In their own words

An analysis of bereaved parents' comments about their experiences of hospital review into their care, Sands Survey 2021

Sands

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The free text responses to the survey were analysed using a Thematic Analysis technique (Braun and Clarke, 2013). Themes were identified from each free text question (Table 1) and then mapped against each other to identify relationships and to highlight overarching themes. This helped provide a more holistic understanding of parents' responses about their experiences of the hospital review of their care.

Table 1: Survey questions where parents could give free text responses

1. **Where you were not offered the opportunity to contribute to the review of your baby's death, is there anything else you would like to add?**
2. **Have you felt included in the review process so far?**
3. **If there is anything you'd like to add about the content of the letter summarising the review's findings and whether it was sensitively and clearly worded?**
4. **If there is anything you'd like to add about the meeting, whether you had enough time to understand any information you were given and felt supported?**
5. **If you had questions, did the review answer your questions?**
6. **Is there anything else you would like to add about your satisfaction with the review process?**
7. **Is there is anything else you would like to say about your satisfaction with the review's final summary of your care and any explanations for the death of your baby?**

For parents who were not given the opportunity to ask questions or share their views or concerns about their care during the review process

> *I never knew about a review until I reached out at breaking point to a bereavement midwife in my own area. I've since completed the review but still not heard much. It would just feel nice to be listened to and cared for. We have no doubt that our care was amazing, and that [name of hospital] did everything they could for our baby. However, a review would provide some kind of closure. I also wanted the review to look at why it happened and give us some insights.*
>
> **Mother of baby who died after birth, Scotland, 2020**

Perhaps not surprisingly, parents who spoke about not being invited to share their views or concerns to the review of their baby's death, expressed some of the most emotive language relating to their views. Poor communication about the review led to parents not feeling listened to and a sense of abandonment for some.

> *Not enough support after we lost our baby, I didn't receive a check-up, had to chase post-mortem results, self-refer for counselling, just felt abandoned.*
>
> **Mother of a baby who died between 22 and 24 weeks' pregnancy, England, 2019**

There was evidence that parents would have wanted to ask questions and share their views and concerns and that they undertook their own work to ensure their voices were heard.

> *There was a hospital review. The findings were discussed with us at a meeting with our consultant once our daughter's post-mortem results had been returned, 2 months after her death. We were not told of the review before this. I researched about it myself and asked if there had been/was going to be one. I would have liked to have had the opportunity to feedback my feelings about our care into that initial hospital meeting. I believe they were communicated after our debrief with our consultant. I did feel listened to at that point but sadly it was all too late.*
>
> **Mother of a baby who was stillborn in Scotland, 2020**

Feeling included in the review process so far

Some parents felt fully informed about the process and progress of the review,

> *I was explained what the process was and was contacted by multiple people to submit any questions.*
>
> **Mother of a baby who was stillborn, England, 2021**

However, there was evidence that poor communication and lack of information, could lead to confusion for parents and lost opportunities for parents to contribute to the review.

> *I'm not certain if they received my questions. I'm also confused as I requested a full report to my house after being asked by the bereavement midwife if this was what I wanted, and I've since been told I won't get one. Also, I've received a letter addressed to only me for a hospital appointment which nobody can tell me what it's about.*
>
> **Mother of a baby who was stillborn, England, 2021**

The issue of the timing of informing parents about review, in relation to the process overall, was also evident.

> *We did not receive the letter asking us if we wanted to ask questions or make comments until after the initial review meeting took place.*
>
> **Mother of a baby who died after birth, England, 2020**

Content of the letter from the hospital, summarising the review findings and any explanations for the death of their baby

It was important for parents that letters were clear, sensitive and had the right level of detail. A letter that summarised the discussions that had previously taken place with healthcare professionals, such as the consultant, was written in language that parents understood, but also gave an adequate level of detail made parents feel confident in the process of the review

> *It was sensitivity worded, it explained everything to me in terms I could understand but also included all the official documentation that went alongside this.*
>
> **Mother of a baby who died after birth, England, 2019**

> *It was very compassionate as well as giving me all of the detail we needed.*
>
> **Mother of a baby who was stillborn, England, 2021**

A sensitive letter included personal details:

> *It was very sensitive, they referred to our baby by name and again sent their condolences.*
>
> **Mother of a baby who was stillborn, England, 2019**

In contrast, a letter that was poorly worded, contained inaccurate detail and lacked sensitivity caused additional harm to bereaved parents:

> *In a letter describing the events chronologically it stated "you gave birth to a live baby boy" which I obviously did not. This was very upsetting.*
>
> **Mother of a baby who was stillborn, Wales, 2020**

> *It was very blunt and not personal. It states that the loss of my son was moderate harm to myself that was very upsetting to read.*
>
> **Mother of a baby who was stillborn, England, 2020**

Where letters were poor in this way, there was sometimes a sense of mistrust in the process:

> *It was just a basic letter. Wouldn't say sensitive. Just to the point. Just cleverly written to protect themselves.*
>
> **Mother of a baby who died after birth, England, 2019**

Parents found this even more difficult when there were differences between the information in the letter and other types of communication with healthcare professionals.

> *There was also information that we had not previously been told that brought a new level of distress to the situation.*
>
> **Mother of a baby who was stillborn, England, 2019**

The meeting with a consultant to talk about the final summary of the review and any explanations for the death of their baby

Parents were most likely to comment on questions about the meeting with the consultant to discuss care. There was a clear link between perceptions of the time taken for the meeting, the environment the meeting was held in, and the attitude of the healthcare professionals present with the parents' ability to process the information given to them.

A number of responses demonstrated how parents felt supported to discuss care within the meeting.

> *We felt we had enough time to discuss our son's death and they explained what had happened in detail while being as sympathetic as possible.*
>
> **Mother of a baby who was stillborn, England, 2021**

> *This meeting was incredibly important to us, we met in comfortable surroundings & we were invited to take our time & talk through any questions or concerns we had. The staff couldn't have been more lovely.*
>
> **Mother of a baby who was stillborn, England, 2020**

Parents were less satisfied with the meeting if they felt rushed or healthcare professionals did not communicate effectively.

> *Not enough time was given to discuss how we were feeling or about why our baby died. The focus was mostly on future pregnancy if it were to happen.*
>
> **Mother of a baby who was stillborn, England, 2020**

Senior consultant was cold. He also treated me as though I was not educated. Whether educated or not, should not be a factor but I could tell he thought I wasn't. In fact, I am educated to a Masters level and understood everything very clearly.

Mother of a baby who died after birth, Wales, 2019

Inaccurate details in the meeting resulted in unresolved issues for parents, leading to parents working harder to get answers.

The information we were given at the meeting was incorrect. The post-mortem had been incorrectly interpreted. It took contacting other professors and further investigations to get accurate answers.

Mother of a baby who was stillborn, England, 2019

Processing information in the meeting is understandably challenging for parents when the discussion centres on the death of their baby. It may require additional support and communication skills on the part of healthcare professionals. There were several examples of healthcare professionals taking extra steps to ensure parents were supported to access information about their care within the meeting and beyond.

The meetings are quite overwhelming, and it is a lot to process, especially if things are highlighted. We had a post-mortem for our daughter and the results showed multiple reasons why she died. I think a follow up with someone (maybe a bereavement midwife) a week or so after would be helpful. I found it very hard after the appointment and to talk it through with someone after you have processed some of the information would be helpful.

Mother of a baby who was stillborn, England, 2019

The bereavement midwife also sat with us for a 'debrief' afterwards and told us we could ask her any further questions when we had read the report.

Mother of a baby who was stillborn, England, 2021

Whether the review fully answered parents' questions

Sadly, several of the free text responses related to the theme of unresolved issues and parents having to work harder to obtain the answers to questions that were still unresolved.

> *Didn't answer why I wasn't given additional support following two other pregnancy losses at various stages - it was acknowledged this should happen but nothing as to why it was missed. I don't feel confident falling pregnant again now.*
>
> **Mother of a baby who was stillborn, England, 2019**

> *Some of the questions were avoided and not answered accurately and fully. Some of the answers given were not accurate and took further investigation.*
>
> **Mother of a baby who was stillborn, England, 2019**

There were clear themes relating to parents' grief and the timing and nature of the approach by hospitals around the review, which affected parents' ability to contribute in a meaningful and timely way.

