

BMJ Open PARENTS 2 Study: a qualitative study of the views of healthcare professionals and stakeholders on parental engagement in the perinatal mortality review – from ‘bottom of the pile’ to joint learning

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ABSTRACT

Objective Engaging bereaved parents in the review process that examines their care before and after a perinatal death might help parents deal with their grief more effectively and drive improvements in patient safety. The objective of this study is to explore whether healthcare professionals would accept or support parent engagement in the perinatal mortality review process.

Design Qualitative focus group interviews. Transcripts were analysed with an inductive thematic approach.

Setting Two geographically distinct tertiary maternity hospitals in the UK.

Participants Five focus groups were conducted with clinical staff including midwives, obstetricians, neonatologists, nursing staff and chaplaincy services.

Results Twenty-seven healthcare professionals unanimously agreed that parents’ involvement in the perinatal mortality review process is useful and necessary. Six key themes emerged including: parental engagement; need for formal follow-up; critical structure of perinatal mortality review meeting; coordination and streamlining of care; advocacy for parents including role of the bereavement care lead; and requirement for training and support for staff to enable parental engagement.

Conclusions Healthcare professionals strongly advocated engaging bereaved parents in the perinatal mortality review: empowering parents to ask questions, providing feedback on care, helping generate lessons and providing them with the opportunity to discuss a summary of the review conclusions with their primary healthcare professional contact. The participants agreed it is time to move on from ‘a group of doctors reviewing notes’ to active learning and improvement together with parents, to enable better care and prevention of perinatal death.

INTRODUCTION

In the UK, more than 5000 babies per year die before or shortly after birth (stillbirth and neonatal death),¹ with 15 families affected by the death of their baby every

Strengths and limitations of this study

- This is the first study, to our knowledge, to investigate the views of healthcare professionals on implementing parental engagement in the perinatal mortality review process.
- A diverse range of health professionals across two geographically different hospital sites in the UK were sampled.
- In-depth focus group interviews were conducted, and data were analysed using robust qualitative methodology.
- A bereaved parent and coinvestigator was involved in the study design, topic guide for interviews and data analysis for the *Parents’ Active Role and ENgagement in The review of their Stillbirth/perinatal death 2 Study*, strengthening the research findings.
- Limitations of this study include: only sampling healthcare professionals from UK tertiary maternity units, potential selection bias and limited stakeholder representation.

day.¹ Following the loss of a baby, a systematic, multidisciplinary review of the circumstances surrounding the stillbirth or neonatal death should take place (perinatal mortality review). This structured process should incorporate an evaluation of the medical notes, clinical investigations, input from the clinicians involved in the case and the views of the parents to help to gain a clearer understanding of why each baby died.

Evidence from a recent confidential enquiry of 225 perinatal deaths (2017) found that nearly half of reviews were of poor quality and in only 7% of cases were parents actively involved.² Furthermore, the Mid-Stafordshire public enquiry³ and Care Quality

Commission report⁴ found that learning from these deaths was not being given enough priority in some hospitals, and valuable learning opportunities for improvement were being missed.⁵ It has been debated that there is more we could do to engage families so that learning could be achieved by gaining insights into their care.⁵ Subsequently, the National Quality Board published its first guidance on 'Learning from Deaths' in March 2017,⁵ which is applicable to maternity but across all specialities (including acute, community and mental health trusts), whenever there has been any concern about the care surrounding patient death(s). The guidance underlines how learning from the care of those who die should be integral to clinical governance and quality improvement and why a clear policy for parental engagement should be a top priority.⁵

Research from a large focus group of bereaved parents who had experienced a stillbirth or neonatal death (*Parents' Active Role and ENgagement in The review of their Stillbirth/perinatal death 1* (PARENTS 1) study) demonstrated that most parents want the opportunity to provide input in the perinatal mortality review.⁶ Parental engagement may provide additional perspectives and insights and drive improvement in patient safety and healthcare quality.⁷ Involving parents in the investigation process promptly, fully and compassionately could also help them cope better with their grief, as mounting evidence indicates that good care at and around the perinatal death can positively influence outcomes for parents.^{8–11} Moreover, ensuring the investigation is comprehensive and transparent could potentially help prevent events escalating to formal complaints and legal claims. However, how best to involve parents in the review process has not been examined and is likely to involve many challenges.

