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

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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 meta-summary 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 were analysed using the Sandelowski meta-summary technique that calculates frequency and intensity effect sizes (FES/IES).

Main results In all, 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.

Keywords Bereavement care, global health, Low- and middleincome countries, qualitative meta-summary, stillbirth, systematic review.

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

Linked article This article is commented on by E Denny, p. 22 in this issue. To view this mini commentary visit https://doi.org/ 10.1111/1471-0528.15461.

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Care after stillbirth in low- and middle-income countries

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 stillbirths 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 2016⁵ addressed the 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 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 is already being used to inform national care pathways (nbcpathway.org.uk).

No previous literature synthesis has focused on evidence from LMICs, where most stillbirths occur. There is a lack of evidence-based recommendations about care 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 source of stress and challenge for healthcare 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

The aim of the study was systematically to review and perform a qualitative meta-summary 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 (Supporting Information Appendix S1). LMICs were defined by the December 2016 World Bank classification.⁷ The databases searched were AMED, EMBASE, MEDLINE, PsychINFO, BNI and 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. There was no patient and public involvement in the systematic review, and no funding was required. No relevant core outcome sets are available.

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 accurately to 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 were 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 were assessed using standard checklists for observational⁹ and qualitative¹⁰ studies. The overall quality assessment was synthesised using the Gough weight of evidence framework¹¹ 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 the basis of quality, as the Sandelowski meta-summary method allows for inclusion of all potentially useful findings.

Data extraction

Data were independently extracted from included studies in duplicate by two authors (CSh, DB) using a standardised data extraction form (Supporting Information Appendix S2). The data extraction form was piloted before use, and no changes made. Shakespeare et al.

Data analysis

Sandelowski's meta-summary approach^{12,13} was used for quantitative aggregation of qualitative and quantitative findings. First, data were extracted from each paper regarding the events or experiences investigated. Similar findings were then grouped into topics, enabling identification of recurring findings while 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'). 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 hand-searching conference abstracts and review references. After duplication and eligibility screening, 118 full texts were obtained, of which 34 were eligible for inclusion (Figure 1).

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 Supporting Information Appendix S3.

The 34 studies were conducted in 17 countries across five regions (Figure 2) by 26 different research groups. All but five were conducted in middle-income countries (85%), with an equal number of studies in upper middleincome 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); 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, and 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 focused on 33 men whose wives 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' (Supporting Information Appendix S4). From these, 13 thematic sentences were agreed which are represented schematically in Figure 3. These were used for the 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 often suppressed. The healthcare community 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 HICs, were not universally supported; for example, 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 derived positivity from their experience, felt gratitude for their own survival, and were motivated to provide support for others in similar situations.

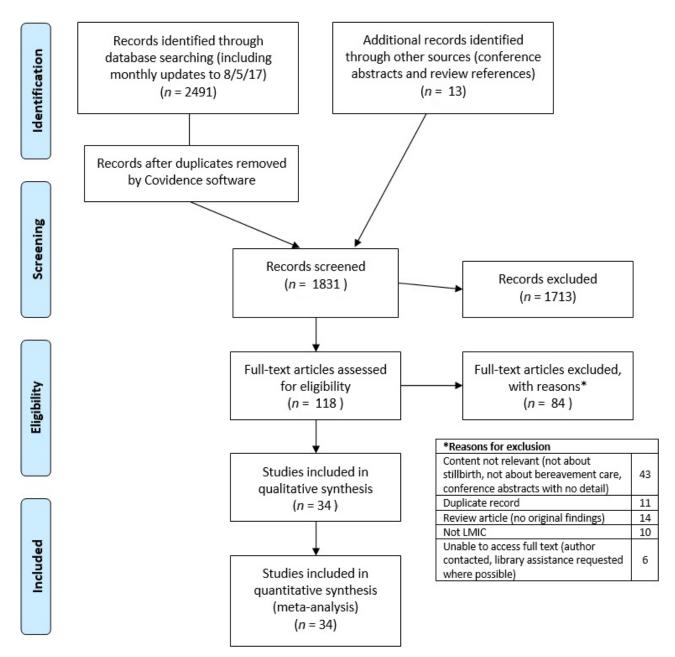


Figure 1. Prisma diagram.

Access to timely and culturally appropriate psychological support is valued.^{14,15,19–24,28,29,31,34,35,39,42–47} (FES 59%): Cultural- 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 acknowledged that it would not be a replacement for the loss. Women desired information,

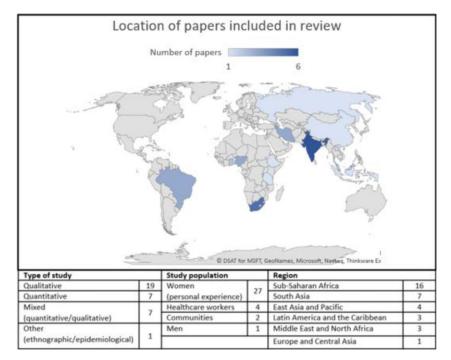


Figure 2. Study location and type.

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 decision-making dominated by the male or the mother-in-law.

