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Parent engagement in perinatal mortality reviews: An online survey of clinicians from six high income countries

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Running title:

Parent engagement in perinatal mortality reviews

ABSTRACT

Objective

Parent engagement in perinatal mortality review meetings following stillbirth may benefit parents and improve patient safety. We investigated perinatal mortality review meeting practices, including the extent of parent engagement, based on self-reports from health care professionals from maternity care facilities in six high income countries.

Design

Cross-sectional online survey

Setting

Australia; New Zealand; United Kingdom; Ireland; United States; and Canada.

Population

A total of 1,104 health care professionals, comprising mainly obstetricians, gynaecologists, midwives and nurses.

Methods

Data were drawn from responses to a survey covering stillbirth-related topics. Open- and closed-items that focused on “Data quality on causes of stillbirth” were analysed.

Main Outcome Measures

Health care professionals’ self-reported practices around perinatal mortality review meetings following stillbirth.

Results

Most clinicians (81.0%) were aware of regular audit meetings to review stillbirth at their maternity facility, although this was true for only 35.5% of US respondents. For 854 respondents whose facility held regular meetings, less than a third (31.1%) reported some form of parent engagement, although this was usually as one-way post-meeting feedback. Across all six countries, only 17.1% of respondents described an explicit approach where parents provided input, received feedback and were represented at meetings.

Conclusions

We found no established practice of involving parents in the perinatal mortality review process in six high income countries. Parent engagement may hold the key to important lessons for stillbirth prevention and care. Further understanding of approaches, barriers and enablers is warranted.

Funding:

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Bereavement care; Stillbirth; Perinatal mortality review; Parent engagement

Tweetable abstract:

Parent engagement in mortality review after stillbirth is rare based on data from 6 countries. We need to understand the barriers.

Accepted Article

INTRODUCTION

Parent engagement in the perinatal mortality review process following stillbirth or newborn death is strongly advocated by bereaved parents, their support organisations, and many health care professionals yet there has been little formal study of the process. A small qualitative study in the United Kingdom (UK) reported that while parents were frequently unaware that a review of their baby's death took place, many would welcome the option to engage in a perinatal mortality review process that provided feedback to them on the outcomes and lessons learned (PARENTS1 study).¹ A possible corollary is that not being involved in or informed of the outcomes of a perinatal mortality review may be a source of parent distress or its exacerbation.

Using a Delphi exercise with experts and stakeholders in bereavement care across the UK, the follow-up PARENTS2 study undertook to establish a national consensus around a robust process of parent engagement in perinatal mortality reviews based on the Perinatal Mortality Review Tool (PMRT)² that was subsequently piloted in two maternity units.^{3,4}

Involving parents in perinatal mortality reviews has potential benefits. The process could potentially help parents process their experiences and help to meet the information needs of parents with a strong desire to know what caused their baby's death. Information from parents may also help health services to improve patient safety and health care quality. In Australia and New Zealand (NZ) national guidelines recommend that all hospitals where births occur should implement a formal process for perinatal mortality audit of all perinatal deaths.⁵ However, to our knowledge, there has been no exploration of the role of parents in perinatal mortality review processes in many countries, including Australia, NZ and North America. A recent review of best practice for mortality and morbidity reviews (MMRs) across various health care settings showed wide variation in their conduct but made no mention of patient or consumer engagement.⁶

Questions about perinatal mortality review processes including parent engagement were included in a comparative cross-country online survey. This study explored clinicians' responses to these questions to gain understanding of current practices in six high income countries: Australia; NZ; UK; Ireland; United States (US); and Canada.

