

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

*Title page*

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### **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, Behavioral Research Ethics Board on 22 December 2014 (Ref #H14-02784) (Vancouver, Canada).

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#### Background

Stillbirth, the death of a baby before birth, 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 as valued by parents has become an important indicator of care 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 proportions of reported practices and their associated odds ratios were calculated to compare high- and middle-income countries.

#### Results

Over three-thousand parents (3041) with a self-reported stillbirth in the preceding five years from 40 countries responded. At least 40 responses came from 15 countries.

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 significantly more frequently by women in HICs, including opportunity to see and hold their baby (OR=4.8,

95% CI 4.0-5.9). Widespread occurrence of all nine practices was reported only for The Netherlands.

## Conclusions

Bereavement care after stillbirth varies between countries. Future research should look at why these differences occur, their impact on parents, and whether differences should be addressed, particularly how to support effective communication, decision-making and follow-up care.

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

**WORDS:2815**

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

### Background

The death of a baby during pregnancy or shortly after childbirth is a major traumatic event. Stillbirth accounts for the majority of these deaths and is an overwhelming and devastating pregnancy outcome for parents. It is associated with significant short- and long-term psychological and social consequences.<sup>1</sup> Some adverse outcomes can be mitigated by respectful and supportive bereavement care.<sup>2</sup>

Bereavement care, a broad generic term, encompasses the professional support provided to people who experience the death of someone they love.<sup>3</sup> Perinatal bereavement care necessarily has a unique scope compared with bereavement care in other situations. This is because 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<sup>4,5</sup>, making memories and mementoes of their baby and organising funerals or other commemorative rituals.<sup>6</sup>

In their conceptual analysis of perinatal bereavement—defined as the experience of parents that begins immediately following 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.<sup>7</sup> Numerous studies of parents' experiences show that many parents wish to be involved in decisions and/or in parenting activities.<sup>4,5,8-10</sup>

Incorporating personal values and preferences is essential to any evidence-based practice,<sup>11</sup> but has particular relevance in perinatal bereavement care, where evidence related to effective care is limited or often missing<sup>12</sup> and where wide variation in personal views and cultural expectations associated with the death of a baby exist.<sup>7,13</sup> The absence of high-level evidence to support the broad scope of perinatal bereavement practices means that ensuring that parents who experience stillbirth are offered a range of options identified as valued and important by bereaved parents has, in itself, become an important indicator of quality.<sup>2</sup> Critical 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.<sup>14-18</sup> 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 the availability of options can empower parents and enhance their experience of care:<sup>6</sup>

... 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)<sup>19</sup>

Parents who experience stillbirth consistently link their grief intensity 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.<sup>20-22</sup>

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<sup>22</sup> 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-UNFPA<sup>23</sup> and countries, such



as Ireland<sup>24</sup> the United Kingdom<sup>17</sup> and Canada.<sup>25</sup> 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.<sup>26,27</sup>

The PSANZ/CRE guideline was informed by the largest source of international data that includes parent-reported bereavement care practices, which comes from *The Lancet's* Ending Preventable Stillbirths series<sup>1,2</sup>, 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.<sup>28</sup>

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).<sup>29</sup> For detailed methods, see Flenady et al. (2016).<sup>2</sup> 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 subsequently mapped to the nine items relating to bereavement care practices that were included 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,<sup>26</sup> 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, which was constructed prior to the framework development. 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 and confidence intervals (95%) were calculated with the Medicalc free web calculator.<sup>30</sup>

The second stage of the analysis involved a comparison of 15 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).<sup>31</sup> The WCFOR scale uses similar descriptive terms to incorporate a quantitative approach to categorising reported occurrence:

- Widespread, more than 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.

## **Results**

### **Study sample**

A total of 3,041 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.<sup>32</sup> 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).

At least 40 responses were received from parents from 15 countries 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 prevalence difference of the nine care practices reported between HICs and MICs fell into three distinct groups: small differences (6%); large differences (19-26%), or very large differences (34%-41%). Receiving information about autopsy or post-mortem examinations was the reported 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 of 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 opportunity to take the baby home, which was uncommon in both settings, but was more common in HICs (difference=6%, 95% CI 2.3, 9.3; OR=1.4, 95% CI 1.1-1.8).

### **Country comparison**

Two MICs contributed to the comparison of individual countries (Argentina and Mexico). The Netherlands was the only one of the 15 countries 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. If offering care known to be valued by parents is accepted an indicator of the quality of bereavement care, there is room for improvement in most countries. Only in the Netherlands was there widespread offering of all nine bereavement care practices explored in this study. Bereavement care following stillbirth is recognized to be a global priority;<sup>33</sup> this study offers insights into where improvement could occur and where to focus research in this area more effectively. Further insight is needed to understand the factors influencing variation in perinatal bereavement care and how to minimise adverse outcomes.

