

**Parents' experiences of care offered after stillbirth: International online survey
of high- and middle-income countries**

Authors – name and degree

Affiliations (primary and job title)

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Background

Stillbirth is one of the most common adverse pregnancy events and is associated with significant psychological and social consequences, that can be mitigated by respectful and supportive bereavement care. The absence of high-level evidence to support the broad scope of perinatal bereavement practices means that offering a range of options identified by parents as valued has become an important indicator of quality. This study aimed to describe bereavement care practices offered to parents across different high- and middle-income countries.

Methods

An online survey of parents of stillborn babies was conducted between December 2014 and February 2015.

Frequencies of nine practices were compared between high- and middle-income countries. Differences in the proportions of reported practices and associated odds ratios were calculated.

Results

Over three thousand parents (3041) with a self-reported stillbirth in the preceding five years from 40 countries responded, including 15 countries where there were at least 40 responses.

Significant differences in prevalence of offering nine bereavement care practices were reported by women in high-income countries (HICs) compared with women in middle-income countries MICs. All nine practices were reported to occur more

frequently by women in HICs. All differences were statistically significant.

Widespread occurrence of all nine practices was reported only for the Netherlands.

Conclusions

Scope for improvement in perinatal bereavement care exists in most countries.

Future research should look at why the differences we found occur, their impact on parents, and how they might be addressed, particularly how to support effective communication, decision-making and follow-up care.

stillbirth, bereavement care, high-income countries, middle-income countries,
parents

The death of a baby during pregnancy or in or shortly after childbirth is a major traumatic event. Stillbirth is overwhelming for parents, and one of the most common adverse pregnancy events. It is associated with significant short- and long-term psychological and social consequences.¹ Some adverse outcomes can be mitigated by respectful and supportive bereavement care.²

Bereavement care, a broad generic term, encompasses the *professional* support provided to people who experience the death of someone they love.³ Perinatal bereavement care necessarily has a broader scope than other types of bereavement care. It includes involving and supporting grieving parents in decisions and practices associated with both birth and death, such as giving birth, naming their baby and taking part in parenting activities that may include seeing and holding their baby^{4,5}, making memories and mementoes of their baby and organising funerals or other commemorative rituals.⁶⁻⁹

In their conceptual analysis of perinatal bereavement – defined as the experience of parents that begins immediately following knowledge of the loss of an infant through death by miscarriage, stillbirth, neonatal loss, or elective termination for fetal anomalies – Fenstermacher and Hupcey (2013) describe the perinatal bereavement experience as complex, multifaceted and influenced by multiple factors.

Bereavement support interventions such as creating mementoes, naming the baby, seeing and holding the baby and having a funeral service are identified as important modifiers of the intensity and duration of grief. Numerous studies of parents' experiences show that many parents wish to be involved in decisions or encouraged to be involved in parenting activities.⁴⁻⁸

Incorporating personal values and preferences is essential to any evidence-based practice,¹⁰ but has particular relevance in perinatal bereavement care, where evidence related to effective care is limited or often missing¹¹ and where wide variation in personal views and cultural expectations associated with the death of a baby exist.^{9,12} The absence of high-level evidence to support the broad scope of perinatal bereavement practices means that ensuring parents who experience stillbirth are offered a range of options identified by parents as valued and important has in itself become an important indicator of quality.² Important to the development of perinatal bereavement care has been the advocacy of parent groups, who promote awareness of different practice choices, including spending time with the baby, and taking the baby home.¹³⁻¹⁷ Offering practices that are known to be valued by parents is not equated with an expectation that each practice will be taken up by all parents, but can empower parents and enhance their experience of care:

... choice and empowerment is key. Making sure that families are still given time and choice in those initial days. I always say - they will leave, and discover what you did not offer them. So make sure you offer it. (Jess, 2020)¹⁸

Parents who experience stillbirth consistently link their grief with the need for improvements in the care they receive, including the need for hospital staff who are better trained and better integrated with support services.¹⁹⁻²¹

Due to the broad nature of perinatal bereavement care and the changing expectations associated with it, many health professionals can feel unprepared when a perinatal death does occur,²¹ leaving parents feeling let down. To fill the gap between the needs of parents and professionals, a number of clinical practice perinatal bereavement guidelines have been developed over the past 20 years, including by WHO-UNICEF-UNFPA²² and several countries, such as Ireland,²³ the

United Kingdom¹⁶ and Canada.²⁴ In Australia, the Perinatal Society of Australia and New Zealand (PSANZ)/Stillbirth Centre of Research Excellence (Stillbirth CRE) *Clinical practice guideline for respectful and supportive perinatal bereavement care* includes an organising framework – *Framework for the practice of respectful and supportive perinatal bereavement care* (the PSANZ/CRE Framework) – that sets out four overarching domains of care: good communication; shared decision making; recognition of parenthood; and effective support.²⁵

The largest source of international data that includes parent-reported bereavement care practices comes from *The Lancet's* Ending Preventable Stillbirths series², where three multi-country online surveys included one that targeted parents who had experienced stillbirth with no time exclusion. The supplementary material to that series includes data that shows the variability in parents' preferences for care related to recognition of parenthood in high- and middle-income countries.