METHODS

Data are from a multi-country online survey conducted for the Lancet Ending Preventable Stillbirths series between December 2014 and February 2015 (see Flenady et al. (2016) for detailed methods).⁷ The survey comprised a suite of three questionnaires designed to elicit responses regarding the experience of

stillbirth from the perspectives of parents, clinicians and the wider community. The questionnaires aimed to assess: stillbirth prevention practices; awareness of risk factors related to stillbirth; quality of pregnancy, labour and bereavement care; stillbirth investigations and audits; classification of stillbirths; and research and action priorities. No core outcome sets currently exist in this area of research. Parents were involved throughout the study. Eight representatives from parent organisations in Australia, Japan, NZ and the UK were included in the *Lancet Stillbirths In High-Income Countries Investigator Group*⁷ and parent-based member organisations of the International Stillbirth Alliance (ISA)⁸ distributed surveys to parents. An invitation to participate and link to the online questionnaire for clinicians was distributed via member organisations of the ISA, the International Confederation of Midwives, International Federation of Gynaecology and Obstetrics and other relevant national professional societies. Data from the clinician survey are presented here. Funding and infrastructure support for the study was provided by the University of Queensland's Mater Research Institute.

The intention was to reach a large group of clinicians, but it was not possible to ascertain the number of clinicians who received survey invitations or the corresponding response rate. The questionnaire included a section on "Data quality on causes of stillbirth". Respondents were asked: *Are regular perinatal audit meetings held at your health facility to review stillbirths? (Yes/No/Unsure)*. Those who replied Yes were asked: *In what ways, if any, are parents involved in the audit process? e.g., are parents informed of the process, encouraged to submit questions, do they receive feedback from formal review?*

Responses to these questions were analysed for six countries where clinician responses were provided in English. Frequencies were calculated using SPSS v 24⁹ to describe participant characteristics, their health care facilities and whether regular perinatal audit meetings were held. Where criteria were met, a chi-squared test was used to compare the observed frequencies of responses between countries to confirm whether differences were statistically significant. Open-text data were transferred to Microsoft Excel for coding and analysis. Open-text responses were read carefully and organised into a smaller set of thematic categories using an inductive approach led by FB and DH. These categories were reviewed and agreed by all co-authors. Responses that were ambiguous or did not readily fall into the coding categories were discussed. This content analysis¹⁰ allowed us to quantify responses, and to compare the frequency of their occurrence between countries.

Details of ethics approval

This study was approved by the Mater Health Services Human Research Ethics Committee on 29 November 2013 (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).

RESULTS

Description of participants and their health care facilities

In total, 2,137 health care professionals from more than 40 countries completed the online survey of whom 1,104 were from Australia, NZ, UK, Ireland, US or Canada (Table 1). The majority were from Australia (47.0%; n=519) with smaller numbers from the UK (17.2%; n=195), Canada (13.4%; n=148), NZ (10.8%; n=119), the US (9.2%; n=102), and Ireland (1.9%; n=21).

There was significant difference between countries in terms of the respondents' disciplinary background, facility location and level of care provided by their facility (Table 1). Overall, the disciplinary background of respondents was evenly distributed between obstetrics or gynaecology (47.0%; n=519) and midwifery or nursing (46.4%; n=512). Respondents from Australia and the US included a higher proportion of obstetricians and gynaecologists than midwives and nurses, while for Ireland and Canada most respondents were midwives and nurses.

The majority of respondents from each country were based in metropolitan locations (64.6% overall, range 50.0 to 79.4%). Apart from Canada, where nearly half of respondents were from facilities with less than 1,000 births per year (48.6%), most respondents worked in facilities with at least 2,000 births per year. Respondents from Australia, NZ and the UK reported similar distributions in terms of the level of care.

Tertiary care was most commonly reported and accounted for half of those from NZ (51.3%). The majority of respondents from the US and Ireland worked in tertiary care (69.6-76.2%) compared with only 20.9% of Canadian respondents.

TABLE 1 HERE

Regular perinatal audit meetings

The extent to which regular perinatal audit meetings were held to review stillbirths at health facilities is shown in Table 2. This question was only asked of respondents with a clinical discipline who were invited to complete the section of the survey on "Data quality on causes of stillbirth". Most respondents from Australia, NZ, the UK and Ireland were aware of regular audit meetings. Only 35.5% of US respondents indicated that regular audit meetings were held while the remainder were unsure or unaware of such meetings.