One challenge is consideration of the impact on healthcare professionals. There is mounting evidence demonstrating the effect of perinatal death on doctors, midwives and nurses, yet support for staff is often minimal.^{12–13} Staff may experience grief, self-blame, depression and self-doubt.¹⁴ The long-term consequences include post-traumatic stress and even risk of suicide, often triggered by the pressure of litigation.^{15–19} Additionally, financial and organisational issues may also impact the engagement of parents in the review process, which likely requires support and 'buy-in' from stakeholders (including but not limited to government, commissioners, managers and clinicians) throughout the whole process.

It is important to note we did not expect parents to attend the perinatal mortality review meeting, however for them to be actively engaged and provide optional input or feedback about the care they have received in the antenatal and postnatal period (including care received in the neonatal intensive care unit), which could be addressed during the review process. To effectively integrate a standardised perinatal mortality review process with parental engagement, the views and experiences of staff and stakeholders need to be considered. This study aimed to explore the perceptions

of healthcare professionals and other key stakeholders on the engagement of parents in the perinatal mortality review.

METHODS

The study methods have been published in detail in the full *Parents' Active Role and ENgagement in The review of their Stillbirth/perinatal death 2* (PARENTS 2) protocol.²⁰

Setting

Location

Five focus groups took place in two different tertiary maternity hospitals in the UK: North Bristol NHS Trust (NBT; Bristol, UK) and three focus groups at Manchester University Foundation NHS Trust (MFT; Manchester, UK). NBT is situated in the southwest of England and has over 6000 births per year. In contrast, MFT is situated in the northwest of England and is a very large maternity unit with 8750 per year. Both units have level three neonatal intensive care units that provide care for babies born at less than 28 weeks' gestation, needing significant respiratory support or weighing less than 1000 g. These sites were chosen due to the differing geographic location and variation in ethnic demographic of each population.

Standard perinatal mortality review process and follow-up

In both NBT and MFT, the perinatal mortality review meeting typically takes place between 8 and 12 weeks following the stillbirth or neonatal death, once the postmortem and other clinical investigations have been reported. The review includes discussion of all antenatal deaths above 22 weeks' gestation and all neonatal deaths within 28 days of birth with the multiprofessional team including obstetricians, midwives, neonatologists and neonatal nurses. This review runs alongside the Child Death Review for neonatal deaths, which is a statutory process that must be complied with the death of all children, of any age and from any cause in the UK.²¹ At present, there is no similar national statutory guidance for deaths before birth. Prior to the PARENTS 2 Study taking place, there was significant variation in when the consultant follow-up with the consultant or neonatologist would take place at both NBT and MFT, often being held with the parents prior to the perinatal mortality review process taking place. This would mean that not all information would be available to inform the discussion within the consultation, and parents were not made aware of the subsequent perinatal mortality review meeting.

Participant selection and recruitment

We aimed to recruit 5–10 healthcare professionals per focus group; however, due to participant availability, we held three smaller focus groups in MFT. Participants were purposively selected to ensure a diverse range of healthcare professional and stakeholder viewpoints from different specialties, roles and experience levels. We approached midwives, consultant obstetricians and neonatologists, trainee doctors from obstetric

and neonatal specialties, nursing staff, the director of midwifery, the clinical director and chaplaincy services in each hospital. Healthcare professionals and stakeholders were informed of the study by an introductory email and information leaflet at each unit and were subsequently approached face to face by the research midwife at each site. The number approached declining to participate was documented.

Research team and reflexivity

The authors (CB, DS, CS, ML and DB) who are experienced in qualitative interviewing conducted and facilitated the focus group discussions. CB, DS, ML and DB are colleagues of the healthcare professionals at the NBT site. CB is a female postdoctorate research fellow (MD), DS is a male consultant senior lecturer (MD), ML is a female experienced bereavement research midwife and DB is a female clinical research fellow. CS is a female external research associate with personal experience of perinatal death who cofacilitated discussions at both NBT and MFT. No one else was present besides the participants and researchers. The participants were made aware of the role of the researchers and goals of the research before each focus group.

Data collection and setting

Semistructured focus groups lasting up to 90 min took place with clinical staff and stakeholders. A focus group schedule was developed in collaboration with the PARENTS 2 Study Project Advisory Board (see online supplementary file 1) and was based on findings of the previous PARENTS 1 Study.⁶ Focus groups were organised to enable as many staff as possible to attend and took place in a meeting room separate from the clinical environment.