Women may experience devaluation and stigmatisation 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 were associated with ability to express and manage grief. 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 live births, multidisciplinary and psychology input, and offering management choices including analgesia, appropriate to the local setting. Some staff was motivated to improve quality of care 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 postmortems and burial. This information, provided in their own language, would have helped to dispel fear of childbirth and fears for their own health, and given them control of their situation.

Comprehensive staff training and support systems for staff are a prerequisite to improving care.^{15–18,20,24,45,47} (FES 24%): Both women and staff recognised that healthcare

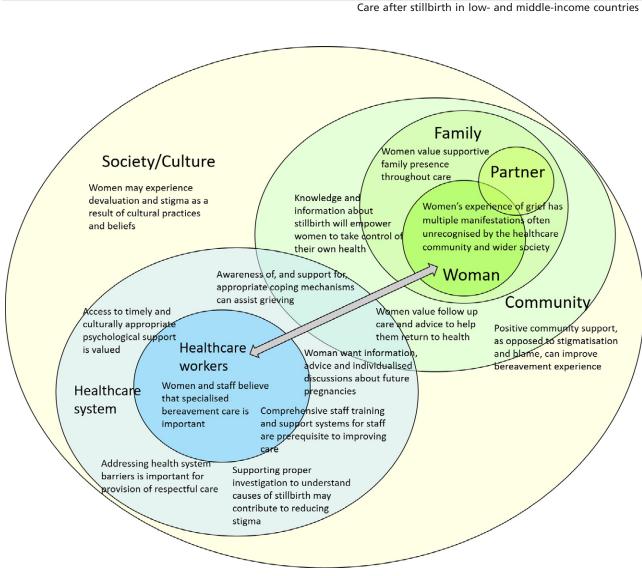


Figure 3. Thematic sentences.

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, were seen as beneficial by women. Women did not want to be left on their own.

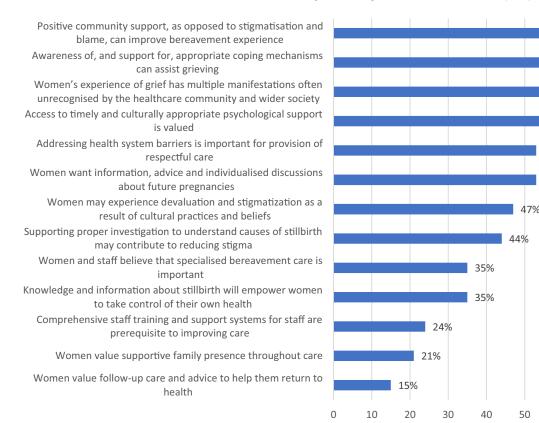
Women value follow-up care and advice to help them return to health.^{21,25,28,30,37} (FES 15%): Both staff and patients considered continuity of care and follow up to be important. Women wanted advice on how to access further support after they had

gone home, and on any underlying health problems. In LMICs, stillbirth is more likely to be associated with physical morbidity or 'near-miss events' as compared with HICs, and women in this review reported long-lasting sequelae for both psychological and physical health.

Intensity effect sizes

The intensity effect sizes for each study are included in Supporting Information Appendix S5. 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.

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Frequency effect sizes (%)

Figure 4. Frequency effect sizes. [Correction added on 12 December 2018, after first online publication: In Figure 4, the percentage values were missing from the graph and the figure has been replaced.]

Quality assessment

Gough's weight of evidence (Supporting Information Appendix S6) 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's 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 improve the 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.

68 %

65%

65%

59%

53%

53%

60

70

80

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 types of studies, while also quantifying the prevalence of each finding and the contribution of each paper to the whole. This enhances a comprehensive overview of the available literature.

The main limitation is the distribution of countries represented by the studies in this review (Figure 2). Gaps exist in areas with no research, whereas others may be overrepresented by an individual researcher's 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 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 and, conversely, a low FES may reflect a lack of research rather than unimportance. 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 unimportant.

The individual studies involved in this review were mostly of low or 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 S5) allows readers to determine whether 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 interviews¹⁷ 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 that follow, may 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 first need to be critically adapted to local social norms and cultural practices.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 still birth outcomes which noted stigmatisation to be reported frequently in LMICs compared with 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 focusing attention on biomedical explanations.⁴⁹

There is more emphasis on future pregnancy in the literature included in this review than in a 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, 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 healthcare 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 do require changes in attitudes and behaviours that might not always be easy to achieve.

Overall, our findings correlate well with literature from HICs⁵ 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 many resources.

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

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 is 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 a signal to society that we must not blame women or staff. It is important to work with all stakeholders, clinicians, and politicians to implement improvements in bereavement care to reach all families. Educate, investigate, and respect, and we might be closer to improving global bereavement care than we think.

Disclosure of interests

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Contribution to authorship

DS conceived the study. DS, CSh and AM designed the study with input from the rest of the group (CSt, HB, FB, VF, KG, DH, TM). CSh, AM, DB, RB and KB performed searches, screening and data extraction. CSh, CSt, RB, ML, AM and DS analysed the data. CSh was responsible for writing the first draft and all authors contributed to finalising the manuscript.

Details of ethics approval

Not applicable.

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Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Appendix S1. Search strategy.

Appendix S2. Data extraction form.

Appendix S3. Summary of studies.

Appendix S4. Sample extracted findings.

Appendix S5. Intensity effect sizes.

Appendix S6. Quality assessment

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