TABLE 2 HERE

Types of parent engagement in perinatal mortality reviews

A follow-up free-text question for respondents whose health facility held regular perinatal audit meetings to review stillbirths asked: *In what ways, if any, are parents involved in the audit process?* If parents had no involvement, respondents were asked to enter “none”. Responses, which ranged from a single word to several sentences, were coded into five main categories (Table 3). These are discussed below using exemplar quotes accompanied by the respondent’s discipline, country, and their facility’s level of care.

TABLE 3 HERE

Although the distribution of responses varied across the six countries (Table 3), overall less than a third of clinicians (31.1%) reported some form of parent engagement:

Parents are not involved in the audit [Midwife, UK, tertiary care]

They are not involved at all [Midwife, Canada, primary care]

They are generally not involved [Midwife, US, primary care]

Parents often were not made aware that meetings took place:

As far as I know parents are unaware of the process [Midwife, Australia, secondary care]

Parents are not informed of our perinatal mortality meetings [Midwife, NZ, tertiary care]

To my knowledge the parents are not informed of the process, they aren't encouraged to submit questions and they definitely don't receive feedback. [Midwife, Australia, secondary care]

The large majority of respondents from the US and Canada (around 80%) compared with around two-thirds of respondents in Australia, the UK and Ireland and less than half (47%) in NZ reported either no parent engagement or uncertainty about such engagement.

Responses highlighted the clinician-focus of their perinatal mortality review meetings, describing them as not designed for parent involvement, with occasional reference to medico-legal aspects:

Parents are informed of the process, but the meetings are legally protected and are mostly for review of clinical care and any learnings the providers may have. We sometimes have findings that are relevant to the parents and the parents would be informed of these findings by their provider in that case. [Midwife, US, secondary care]

Not sure but I don't think parents are involved as it is a general process involving all cases at once.
[Midwife, Canada, primary care]

No feedback is given to parents as these are closed meetings. All cases discussed are unidentified and learning points are from the discussion rather than the individual case. [Midwife, NZ, tertiary care]

Feedback to parents

The most frequently mentioned form of parent engagement was receiving feedback following the review via a separate follow-up meeting offered to parents. Responses indicated that feedback to parents after the meeting was often routine practice and may be part of a hospital's open disclosure policy:

Parents receive feedback on the discussion of their case when they return to the Bereavement Clinic for follow up and results [Midwife, Ireland, tertiary care]

A review meeting is held with parents during which the outcome and plan for future pregnancy is discussed [Obstetrician, UK, secondary care]

They receive feedback when invited to attend an appointment after the meeting is held
[Obstetrician, NZ, tertiary care]

Parents are not directly involved in M and M meeting or perinatal mortality review committee but staff involved in patient care are at M and M and have follow up discussions with family.
[Pathologist, Australia, tertiary care]

Open disclosure - results of review provided to parents at follow up visit - autopsy and pathology results reviewed - planning for care of subsequent pregnancies commenced [Midwife, Australia, secondary care]

Some respondents who indicated that feedback to parents was available also indicated that parents were told about the meeting beforehand:

Informed of the process and given opportunity for feedback after the meeting/discussion with other clinicians [Obstetrician, Australia, tertiary care]

Parents are made aware that the case will be reviewed. Feedback is provided to the parents following the review. [Midwife, Canada, primary care]

Parents are informed a review takes place and can be shared with them [Midwife, UK, secondary care]

However, responses were sometimes qualified, suggesting that parents may only be given feedback if they requested it:

Not directly, sometimes if they request it the findings will be discussed with the parents afterwards [Midwife, Australia, secondary care]

Only if complaints or comments [Obstetrician, US, secondary care]

They get feedback if the case involves a formal high level investigation [Obstetrician, UK, tertiary care]

Whether parents received information about review meetings, or feedback, may depend on the circumstances surrounding the death, or on their health care provider:

In unexpected unexplained stillbirths the hospital may choose to do an investigation using a root cause analysis methodology. The family will be asked their opinion of their care. The findings and recommendations of the committee are discussed with them. [Obstetrician, NZ, tertiary care]

Depending on the individual case [Midwife, Ireland, secondary care]

Depends on the care provider - some ask if parents have comments or questions, others don't involve parents [Obstetrician, Australia, secondary care]

Higher levels of parent engagement

Higher levels of parent engagement were rarely reported. Only one in twenty respondents across professions described an explicit approach to engaging parents. These included opportunities for parents to provide input to the review, to receive formal feedback from the review, or occasionally attend the review meeting:

Given the opportunity to ask questions, receive feedback from a review or offered debrief with the team [Midwife, NZ, tertiary care]

Parents informed of the process, encouraged to submit questions, they receive feedback from formal review [Obstetrician, NZ, tertiary care]

Parents informed of the process. Pathology and formal review is reviewed with the parents.