Participants were informed of the context, specifically that the final expectation of perinatal mortality review process was not for parents to attend the perinatal mortality review meeting itself, but parental feedback would be sought in verbal or written communication format to input into the meeting. After a brief introduction, the first part of the discussion focused on the current perinatal mortality review practice at the hospital and the second part allowed participants to discuss how to engage bereaved parents in the perinatal mortality review process and to raise concerns about participation. Field notes were kept to interpret the data in context. Transcripts were returned to a subsample of participants for correction and/or comment for internal validation of the results.

Data management and analysis

The audio recordings of the focus group interviews were transcribed verbatim and stored and analysed using NVivo 10 software. The focus group data were analysed using 'Inductive Thematic Analysis' technique described by Braun and Clark.²² This is a six-stage process: familiarisation with the data; generation of initial codes; searching for themes; reviewing themes; defining themes; and naming themes. The transcripts were coded

independently in duplicate, while the wider members of the research team had the opportunity to read each focus group transcript. The resulting themes were discussed with the whole research team to enable cross-sectional analysis and agreement of themes. Furthermore, findings from interim data analyses were discussed in meetings of the Project Advisory Board and circulated to participants for validation. The purpose was to identify procedural issues, finalise the analysis, establish the credibility and applicability of the results, triangulate with other sources of evidence and combine the findings with the previous PARENTS 1 Study focus group.⁶

Ethical considerations

Focus group attendees were asked to provide written consent to be audio-recorded and for anonymised quotes to be used in reporting. Refreshments were provided; however, no other compensation was given for participation.

Patient involvement

Bereaved parents were instrumental to the initial study idea. The PARENTS 1 Study indicated the requirement for parental involvement in the review of perinatal deaths.⁶ A bereaved parent and coinvestigator was involved in the study design, topic guide for interviews and data analysis for the PARENTS 2 Study, strengthening the research findings. Furthermore, a bereaved parent also participated on the Project Advisory Board informing the direction of the research.

FINDINGS

Five focus group interviews took place between May and June 2017 (two focus groups were held at NBT and three focus groups were held at MFT). Data saturation was achieved by the fifth focus group. Twenty-seven participants were recruited into the focus group discussions. Five healthcare professionals declined to participate due to clinical commitments. The age range of participants was from mid-20s to 60 years. See online supplementary file 2 for participant demographics.

Following inductive thematic analysis, six key themes emerged including: parental engagement; need for formal follow-up; critical structure of perinatal mortality review meeting; coordination and streamlining of care; advocacy for parents including role of the bereavement care lead; and requirement for training and support for staff to enable parental engagement. A coding tree was produced, and the themes were well represented by quotes from participants. (See online supplementary files 3 and 4).

Parental engagement

The recognition of parental engagement as a priority

All participants agreed that parents should be involved in the perinatal mortality review process. However, participants debated the perceived priority of parental engagement in the perinatal mortality review process

at a departmental, hospital and national level. There was agreement in one discussion that *'we would all like to prioritise'* parental engagement, and if parental input was implemented, it should be a service that is universal and every parent can access. In another focus group, there were conflicting views whether bereavement care, including initiatives such as parental engagement in reviews, was a local Trust priority, and other issues were perceived locally as more important.

I can't speak from a Trust point of view, but I know on a ward basis then it is a lower priority unless they've recently just delivered. If they're a few hours later down the line or the next day, then they are at the *bottom of the pile*. (F1M1)

Participants identified the variation in bereavement care service provision across the UK as a barrier to implementation of parental engagement in the perinatal mortality review. Healthcare professionals recognised the importance of support from the government to ensure that parental input and support for families is implemented universally in every hospital.

I've just met a family not so long ago that had no bereavement care at all after the loss of their baby, and that worries me,... so they're not gonna get the same opportunity in a perinatal review as somebody at this hospital. (F1M1)

Benefits of parental engagement

Parental engagement could help inform the perinatal mortality review and lead to a better meeting according to participants. Obtaining the parents' perspective of events or the *'parental story'* was believed to be important to gain additional, clinically useful, information not documented in the medical notes, which could help address additional issues.

