child-bearer, son preference, and blaming women or curses/spirits for stillbirth instead of medical reasons, were associated with guilt, shame and domestic violence, and ultimately stigma for women. Tendency to suppression of mourning, lack of acknowledgement of motherhood after stillbirth, or absence of burial traditions may lead to disenfranchised grief

Supporting proper investigation to understand causes of stillbirth may contribute to reducing stigma.(20–23,27,29–31,33,36,38–40,44,45) (FES 44%): In the absence of a medical cause, women and communities relied on other explanations including superstitions and witchcraft, society, and

poverty, often blaming themselves and others. Conversely, knowing the cause of death helped women make sense of the loss and reduced fear of stigma. Women valued explanation of cause of stillbirth from healthcare workers, however, access to investigation of cause of death was limited by availability of autopsy and financial barriers.

Women and staff believe that specialised bereavement care is important.(15–

18,20,23,30,31,33,36,39,45) (*FES 35%*): Both women and staff described the need for specific guidelines to provide specialised care for women experiencing stillbirth. Suggestions included separation from women with livebirths, multidisciplinary and psychology input, and offering management choices including analgesia, appropriate to the local setting. Some staff were motivated to improve the quality of care provided by their experience of poor outcomes, including stillbirth.

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

health.(14,20,22–24,29,31,33,36,44,45,47) (*FES 35%*): Women wanted more information, and opportunity for discussion, about delivery, cause of death, and postnatal care. In some settings this may also include postmortem and burial. This information, provided in their own language, would have helped to dispel fear of childbirth, fear for their own health, and given them control of their situation.

Comprehensive staff training and support systems for staff are prerequisite to improving care.(15–

18,20,24,45,47) (*FES 24%*): Both women and staff recognised that healthcare workers need more training in general communication and counselling skills, as well as specialist training in bereavement care and the needs of women after stillbirth. Staff caring for women with stillbirth also wanted support with the emotional impact, particularly in settings with high levels of perinatal loss where coping mechanisms and staff resilience were especially important.

Women value supportive family presence throughout care.(15,20,21,33,36,40,45) (*FES 21%*):

Family presence and involvement, especially from their spouse, from time of diagnosis and throughout care, was seen as beneficial by women. Women did not want to be left on their own.

Women value follow-up care and advice to help them return to health.(21,25,28,30,37) (*FES 15%*):

Both staff and patients considered continuity of care and follow up to be important. Women wanted advice on how to access further support after they had gone home, and on any underlying health problems. In LMICs stillbirth is more likely to be associated with physical morbidity or 'near-miss events' than in HICs, and women in this review reported long lasting sequelae, related to both psychological and physical health.

Intensity effect sizes:

The intensity effect sizes for each study are included in supplementary file 5. Two studies contributed a larger proportion of findings(23,29), including after adjustment for findings with higher frequency effect sizes. These studies were both of medium quality and located in sub-

Saharan Africa (Uganda and South Africa). The majority of the studies had an intensity effect size between 1.5 and 4.5, suggesting that a similar proportion of findings came from each study.

Quality assessment:

Gough's weight of evidence (supplementary file 6) included study quality and risk of bias (rated low, medium or good), methodological and topic relevance (rated 1-3). No studies were of overall good quality, the majority (24/34) were of medium quality and rated 2 or 3 for relevance (21/34).

Discussion:

Main findings:

This systematic review identified a range of literature addressing staff and parent experiences of care after stillbirth in LMICs. It also highlights the gaps in published literature on stillbirth experiences in many settings (Figure 1). There is considerable heterogeneity in cultural and healthcare provision among different LMICs and even within the same country. Further research needs to explore the generalisability of any findings.

Women experience a broad range of manifestations of grief following stillbirth across all settings, which may not be recognised by healthcare workers, or in their communities. This exacerbates negative experiences of stigmatisation, blame, devaluation, and loss of social status as a result of stillbirth. Positive attitudes and support during bereavement from family, communities and healthcare workers improves bereavement experience. Adequately developed health systems, with trained and supported staff, are better equipped to provide the support and information that women want after stillbirth.

Strengths and Limitations:

A key strength of this review is its inclusivity, involving a wide range of studies of varied methodology, population groups, and outcomes. The meta-summary method enables synthesis of relevant information from all different study types, whilst also quantifying the prevalence of each finding and the contribution of each paper to the whole. This enhances a comprehensive overview of the literature available.