Some bereavement practices are now widely established. As such, there is little justification for further studies designed to assess their effectiveness. Rather the focus of research could shift to analyses of integration of care to accommodate individual preferences and needs. For example, practices, such as seeing/holding and spending time with the baby are the most studied areas of perinatal bereavement care,<sup>4,5,34,35</sup> and are frequently envisaged as stand-alone interventions that can be controlled without attention to the context of the situation. Yet, care related to the recognition of parenthood comprises multiple practices that can have a cultural basis. These are often intertwined with other, under-researched aspects of care, such as supported decision-making, effective communication strategies and follow-up support. Some research questions lend themselves to clinical trials. For example, it would be helpful to establish whether the use of decision-support tools, different approaches to follow-up care, and the use of other technologies have potential to significantly improve parent experiences by addressing current gaps in care or by enabling options not now readily available to parents, such as taking their babies home (or to other locations that hold meaning for a family). Such experiences could have a profound impact on personal, or the internal, modifiers of perinatal bereavement such as attachment to the baby.<sup>7</sup>

Bereavement care practices do change over time, and so 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.<sup>7</sup> One 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 such as Canada and the United States. Our study underlines the role of health care settings as modifiers of perinatal bereavement care. The availability of bereavement care practices is influenced by the education and training of health care providers and by local laws<sup>22</sup>; they do also have an impact on parents' experiences.

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 have greater reliance on community-based support. Recent international events, such as the COVID-19 pandemic, show the need for health services innovation, including developing appropriate 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 study<sup>36</sup> 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) have an important role and it is noteworthy that ISA conferences that promote and educate on best practice in stillbirth care, have been hosted (Spain 2019) or planned (Italy 2021, although this has now been deferred) in regions where the nine practices were reported to be rare. It is also notable that although grief may be considered culturally and socially specific, in countries such as Spain and Italy where bereavement care is more limited compared with other HICs, parents are asking for the same options and opportunities.<sup>37</sup>

Limitations of this study include the self-selected study sample, the use of an online survey and variable survey promotion across countries, which may have limited the potential of some parents to participate, particularly those in middle-income countries. However, despite responses from more than 600 parents in MICs, these were not the target of the original

survey although they made analyses included in this paper possible. Only two MICs (Argentina and Mexico) provided 40 or more responses, which limited comparisons between individual countries. While the original survey was conducted five years ago, there is little to suggest that there have been 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.<sup>38</sup> 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 focused. As the PSANZ/CRE Framework was developed after the survey, items for its other domains were limited (shared decision-making, effective support) or missing (good communication, organisational response). 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 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**

Parents will make different choices in bereavement care, but all need options to be made available to them to do so. 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 for families who are grieving.

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TABLE 1: REPORTED OCCURRENCE OF 9 BEREAVEMENT CARE PRACTICES AFTER STILLBIRTH IN HIGH-INCOME AND MIDDLE-INCOME COUNTRIES

	% ALL (N=3041)	High Income Countries (%) (N=2480)	Middle Income Countries (%) (N=561)	Prevalence Difference (%) (95% CI)	Odds Ratio (95% CI)
After your baby was stillborn, were you given the opportunity:					
• To name your baby	84	89	63	26 (21.9, 30.2)	3.7 (3.0, 4.6)
• To see and hold your baby	81	87	53	34 (29.7, 38.3)	4.8 (4.0, 5.9)
• To have a funeral (or other service or ceremony) for your baby	81	86	60	26 (21.8, 30.3)	3.4 (2.8, 4.1)
• To spend time with your baby	77	84	48	36 (31.6, 40.3)	4.8 (4.0, 5.8)
• For other family members or friends to meet your baby	72	76	57	19 (14.6, 23.4)	2.1 (1.8, 2.6)
• To create memories of your baby (e.g., photos, fingerprints, handprints)	66	73	38	35 (30.5, 39.2)	4.0 (3.3, 4.8)
• To take your baby home	22	23	17	6 (2.3, 9.3)	1.4 (1.1, 1.8)
Were you counselled or given information about having an autopsy/post-mortem examination of your baby?	69	76	35	41 (36.6, 45.2)	5.2 (4.3, 6.4)