I don't know that they're happening or when they're happening. A lot of things get circulated within little groups. (F1M3)

Flexible yet specific process

Participants acknowledged different parental needs and felt parents should be made aware of the perinatal mortality review and offered the choice as to whether to be involved. It was apparent that not all parents know that formal meetings take place, according to health professionals participating in the focus groups. Participants believed a standard set of basic information about the purpose of the perinatal mortality review process should be given to parents; however, there should be the opportunity for personalisation according to the individual case.

[Y]ou can't get rid of the personalised touch, because actually, that's the bit that is meaningful to families, but there needs to be some kind of something, so that the same sort of information is going to the same (families)... (F1B1)

Inclusive

A subtheme that emerged was the need for inclusivity of the perinatal mortality review by which respondents identified the need to address feedback from partners and the wider family and feedback relating to both clinical and non-clinical care within the process. When discussing what questions parents might ask, healthcare professionals thought the reasoning behind decision making as opposed to the medical science would be brought up.

[T]he clear majority of the conversation is about what happened, and right down to the, 'Why did somebody say this to me? Why did I have this test done? Why didn't I have that test done? Why did...?' – rather than the real, medical. (F4B2)

Participants also noted that some parents might also want to give positive feedback to members of staff, which would be beneficial.

Obtaining feedback from parents

Discussions in the focus groups covered how to obtain feedback from parents, including the role of the consultant, the bereavement care midwife or nurse and the use of email and electronic devices such as smartphones. One participant also highlighted how parents might ask different questions depending on which healthcare professional they were speaking to.

But I think the questions they ask of different professional groups are different, because I think there's always the expectation on seeing a doctor that you should have a question that's bigger, almost, you know, that you should come prepared with, you know, a bigger question, whereas actually some of the questions that you get asked as a midwife are less big. (F1B5)

Challenges to parental engagement

Specific challenges of parental engagement were discussed including: how to approach parents asking excessive, unexpected or unanswerable questions or demanding additional investigations that were not medically indicated; how or whether to involve both parents when there are relationship issues or breakdowns; and how to involve vulnerable parents.

You have to be mindful of the whole family that you're involved with before too much information is put on a letter that goes to both parents, without really understanding the dynamic of what you're dealing with. (F1B2)

Parental engagement in the perinatal mortality review process was recognised by participants as a new process that could generate additional parent appointments, duties for a bereavement care midwife, administration and coordination time and support for parents, which would all translate into additional costs to the healthcare system. Healthcare professionals explained how

resources were currently limited and how certain services are already overloaded with work. Participants discussed potential solutions to minimise costs, including mapping local and shared services across cities and using existing resources and staff skillsets.

Another challenge to address, mentioned in one focus group, was improving communication between the obstetric and neonatal team, particularly when a baby was transferred to another Trust for further care, or when a baby had spent a protracted time on the neonatology unit.

They had a baby down in the Children's Hospital, very sick... there was an informal complaint and... you could just see the catalogue of lack of communication because of the movement from one unit to the other, and one Trust into another Trust... (F1B2)

...They get their NICU follow-up, but nobody talks to them about the fact that, 'Actually, you should come to the pre-term labour clinic next time round, and you need swabs for this, and you need potentially progesterone'. (F2B2)

Supporting parents through the process

Healthcare professionals recognised that participation in a review process could be stressful or upsetting and some parents would need short-term and long-term support. Information leaflets were mentioned, and key individuals identified that could facilitate supporting parents included the bereavement care midwife, lead clinician, general practitioner, chaplain or bereavement counsellor. Support groups were also identified as having a role in helping parents engage through the perinatal mortality review process. Setting a realistic timeline of when the perinatal mortality review meeting and the postnatal follow-up would take place, and communicating that to parents, were considered imperative to alleviate any 'false hope' or assurances.

I think, from the parents' perspective, they want to know the timeline, and if it's going to be an extended timeline to get the right answers for the future, then we should review at the beginning, because I think where we fall foul quite a lot is that we set these artificial, if you like, six week review – 'We're gonna see you then and we're gonna have everything back,' and we don't always have everything back... (F1B2)

The need for formalised follow-up

Timing of follow-up

At both hospitals, the perinatal mortality review meetings take place 8–12 weeks after the perinatal death after investigations to determine the cause of death are complete. There was variation within both hospitals as to whether the postnatal debriefing appointment with the consultant takes place before or after the perinatal mortality review meeting. Having the appointment too soon meant that not all the investigations such as the postmortem were available to discuss with parents and that it might have

been too soon for the parents to process any information and benefit from the follow-up.