The main limitation is the distribution of countries represented by the studies in this review (Figure 2). Gaps exist in areas with no research, whilst others may be over-represented by an individual researchers work; for example we found six papers for inclusion from one group in India(14,37,38,42,43,46). Cultural and healthcare practices may vary widely between, and even within, individual LMICs. Better understanding of the range of practices and experiences is needed before generalisations can be made. Deeply embedded cultural beliefs and practices related to stillbirth and bereavement mean that any findings must be interpreted with cultural sensitivity to any given location before implementation. Moreover, each individual woman's circumstances or preferences must be considered, before generalising findings to her.

The frequency effect sizes (FES) quoted should be interpreted as a description of prevalence in the literature, rather than clinical relevance or importance to women and families. A high FES may be influenced by multiple papers published by one research team with an interest in a particular topic, or conversely a low FES may reflect a lack of research rather than un-importance. As an illustration of this, in our review the theme around staff training and support has a low FES. This could be

explained by only 4/34 studies explicitly addressing healthcare workers experiences, rather than indicating that the topic is un-important..

The individual studies involved in this review were mostly of low and medium quality. The meta-summary method considers that all studies may contribute useful information about the presence of themes despite issues of quality, and provision of intensity effect sizes (IES) (Appendix 5) allows readers to determine if any findings originate only from weaker studies. The description of study quality issues remains important, to drive improvements in quality in future studies. Some authors identified particular challenges including the richness of qualitative data improving in the absence of 'outsider' or 'western' investigators(27), and problems engaging staff with limited time for qualitative interviews(17) which could inform changes in future study design.

Finally, many of the principles and guidelines being proposed and investigated in other settings, and the themes and analysis following might still reflect Western sociocultural perspectives, particularly if the researchers were not native to the countries studied. It cannot therefore be assumed that findings can be imported to every LMIC, including the very countries the studies originated from, rather they would need to be critically adapted to local social norms and cultural practices first(30).

Interpretation:

A key theme running through the findings was the negative experiences of women, particularly regarding, blame, stigmatisation, devaluation and lack of understanding among families, communities and healthcare workers, based on their reproductive status. This corresponds with a previous review of stillbirth outcomes which noted stigmatisation to be reported frequently in LMICs, in contrast to high-income countries (HICs)(6).

Improved awareness and public education about stillbirth could reduce the stigma experienced by women. It follows that increased understanding of the causes of stillbirth may reduce supernatural explanations in LMICs that focus blame on the woman. This correlates with recent findings about public perceptions of stillbirth in Ireland(48). In this high-income setting, it was found that the lack of awareness about causes of stillbirth led to blame of healthcare staff by the public. A common solution to this thread of misplaced blame may be public education, followed by appropriate stillbirth investigation, as allowed by local resources. Supporting investigation for causes of stillbirth, therefore, could help to reduce stigma in LMICs and HICs alike by focussing attention on biomedical explanations(49).

There is more emphasis on future pregnancy in the literature included in this review, than in the similar HIC review(5). This emphasis on future fertility in LMICs may come from a perception of women's value being linked to their reproductive status(25,27,29,41). Conversely, there was less emphasis on making memories, by seeing, holding and naming the baby, which may reflect cultural beliefs and practices.

The need for adequately equipped and developed health systems to provide care is clear in this review. Women report negative experiences related to poor attitudes and communication from health care workers, and healthcare workers report barriers to providing care including staff shortages and lack of training, facilities and equipment. Some interventions, such as developing localised guidelines, providing separate facilities for women experiencing stillbirth, and providing services for further investigation, would require financial and resource investment. Other changes, such as use of any available analgesia, and provision of respectful maternity care(50), require less material investment but could significantly change experience. Finally, some changes might not need

investment, for example promoting support by family and friends during bereavement, but require changes in attitudes and behaviours that might not always be easy to achieve.

Overall, our findings correlate well with literature from HICs(5), suggesting that a set of common principles for bereavement care can be developed, and some of these principles could and should be promoted as a matter of urgency and without much resource.

Further research would be beneficial, particularly expanding the coverage of different cultures and countries to increase the breadth of the literature.

Conclusion:

This systematic review shows that there is some literature available from LMICs providing insight into the experience of women, families and healthcare workers, with findings which could be used to inform improved care practices.

Further research will be needed to better understand issues and design appropriate solutions, but there are already possible interventions that could make an immediate difference. These include public education to reduce stigma and blame and promoting the respectful maternity care agenda. The mere act of investigating stillbirth appropriately will send the signal to society that we must not automatically blame women or staff. It is important to work with all stakeholders, clinicians, and politicians to implement improvements in global bereavement care to reach all families. Educate, investigate, and respect, and we might be closer to improving global bereavement care than we think.

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Figure 1: Prisma diagram

Figure 2: Study location and type

Figure 3: Thematic sentences

Figure 4: Frequency effect sizes