Once you were back at home after your baby was stillborn, did you receive a follow-up telephone call OR home visit from a care provider?	43	50	14	36 (32.3, 39.3)	6.2 (4.8, 8.0)
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**HICs:** Australia (n=297); Austria (n=11); Belgium (n=21); Canada (n=50); Chile (n=48); Croatia (n=1); Denmark (n=39); France (n=7); Germany (n=160); Italy (n=572); Netherlands (n=85); New Zealand (n=41); Norway (n=68); Portugal (n=31); Ireland (n=87); Puerto Rico (n=4); Singapore (n=1); Spain (n=213); Sweden (n=70); Switzerland (n=8); United Kingdom (n=344); United States (n=307); Uruguay (n=15); **MICs:** Argentina (n=337); Bolivia (n=5); Brazil (n=7); Colombia (n=25); Costa Rica (n=8); Ecuador (n=5); Guatemala (n=5); Mexico (n=144); Peru (n=9); Venezuela (n=5); South Africa (n=2); Dominican Republic (n=2); Paraguay (n=2); Panama (n=1); Pakistan (n=1); Honduras (n=2); El Salvador (n=1)

TABLE 2: COMPARISON OF 9 BEREAVEMENT CARE PRACTICES AFTER STILLBIRTH IN 15 COUNTRIES: MOTHERS' REPORTED FREQUENCY OF OFFERING

Country	After your baby was stillborn, were you given the opportunity:							Were you given information about autopsy/post-mortem examinations? (% yes)	Did you receive a follow-up telephone call or home visit from a care provider? (% yes)
	To name your baby (% yes)	To see and hold your baby (% yes)	To have a funeral (or other service or ceremony) (% yes)	To spend time with your baby (% yes)	To create memories of your baby (% yes)	For other family members or friends to meet your baby (% yes)	To take your baby home (% yes)		
Domains of Bereavement Care	<b>ACKNOWLEDGEMENT OF PARENTHOOD</b>							<b>SHARED DECISION-MAKING</b>	<b>EFFECTIVE SUPPORT</b>
The Netherlands (n=85)	98	96	97	98	98	98	90	88	87
Republic of Ireland (n=87)	99	99	98	99	95	92	82	82	79
Canada (n=50)	100	100	91	100	93	89	2	82	85
New Zealand (n=41)	97	97	87	95	95	87	84	74	93
Australia (n=297)	98	97	93	97	93	86	24	78	73

United Kingdom (n=344)	98	97	99	98	95	89	20	78	74
United States (n=307)	98	97	93	96	91	89	6	72	59
Sweden (n=70)	95	100	98	100	98	73	36	89	74
Germany (n=160)	92	90	90	86	84	68	15	64	58
Norway (n=68)	91	94	94	95	94	78	30	88	75
Chile (n=48)	78	72	83	64	38	55	22	46	8
Italy (n=572)	77	70	77	60	31	60	16	65	15
Mexico (n=144)	73	52	59	43	41	53	29	16	13
Argentina (n=337)	54	53	55	48	35	58	8	36	12
Spain (n=213)	64	63	43	56	34	45	7	45	12

KEY	Practice is widespread, reported by $\geq 80\%$ parents	Practice is common, reported by 50-79% parents	Practice is frequent, reported by 25-49% parents	Practice is occasional; reported by 10-24% parents	Practice is rare; reported by $< 10\%$ parents
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TABLE 3: FREQUENCY DISTRIBUTION OF 9 BEREAVEMENT CARE PRACTICES OFFERED AFTER STILLBIRTH (% of 15 COUNTRIES)

DOMAIN	ACKNOWLEDGEMENT OF PARENTHOOD	SHARED DECISION-	EFFECTIVE SUPPORT
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		OPPORTUNITY TO:							MAKING	
PRACTICE	NAME BABY	SEE AND HOLD BABY	FUNERAL (OR OTHER SERVICE OR CEREMONY)	SPEND TIME WITH YOUR BABY	CREATE MEMORIES OF BABY	FAMILY MEMBERS / FRIENDS TO MEET BABY	TAKE BABY HOME	INFORMATION ABOUT AUTOPSY	RECEIVE A FOLLOW-UP CALL OR VISIT	
	F	WIDESPREAD (>80% reported)	10 (67%)	10 (67%)	11 (73%)	10 (67%)	10 (67%)			7 (47%)
R	COMMON (50-79% reported)	5 (33%)	5 (33%)	3 (20%)	3 (20%)	0	7 (47%)	0	6 (40%)	7 (47%)
E	FREQUENT (25-49% reported)	0	0	1 (7%)	2 (13%)	5 (33%)	1 (7%)	3 (20%)	2 (13%)	0
Q	OCCASIONAL (10-24% reported)	0	0	0	0	0	0	5 (33%)	1 (7%)	3 (20%)
U										
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N										
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FIGURE 1: Framework for the practice of respectful and supportive perinatal bereavement care