I was like 'they're not going to process anything, you know to me it almost felt like they were being just pushed out of the – you know like 'well we've done it. We've done your postnatal, out you go, we've fulfilled our obligations... (Participant discussing postnatal appointment two weeks after discharge). (M1M1)

There was agreement among most participants that it was preferable to have the postnatal consultant appointment only after all the investigations had been formally reported and after the perinatal mortality review meeting had taken place, so that feedback could be discussed. A checklist was discussed as necessary to ensure healthcare professionals had all the information before parents. There was discussion around having two postnatal appointments with the parents: one interim appointment before the perinatal mortality review meeting, potentially with the bereavement care midwife or nurse, and one after the review meeting, with the consultant obstetrician or neonatologist. It was acknowledged that such an arrangement would avoid a long wait for parents between appointments yet would have cost and time implications to the service.

Consultant follow-up appointment

Obtaining parental feedback in advance of the postnatal consultation was viewed as advantageous by clinicians in the focus groups, as they could have a framework to initiate, set the tone and personalise the conversation with the parents. Receiving specific questions from parents would also facilitate the consultants feel more prepared for the postnatal review.

The issues are rather they sometimes want answers to questions that ... from our point of view as clinicians, come as a bit of a sideswipe, you know, you're thinking, 'Oh, crikey, I never thought about that. That never hit me.' (F3B2)

Critical structure of perinatal mortality review meeting

Role of the perinatal mortality review meeting

Attending the perinatal mortality review process has multiple purposes, according to the healthcare professionals interviewed including: following up on patients they had looked after, having an opportunity to debrief, facilitating the postnatal consultation, helping to prevent future perinatal deaths, improving care in general, informing training and learning for staff and enhancing professional development.

Multidisciplinary attendance

Participants recognised the importance of multidisciplinary attendance at the perinatal mortality meetings. Members of staff highlighted as important to attend included consultants, specialty trainee doctors, neonatologists, perinatal pathologists, ultrasonographers,

chaplaincy staff, community midwives and general practitioners. The pathologist was viewed as an important member of staff who should attend as they could discuss the findings, not just of the postmortem, but also of other histopathology and the placental biopsy and could help '*individually interpret the case*'.

It was important to participants to offer the midwife who is looking after individual parents to attend the perinatal mortality review meeting. Furthermore, it was discussed in one focus group that the perinatal mortality meeting was very '*doctor-focused*', and more midwifery representation was required to make the reviews more meaningful. When addressing questions parents might have, participants thought that midwives could potentially provide further answers about their general care that the doctor could not answer.

'cause some of them might not be doctor related, they might be just about their general care that they've received and getting... which you guys can't answer because you... (F1M1)

Weren't there... (F2M1)

... or you don't know the whole scope of it. (F1M1)

Healthcare professionals emphasised the importance of having dual input from the obstetricians and neonatologists during the review of a neonatal death, particularly when there had been an obstetric complication and the baby had spent a significant duration of time in the neonatal intensive care unit. One difference between NBT and MFT was that MFT had a separate meeting for stillbirths and a separate meeting for neonatal deaths. Overall, the consensus was that it was essential that all healthcare professionals that had looked after the parents and baby should be invited to contribute to the perinatal mortality review meeting.

Barriers to attendance

A subtheme that emerged was the existence of barriers to attendance at perinatal mortality review meetings. In both hospitals barriers included: being unaware the meetings are taking place; lack of communication to the wider staff groups; not having allocated time in job plans; having an increasing volume of clinical workload to attend; and staff shortages.

Every month we have a meeting in here about the unit. I've been here five years and I've never been able to go to one. (F1M2)

I don't know that they're happening or when they're happening. A lot of things get circulated within little groups. (F1M3)

At both units, staff mentioned they were '*too busy*' on the clinical shop floor to attend most of the time. When discussing holding the meetings during the lunch break, it was agreed there would be no time to attend.

And the problem is, we get a half-hour break between morning and afternoon sessions now, by the

way the Trust has stated things, but that half-hour break doesn't really exist, because by the time your clinic's overrun by 15 min ... you don't have a lunch break. (F1B2)

Participants thought that unless they were specifically allocated to attend the meeting on their off-duty or supported by managers to have the time to go, they were unable to attend. Those that could attend the meetings often had to go in their own time, out of professional obligation.