Parental questions can be forwarded to the review committee [Family Physician, Canada, secondary care]

Parents are informed, invited to submit questions. They are offered the investigation report. They have a debrief with a consultant Obstetrician. [UK, Obstetrician, secondary care]

Parents informed of the process, encouraged to submit questions, they receive feedback from formal review [Midwife, Canada, secondary care]

I think there has been occasion when bereaved families have been asked to address the meeting to give their thoughts/opinions on how the situation was handled and their experiences [Midwife, Australia, not stated]

A small number of responses indicated that parents' views were more formally integrated into review meetings. This usually occurred via an advocate for the parents, such as a health care professional who asked questions on behalf of the parents, or through a consumer representative at the review meeting, rather than the parents themselves attending:

There is a consumer representative on the investigation committees. Some facilities enable parents to participate in the mortality reviews. Most facilities feedback the discussion and outcome to the parents. [Midwife, NZ, tertiary care]

The parents are involved with us, in the birthing center but not during the analysis of the file during the perinatal committee. They are however invited to send their questions, the midwife responsible for follow-up will make sure to send them the answer [Midwife, Canada, primary care]

We are actively seeking patient representation on the committee [Obstetrician, Australia, tertiary care]

DISCUSSION

Main findings

We found no established practice of involving parents in the perinatal mortality review process in six high income countries (Australia, NZ, UK, Ireland, US, Canada). Variation in practices was evident across countries, health facilities, and care providers. Parent engagement was rarely reported as a routine feature of perinatal mortality reviews. With few exceptions, when it occurred, parent engagement was

confined largely to a passive role where health professionals provided information to parents after the review.

Only a small number of respondents indicated that parents were invited to provide input or submit questions to reviews at their facility and it is likely that many parents, as subsequently found in the PARENTS1 Study,¹ are not made aware of a review prior to its occurrence, if at all. With less than a third of respondents in our study reporting parent involvement in a review (31.1%), and the large proportion of involvement associated with feedback after the review occurred (82.9%) the findings of the PARENTS1 Study are not surprising.

Strengths and limitations

Our large sample of responses from more than 1,000 maternity care providers in six countries provides a snapshot of practice around parent engagement in perinatal mortality reviews and offers a baseline for assessing the impact of recent initiatives to enhance parent engagement. Study limitations include potential sample bias and the nature of the available data. Findings need to be interpreted carefully as health systems differ and there is bias within and among countries with regard to both respondent and facility characteristics. It is difficult to determine the extent of sample bias due to the recruitment process, however it is reasonable to assume that respondents represent those with interest and experience in stillbirth. This, together with a high representation of large tertiary hospitals, suggests that our data capture a broad picture of parent engagement in perinatal mortality reviews. Mortality reviews and parent involvement in reviews may be even lower in lower volume hospitals.

Open-ended survey responses have limitations as, unlike qualitative methods such as interviews, clarification or elaboration is not possible. Some responses were difficult to interpret due to lack of contextual information. Also, since we did not ask all respondents directly about particular aspects (e.g., are parents informed of the review process), our data rely on spontaneous mention of these topics and may under-estimate how commonly they occur. It is also possible that the term *perinatal audit meeting* may not have been interpreted in the same way by all respondents. Asking respondents to enter “none” helped guard against missing responses. Data were collected in 2014-2015 and some changes in practice may have occurred since. However, the most recent data available from the UK, where there has been considerable emphasis placed on parent engagement, suggests that improvements may only be gradual.¹¹

Interpretation

When a baby is stillborn, parents generally place high value on information about the causes of and contributors to their baby's death.^{12,13} This includes being involved in review processes to the extent they

wish⁴ but this is often not their experience. The Royal College of Obstetricians and Gynaecologists Each Baby Counts report (2018)¹¹ found that in 22% of local reviews in 2016, parents were neither involved in reviews nor made aware that a review was taking place. In 37% of reviews parents were merely made aware of the review and/or informed of the outcome; in only 41% of reviews were parents invited to contribute to the review if they wished. Similar data are not available for other countries included in this study and we are not aware of data available elsewhere.