The aim of this paper is to describe bereavement care practices offered to parents in different countries. It extends a previous analysis to give a more contemporaneous view by focussing on parents who experienced stillbirth within five years of the survey and includes additional questions addressing other domains in the PSANZ/CRE Framework and a more detailed country analysis.

Methods

The *Ending Preventable Stillbirths* multi-language online survey of parents of stillborn babies was conducted between December 2014 and February 2015. The survey was distributed primarily through parent-based member organisations of the International Stillbirth Alliance (ISA).²⁶ For detailed methods, see Flenady et al. (2016).² While the main target audience for the survey was bereaved parents from high-income countries (HICs), more than 600 parents from middle-income countries

(MICs) also responded. Analyses reported in this paper excluded responses from parents whose loss occurred more than five years prior to completion of the survey.

The domains of the PSANZ/CRE Framework were mapped to nine items that relate to bereavement care practices in the online survey. Seven items asked whether opportunities were provided for specific events or activities that can be related to the *Recognition of parenthood* domain,²⁵ specifically: to name the baby; to see and hold the baby; to have a funeral (or other service or ceremony); to spend time with the baby; to have other family members or friends meet the baby; to create memories (e.g., photos, footprints, handprints); and to take the baby home (see Figure 1). The other domains of the PSANZ/CRE Framework were not directly addressed in the survey. However, one question asked whether parents were given information about autopsy or post-mortem examinations (relates to the *Shared decision-making* domain) and one item asked whether follow-up care had occurred (relates to the *Effective support* domain).

Analysis occurred in two stages. First, frequencies of each of the nine practices were compared between parents from HICs and MICs. Differences in the proportions of reported practices between high- and middle-income countries and the associated odds ratios were calculated with the Medicalc free web calculator.²⁷ Confidence intervals (95%) were also calculated.

The second stage of the analysis involved a comparison of countries where at least 40 parents provided responses. Clustering of the frequency of reported practices or activities was observed. As no existing scale could be identified, a scale was developed to describe this distribution. The Widespread-Common-Frequent-Occasional-Rare scale (WCFOR) was based on two subjective ecological scales

used to measure the abundance of species or flora in the environment: the Abundant-Common- Frequent-Occasional-Rare scale (ACFOR) and the Dominant-Abundant-Frequent-Occasional-Rare scale (DAFOR).²⁸ The WCFOR scale uses similar descriptive terms to incorporate a quantitative approach to categorising reported occurrence:

- *Widespread*, at least 80% of parents in a country reported occurrence of a bereavement care practice (that is, at least four in five parents reported that the care practice had been offered to them)
- *Common*, when between 50% and 79% of parents reported that a practice was offered
- *Frequent*, when between 25% and 49% of parents reported that a practice was offered
- *Occasional*, when between 10% and 24% of parents reported that a practice was offered
- *Rare*, when less than 10% of parents reported that a practice was offered (that is, reported by less than 1 in 10 parents from that country).

Frequencies were calculated using Microsoft Excel.

Ethics approval

The survey was approved by the Mater Health Services Human Research Ethics Committee (Ref #HREC/13/MHS/121), within the guidelines of the Australian National Statement on Ethical Conduct in Human Research, and by the University of British Columbia Office of Research Services, Behavioural Research Ethics Board on 22 December 2014 (Ref #H14-02784) (Vancouver, Canada).

Results

Study sample

A total of 3041 responses were received from parents in 40 countries classified according to the World Bank as high- or middle-income in 2014-15 where the stillbirth had occurred in the preceding five years. Most respondents were mothers (2918, 96.0%; 4% were partners), and most (2480, 81.6%) were from 22 HICs; 561 (18.4%) were from 18 MICs (see Table 1).

Fifteen countries provided at least 40 responses from parents and were included in the country comparison (see Table 2). This subsample included 2823 parents (92.8% of all parents from HIC and MICs who responded to the survey). Sample sizes in this subsample ranged from 41 (New Zealand) to 572 (Italy).

Prevalence of bereavement care practices

Significant differences in the prevalence of offering the nine identified bereavement care practices were reported by women in HICs compared with women in MICs. All nine practices were reported to occur more frequently by women in HICs, and all differences were statistically significant (see Table 1).

The difference in prevalence of the nine care practices reported between HICs and MICs fell into three distinct groups: small differences (6%); large differences (19-26%), and very large differences (34%-41%). Receiving information about autopsy or post-mortem examinations was the practice with the largest difference between high- and middle-income settings (difference=41%, 95% CI 36.6, 45.2; OR=5.2, 95% CI 4.3,6.4). Follow-up calls or visits were reported by about half the parents in high-income countries (50%), while fewer than one in seven parents in middle-income countries reported that this practice was offered to them (difference=36%, 95% CI

32.3, 39.3; OR=6.2, 95% CI 4.8, 8.0). The smallest difference in practice prevalence was for opportunity to take the baby home, which was uncommon in both settings (difference=6%, 95% CI 2.3, 9.3; OR=1.4, 95% CI 1.1-1.8).