Current and historical process

Participants often referred to the current or historical structure of the perinatal mortality review meeting. It was mentioned that often not all cases are discussed at the meetings owing to time constraints. Therefore, if we were seeking parental engagement by asking parents to submit questions to the meeting, it is vital that their case should be discussed and their questions addressed, otherwise there was a risk of causing disappointment and harm. Participants in one focus group repeatedly mentioned '*the old days*' when suggesting improvements to the current structure of the perinatal mortality review meetings. They described that the meetings were previously held after working hours and were longer than currently.

Need for terms of reference

It became apparent during the focus groups that there was a need for terms of reference for parental engagement in the perinatal mortality review meetings. There were varying degrees of quality of review meetings being reported from '*very structured*' with multidisciplinary attendance to very '*ad-hoc*' with sparse attendance. Acknowledging that the parents' '*questions should be respected*' and having an open, blame-free culture was also thought to be important, and this was thought to be facilitated in one hospital by '*having close working relationship between consultants, doctors, management, midwives*'.

In addition, organisational adaptations were considered necessary to ensure that the process is robust and that staff are given enough notice to attend. Furthermore, that as outputs of the review, reports should be produced for parents and staff who had looked after those parents. A standardised written report was thought to have the added advantage of facilitating and supplementing the conversation with parents during the postnatal consultant appointment.

I think what the report from the perinatal mortality review meeting is to supplement your conversation with the parents, so you've got some factual pieces of information to help you with the conversation. (F1B2)

Facilitating learning from the review

Participants agreed that there could be additional information that we could learn from the review that we were not currently capturing, documenting and sharing with all members of staff and the parents.

And that can be a missed opportunity, can't it, because there's quite valuable debates that go on in the room, and I'm never confident how that's captured and translated out of that meeting. I think there's learning for the professionals in the room, but that's not captured and shared outside with the parents. (F1B2)

Furthermore, lessons learnt could translate to helping future families who experience a perinatal death.

Yeah, so it's whether we learn from the families that have been through that process as to what were the common theme questions that were the most important for families to get out of, to be able to help the other families. (F1M1)

Coordination and streamlining of care

Continuity and streamlining of care

Continuity of care from healthcare professionals was deemed crucial to obtain and discuss feedback from parental engagement in the perinatal mortality review meeting.

It's nice for them to have somebody that knows like their background because otherwise you go into different appointments with different people and you have to keep repeating yourselves... (F1M3)

One focus group highlighted how it was important for the clinician who had seen the parents the most to see them postnatally and not necessarily the clinician they had originally booked under. A streamlined, simplified process was also thought to be key to facilitate parental engagement in the process and improve communication between obstetricians and neonatologists.

Personnel to coordinate care

A lead person was thought to be crucial to help coordinate the perinatal mortality review process. That person was thought to be missing at one hospital Trust.

I think what is missing in this unit, from my knowledge over those many years, is that it is that gatekeeper, it is that person who holds that process, that just doesn't really exist here and does exist in other units. (F1B2)

Alongside the lead person, it was also important have a team or a number '*bereavement champions*' to help support the process in case of absences.

Advocacy for parents: role of the bereavement care lead (midwife or nurse)

A key member of staff that was identified as having a role in the coordination of parental engagement in the perinatal mortality review process and a '*point of contact*' for the parents was the bereavement care midwife or nurse. At one hospital where a previous member of staff had worked the bereavement midwife was described as the '*liaison person*' who would inform the parents of when the

review was taking place and would encourage parents to email any specific questions to her.

The bereavement care midwives interviewed in one focus group believed they were the best healthcare professionals to support parents through the review process as they know parents from the start, are the '*most comfortable*' with them and build '*close relationships with the parents*'.

I think they really trust us and I think they build very close bonds very quickly with somebody that is an absolute stranger. We are a stranger the first time we go into a room with a family – you know, you do take a breath – but I think, the information that they share with us very, very quickly is very powerful and very interesting information, that I think would help with a review like this. (F2M1)

They would also act as representatives for the parents in the perinatal mortality review process as they could '*bring the accounts of some of the families*'. Furthermore, it was having the dedicated title or role of a bereavement care midwife that enabled them to develop strong relationships with the parents.