Studies in the UK with parents¹ and clinicians⁴ found agreement that parents should have opportunities to give feedback on good and poor aspects of their care. These studies (PARENTS portfolio)^{1,3,4} also produced 12 core principles of parent engagement in the perinatal mortality review process that focus on providing information to parents about the review process; how to obtain feedback and support parents; who should represent the parents at review meetings; the outputs of meetings (including action plans for lessons learnt and plain-English summaries); and how to follow up with parents. Piloting and evaluating these recommendations are important, as is establishing their applicability and making necessary adaptations for other country settings.

The PMRT, launched in the UK in 2018, was designed to support active communication with parents by ensuring that parents are told that a review of their care and their baby's death will occur and how they can contribute to the process.² However, the tool has yet to be universally adopted and parent involvement in reviews remains inconsistent across different countries.¹⁴ Barriers to parent engagement are likely to vary according to health system contexts. In the US, for example, the low frequency of perinatal review meetings is notable, and issues related to cost and fear of litigation may be important.

Our findings suggest that there is considerable opportunity to improve parent involvement in stillbirth audits in high resource countries and that tools such as the PMRT may be well-received. While higher level forms of engagement that incorporated similar principles were rare, it is notable that some clinicians across the six countries in this study described explicit approaches to facilitate parent engagement even though our survey preceded the availability of such a tool.

The processes arising from the PARENTS portfolio^{1,3,4} were piloted in two UK maternity units where strong endorsement was found for empowering parents to ask questions, to provide feedback on care and to provide opportunity to discuss a review's outcome. However, despite the recommendation for national roll-out, implementation has been hampered as parent engagement in perinatal mortality reviews adds to an already resource-intensive process. In addition, the support and commitment of all stakeholders is yet to be established. Further understanding of potential benefits and possible harms is needed.

In Australia, parent engagement in perinatal morality review relates to broader open disclosure practices, where opportunities for patients and/or family members to present their perspectives and the impact of an adverse event are an integral part of the health system.¹⁵ Enabling families to ask questions, express their concerns and to have them addressed is challenging. An evidence-based approach to reform in this area is needed.¹⁶

Conclusion

Perinatal mortality reviews can drive health care improvement, but might not always achieve their stated aims, particularly if parents are not engaged. Parent narratives may hold the key to important lessons for prevention and care and their engagement may promote transparency.

Consideration of barriers and enablers to parent engagement and assessment of longer-term consequences, both intended and unintended, is warranted. Cross-country comparisons offer opportunities to identify and overcome different barriers.

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Disclosure of Interests

The authors have no relevant interests or conflicts to declare. Completed disclosure of interest forms are available to view online as supporting information.

Contribution to Authorship

FB and DH conceptualised the work and led the analysis of data. All authors (FB, DH, DS, CB, DB, RS, and VF) contributed to the interpretation of data. FB and DH drafted the manuscript and all authors (FB, DH, DS, CB, DB, RS, and VF) critically revised the manuscript and approved the version to be published.