Country comparison

The Netherlands was the only one of the 15 countries with a relatively high volume of respondents where widespread occurrence of all nine practices was reported.

Respondents from three countries (Ireland, Canada and New Zealand) reported that all but one of the practices were widespread.

In ten of these 15 countries, at least five care practices were widespread (see Tables 2 and 3). The most striking differences related to taking the baby home and receiving follow-up care, which both ranged from rare to widespread depending on the country. None of the nine practices were reported as widespread by parents from four countries (Italy, Mexico, Argentina, Spain). Practices in the *Recognition of parenthood* domain of The Framework were reported as commonly or frequently offered apart from taking the baby home, which was only offered rarely or occasionally. Follow-up care (representing the *Effective support* domain) was reported as occurring rarely or occasionally.

DISCUSSION

Our international comparison of parent-reported bereavement care practices offered following stillbirth shows considerable variation between HICs and MICs, and between different HIC settings. There is room for improvement in most countries. Only in the Netherlands was there widespread offering of all the nine bereavement care practices.

The study findings support the need to improve bereavement care following stillbirth as a global priority²⁹ and offer insights into where that improvement could occur and where to focus research in this area more effectively.

Some bereavement practices are very widely established, indicating that equipoise no longer exists in many countries. There appears to be little justification for undertaking further studies as to whether offering of such practices should occur or not; rather, the focus of research could shift to better integration of different aspects of care to accommodate individual preferences and needs. For example, care related to the recognition of parenthood is largely cultural and interconnected, yet practices such as seeing/holding and spending time with the baby are frequently envisaged as stand-alone interventions that can be controlled without attention to the context of the situation. Moreover, such practices comprise the most studied areas of perinatal bereavement care,^{4,5,30,31} while other aspects of care, such as supported decision-making, effective communication strategies and follow-up care are under-researched. Some areas present opportunities for clinical trials, for instance, there is potential for significant improvement in the experiences of parents in the use of decision-support tools, follow-up care, and other technologies that would allow parents opportunities that are now not readily available to them, such as to take their babies home (or to another location that holds meaning for the family). Such experiences could have a profound impact on personal, or internal, modifiers of perinatal bereavement such as attachment to the baby.⁹

However, these practices need to be considered in the context of external influencers on the experience of perinatal bereavement and the care provided, including culture, religion and tradition.⁹ For example, the opportunity to take the

baby home may be normative and highly valued in some countries (e.g., Ireland, New Zealand), but may be illegal or well outside prevailing social norms in other countries. Our study underlines the health care setting as a modifier of perinatal bereavement by revealing that the availability of bereavement care, that may include the education and training of health care providers and local laws²¹, are also likely to have an impact on parents' experiences. A further current example of external modifiers is the impact of the COVID-19 pandemic on health care services.

We found the largest variations between HICs and MICs were for those practices that were the most resource-intensive, including follow-up care which was generally not well implemented even in some HICs. When health systems are not well resourced, follow-up care is likely to be more reliant on community-based support. Recent international events, such as the COVID-19 pandemic, show the need for health services innovation, including developing telehealth capacities. This may shift the boundaries between hospital and the home and may provide opportunities for more effective and creative support for parents after stillbirth and a greater role for community-based organisations, including parent support groups where they exist.

In seeking consensus for a set of global principles for perinatal bereavement care among stakeholders including bereaved parents and healthcare workers, the RESPECT study³² highlighted the importance of efforts that reduce stigma, train health care workers, and ensure respectful care across all aspects of maternity care. Advocacy, through organizations such as the International Stillbirth Alliance (ISA), has an important role, and it is noteworthy that ISA conferences that promote and educate on best practice in stillbirth care, have been hosted or planned in regions where the nine practices were reported to be rare (Argentina, Spain, Italy).

Limitations of this study include the self-selected convenience study sample and use of an online survey, which may have limited the potential of some parents to participate, particularly those in middle-income countries. While the original survey was conducted five years ago, there have been no major changes in bereavement care following stillbirth since then, and these findings remain the most up-to-date international data available and provide a baseline for future study. The areas covered by the survey focussed mainly on acknowledgement of parenthood, which is one of four domains of care identified as part of the PSANZ/CRE Framework and where most research has focussed. Items for other domains were limited or missing. The questions used in the study were developed for the survey and not validated, which may have implications for how some items were interpreted and/or translated. Despite the limitations of the items addressing some of the domains of the PSANZ/CRE Framework, using this approach shows how meaningful comparisons can be made between countries to highlight differences in current practices. Such differences may be based on different cultural, legal and social needs, and further research is needed to understand these. Additional items are needed in future surveys for a more comprehensive assessment of the domains of perinatal bereavement care.

Conclusions

Scope for improvement in perinatal bereavement care exists in most countries, with striking differences apparent. Despite the complexities of cross-country data comparisons, considerable variation between HICs and MICs and between some HICs was evident. The purpose of this study was to describe the offering of practices reported by parents. Future research should look at why the differences we found

occur, their impact on parents, and how they might be addressed, particularly how to support effective communication, decision-making and follow-up care.

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