Just the title of what you do. You're not a labour ward midwife, you're not a community midwife – you're there for that purpose of what they're going through at that time. (F1M1)

A requirement for training and support for staff to enable parental engagement

It became apparent from the focus groups that training in bereavement care and support would be required to facilitate parental engagement. For junior doctors, obtaining clinical experience in counselling parents who had experienced a perinatal death was often difficult unless they had been trained in fetal medicine, so they felt less confident in engaging parents. Obstetric consultants also wanted more training, for example, in postmortem report interpretation. Midwives were concerned about '*saying the wrong thing*'; they wanted support on the '*practicalities*' of parental engagement and thought that more junior midwives were required to be trained in bereavement care.

DISCUSSION

Principal findings and lessons

Healthcare professionals agreed parental engagement in the perinatal mortality review would be beneficial and could improve the quality of the review process and the safety of maternity care; it could help families in the future and potentially prevent perinatal deaths. However, the participants identified the need for support both locally from their hospital trusts and centrally from government to help address any challenges and implement parental engagement in a meaningful and practical way. The success of the perinatal mortality review was perceived as reliant on multidisciplinary input and on addressing

current barriers to attendance, such as increasing awareness of the meetings and incorporating the meeting into current job plans. Structural adaptations to the current perinatal mortality review format were also deemed necessary to incorporate parental engagement, including defining which cases to discuss and creating terms of reference. The lessons learnt from these meetings need to be formally captured and shared with all staff to ensure that the outcomes of the meetings are valuable and learning points are translated into clinical practice. Key facilitators to parental engagement were continuity of care, having a lead clinician and streamlining the parent pathway. An advocate (a bereavement care midwife/nurse or another parental representative) and a realistic timeline would help parents input into the review process.

Strengths and weaknesses

This is the first study, to our knowledge, to investigate the views of a diverse range of healthcare professionals on implementing parental engagement in the perinatal mortality review process. A study published in 2014 in Texas investigated the best way to incorporate patient engagement in the analysis of medical error events.²³ In line with our findings, six clinicians were interviewed and agreed that patients should be included in the adverse event analysis.²³ Similarly, they supported learning from the review and they believed that hospitals should give patients and families information about what changes will be implemented to prevent similar errors from happening in the future.²³ They also supported involving patients as being member of the healthcare team by them acting as 'safety advocates'.²³

We sampled a diverse range of health professionals for their views across two geographically different hospital sites in the UK and conducted in-depth focus group interviews that were analysed using robust qualitative methodology. A bereaved parent and coinvestigator was involved in the study design, topic guide for interviews and data analysis for the PARENTS 2 study, strengthening the research findings. Reassuringly, we found parallel themes and subthemes to the PARENTS 1 Study where the views of bereaved parents had been investigated⁶; parents had expressed the need for a flexible yet specific process, inclusivity, transparency and a positive process.⁶

A potential limitation was that we only sampled staff from UK tertiary maternity units. Views may be different in smaller, district general hospitals or among professionals in primary care. Furthermore, only 4 neonatal staff participated out of the 27 healthcare professionals; therefore, most of discussions focused on the perinatal mortality reviews of stillbirths in the focus groups. Another limitation is selection bias as healthcare professionals who participated in the focus groups might have been the most supportive of parental engagement and those who did not might have not thought it was not a good idea. Furthermore, we had intended to recruit more senior stakeholders than we managed. To mitigate this, we recruited a larger number of senior stakeholders to the

national consensus meeting, also part of the PARENTS 2 portfolio (a separate report is under preparation), to ensure we capture such views.²⁰

Interpretation

A requirement for training and support for staff to enable parental engagement emerged as a key theme in our study, and it is reassuring to see that the National Quality Board in the UK advocates enhancing skills of providers through targeted training to support this agenda.⁵ Our findings are in keeping with the recommendations of 'Learning from Deaths'. The PARENTS 2 Study has, however, gone beyond to advance our knowledge on the specific challenges to parental engagement and to provide insights as to how we might support parents and staff through the process. The broad lessons learnt from PARENTS 2, including those generated by the consensus and pilot implementation processes, could be transferred across to learning from deaths in other domains of healthcare and to learning from other serious incidents.

CONCLUSION

Healthcare professionals see the benefit of involving bereaved parents in perinatal mortality reviews. For the process of parental engagement to work, perinatal mortality review meetings should be standardised and review processes should be streamlined. There should be support and training for staff in place, clear terms of reference and designated individuals assigned specific tasks to support the process. Further work underway as part of the PARENTS 2 Study, including a pilot implementation, will help understand the challenges and successes of parental engagement in action.