Details of Ethics Approval

This study was approved by the Mater Health Services Human Research Ethics Committee on 29 November 2013 (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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- Accepted Article
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Table 1: Characteristics of 1,104 respondents and their health care facilities – number (and percent) in each of six countries

	Total n=1,104	Australia n=519	NZ n=119	UK n=195	Ireland n=21	US N=102	Canada n=148	χ^2 p value
<i>Discipline</i>								
Obstetrics or Gynaecology	519 (47.0)	299 (57.6)	57 (47.9)	89 (45.6)	3 (14.3)	69 (67.6)	2 (1.4)	199.72
Midwifery or Nursing	512 (46.4)	193 (37.2)	58 (48.7)	98 (50.3)	17 (81.0)	18 (17.7)	128 (86.5)	<0.0001
Other*	73 (6.6)	27 (5.1)	4 (3.3)	8 (4.1)	1 (4.8)	15 (14.8)	18 (12.2)	
<i>Facility location¹</i>								
Metropolitan	713 (64.6)	347 (66.9)	76 (63.9)	119 (61.0)	16 (76.2)	81 (79.4)	74 (50.0)	27.08
Non-metropolitan	390 (35.4)	172 (33.1)	42 (35.6)	76 (39.0)	5 (23.8)	21 (20.6)	74 (50.0)	<0.0001
<i>Births per year¹</i>								
<100	42 (3.8)	12 (2.4)	7 (5.8)	3 (1.5)	1 (4.8)	7 (6.8)	12 (8.1)	N/A
100-999	195 (17.7)	110 (21.2)	12 (10.1)	4 (2.1)	--	9 (8.8)	60 (40.5)	
1000-1999	147 (13.3)	83 (16.0)	29 (24.4)	3 (1.5)	--	14 (13.7)	18 (12.2)	
2000-4999	378 (34.2)	178 (34.3)	24 (20.2)	85 (43.6)	6 (28.6)	49 (48.0)	36 (24.3)	
5000+	320 (29.0)	125 (24.1)	43 (36.1)	100 (51.3)	14 (66.7)	20 (19.6)	18 (12.2)	
<i>Level of care¹</i>								
Primary care	215 (19.5)	62 (11.9)	11 (9.2)	43 (22.1)	3 (14.3)	17 (16.7)	79 (53.4)	178.1
Secondary care	367 (33.2)	210 (40.5)	47 (39.5)	60 (30.8)	2 (9.5)	13 (12.7)	35 (23.6)	<0.0001

Tertiary care	497 (45.0)	235 (45.3)	61 (51.3)	83 (42.6)	16 (76.2)	71 (69.6)	31 (20.9)
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*Other includes clinical (e.g., pathologists; neonatologists; family physicians) and non-clinical (e.g., social workers; pastoral care) disciplines

¹Excludes non-answers and unsure (n ranges from 10 to 22)

Table 2: Occurrence of perinatal mortality review meetings to review stillbirths by country – number (and percent) in each of six countries¹

	Total n=1,061	Australia n=500	NZ n=116	UK n=192	Ireland n=20	US n=93	Canada n=140	χ^2 p value
<i>Regular meetings</i>								
Yes	859 (81.0)	436 (87.2)	111 (95.7)	165 (85.9)	17 (85.0)	33 (35.5)	97 (69.3)	169.4 <0.0001
No/unsure	202 (19.0)	64 (12.8)	5 (4.3)	27 (14.1)	3 (15.0)	60 (64.5)	43 (30.7)	

¹ Excludes not asked when question did not apply to respondents from non-clinical disciplines (n=42) and non-answers (n=1)

Table 3: Summary of open-ended responses regarding parent engagement in perinatal mortality reviews – number (and percent) in each of six countries¹

Parent engagement	Australia n=421	NZ n=109	UK n=160	Ireland n=15	US n=33	Canada n=92	Total N=830	χ^2 p value
None/ Unsure/don't know	304 (72.2)	52 (47.7)	102 (63.8)	12 (80.0)	26 (78.8)	77 (83.7)	573 (69.0)	38.8 <0.0001
Engagement occurs	117 (27.8)	57 (52.3)	58 (36.3)	3 (20.0)	7 (21.2)	15 (16.3)	257 (31.0)	
Type of engagement								
Feedback after review	98 (83.8)	49 (86.0)	47 (81.0)	3 (100)	6 (85.7)	10 (66.7)	213 (82.9)	N/A
Higher level	19 (16.2)	8 (14.0)	11 (19.0)	0 (--)	1 (14.3)	5 (33.3)	44 (17.1)	

¹excludes other, difficult to interpret, out-of-scope (n=24) and missing (n=2)