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REFERENCES

- Office for National Statistics. Stillbirth. <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/stillbirths> (cited 9 Jan 2017).
- Draper ES, Kurinczuk JJ, Kenyon S, eds. *MBRRACE-UK perinatal confidential enquiry: term, singleton, normally formed, antepartum stillbirth*. Leicester: The Infant Mortality and Morbidity Studies, Department of Health Sciences, Un, 2015.
- Francis R. The Mid Staffordshire NHS Foundation Trust Public Inquiry. 2013. <http://webarchive.nationalarchives.gov.uk/20140407084003/http://www.midstaffpublicinquiry.com/> (cited 5 Feb 2017).
- Care Quality Commission. Learning, candour and accountability: a review of the way NHS trusts review and investigate the deaths of patients in England. 2016. <https://www.cqc.org.uk/sites/default/files/20161213-learning-candour-accountability-full-report.pdf> (cited 29 Jan 2018).
- National Quality Board. National Guidance on Learning from Deaths - NHS England. 2017. <https://www.england.nhs.uk/wp-content/uploads/2017/03/nqb-national-guidance-learning-from-deaths.pdf> (cited 6 Oct 2017).
- Bakbakhli D, Siassakos D, Burden C, et al. Learning from deaths: Parents' Active Role and ENGagement in the review of their Stillbirth/perinatal death (the PARENTS 1 study). *BMC Pregnancy Childbirth* 2017;17:333.
- Millman EA, Pronovost PJ, Makary MA, et al. Patient-assisted incident reporting: including the patient in patient safety. *J Patient Saf* 2011;7:106–8.
- Institute of Medicine. *Crossing the quality chasm; a new health system for the twenty-first century*. Washington DC: National Academy Press, 2001.
- Robert G, Bate P. *Bringing user experience to healthcare improvement*. New York: Radcliffe Publishing, 2007.
- Ocloo JE, Fulop NJ. Developing a 'critical' approach to patient and public involvement in patient safety in the NHS: learning lessons from other parts of the public sector? *Health Expect* 2012;15:424–32.
- Langley GL, Nolan KM, Nolan TW, et al. *The improvement guide: a practical approach to enhancing organizational performance*. 2nd edn. San Francisco: Jossey-Bass Publishers, 2009.
- Nuzum D, Meaney S, O'Donoghue K. The impact of stillbirth on consultant obstetrician gynaecologists: a qualitative study. *BJOG* 2014;121:1020–8.
- Menezes MA, Hodgson JM, Sahhar M, et al. "Taking its toll": the challenges of working in fetal medicine. *Birth* 2013;40:52–60.
- Farrow VA, Goldenberg RL, Fretts R, et al. Psychological impact of stillbirths on obstetricians. *J Matern Fetal Neonatal Med* 2013;26:748–52.
- Gold KJ, Kuznia AL, Hayward RA. How physicians cope with stillbirth or neonatal death: a national survey of obstetricians. *Obs Gynecol* 2008;112.
- Aw W. Medical error: the second victim. *BMJ* 2000;320:726.
- Wahlberg Å, Andreen Sachs M, Johannesson K, et al. Post-traumatic stress symptoms in Swedish obstetricians and midwives after severe obstetric events: a cross-sectional retrospective survey. *BJOG* 2017;124:1264–71.
- Säflund K, Sjögren B, Wredling R. The role of caregivers after a stillbirth: views and experiences of parents. *Birth* 2004;31:132–7.
- O'Beirne M, Sterling P, Palacios-Derflinger L, et al. Emotional impact of patient safety incidents on family physicians and their office staff. *J Am Board Fam Med* 2012;25:177–83.
- Bakbakhli D, Siassakos D, Storey C, et al. PARENTS 2 study protocol: pilot of Parents' Active Role and ENGagement in the review of Their Stillbirth/perinatal death. *BMJ Open* 2018;8:e020164.
- HM Government. Child Death Review [Internet]. Statutory Guidance. https://consult.education.gov.uk/child-protection-safeguarding-and-family-law/working-together-to-safeguard-children-revisions-t/supporting_documents/Child_death_review_stat_guidance.pdf (cited 2 May 2017).
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
- Etcheagaray JM, Ottosen MJ, Burress L, et al. Structuring patient and family involvement in medical error event disclosure and analysis. *Health Aff* 2014;33:46–52.