> *The hospital asked whether we had any questions, but at the time it was all so overwhelming. Then the report came back, and I wish they would break the questions down for the parents to give us a guide as to what the report will cover. That would have allowed us a chance to ask questions more specifically. Instead, we just didn't ask anything at all.*
>
> **Mother of a baby who died between 22 and 24 weeks' pregnancy, England, 2020**

> *The review was just two weeks after my baby's death, I wanted to send my account of what happened but I felt it was too painful so I could not bring myself to do it. Getting through each day coping with the loss of my baby so hard every time I tried to write my account of my care I would break down.*
>
> **Mother of baby who was stillborn, England, 2019**

However, parents felt more positive towards the review process and the hospital where opportunities for ongoing contact and any further questions, were maintained.

> *The hospital was brilliant and we were given lots of opportunities to ask questions. Even now, almost five whole months on we feel we could call them to talk about things again.*
>
> **Mother of a baby who died after birth, England, 2020**

Where such opportunities for ongoing contact were not offered, parents were also left with unanswered questions.

> *More questions came to light after the meeting, but I never got an opportunity to ask them.*
>
> **Mother of a baby who was stillborn, England, 2019**

Satisfaction with the review process overall

The theme of unresolved issues was expanded upon within the free text responses around parents' overall satisfaction with the review process.

> *Gave an answer to what happened but didn't answer if it could have been picked up sooner or whether any changes would be made as a result.*
>
> **Mother of baby who was stillborn, Scotland, 2020**

The theme of unresolved issues here correlated to a parent's need to work harder to uncover the answers they were seeking, as well as occasionally a breakdown of relationship or trust between themselves and the healthcare professionals involved in their care or review.

> *From my experience, the Bereavement Midwife on 4 different occasions said she would tell us or ring us with certain updates. That never seemed to happen, I felt like we were the ones chasing them. It has left me not able to approach the hospital for any problems I have now. I feel the aftercare is a hard one. I say I am okay, which most days I am. But when I'm not, it would be nice to know I could reach out to them.*
>
> **Mother of baby who died between 22 and 24 weeks' pregnancy, England, 2020**

Some parents expressed the wish that those involved with their baby's care acknowledged responsibility or that actions were undertaken to ensure individuals were held to account. Some parents felt that an internal hospital review was superficial, not valid or merely a tick box exercise That led them to distrust the process.

> *The focus seemed to be on denying any mistakes had been made. It felt like a legalistic process to avoid liability.*
>
> **Mother of a baby who was stillborn, England, 2019**

> *I feel like it's all a ticking a box process and they don't realise the pain and tragedy that has actually occurred.*
>
> **Mother of a baby who was stillborn, England, 2021**

Some of the parents' desire to ensure accountability related to an altruistic notion of improving care for future parents, including one respondent's wish to work with the hospital to achieve this.

> *Our son died because of them however my partner and I are looking at working with the hospital so that what happened to us never happens again.*
>
> **Mother of baby who died after birth, England, 2019**

Responses around satisfaction with the overall review process emphasised the extended length of time it takes for the review to take place and the delays.

Parents found this even more difficult if they were not kept informed of progress with the review.

> *I was told there would be a review and it would take 8-12 weeks. Received my appointment nearly 5 months after our [daughter's name] died but with zero contact. Would be helpful if they just sent a letter to say they are waiting on results, or an email, something to acknowledge the wait.*
>
> **Mother of a baby who was stillborn, England, 2019**

Conversely, parents expressed satisfaction with the review process when they were kept informed by an identified healthcare professional and felt they had adequate time and space to consider their questions or concerns.

> *Very satisfied with the review process. We were contacted by the bereavement midwife from the hospital to discuss any concerns and found out about the meeting. We were asked if we had any questions or issues we wanted raised and had time to think about this before the meeting. We had phone calls stating the facts from the meeting and giving answers to our questions.*
>
> **Mother of baby who died after birth, England, 2020**

Satisfaction with the final summary of the review of their and their baby's care

The question around satisfaction with the final summary of care was least likely to be described positively.

Themes of unresolved issues for parents and a desire for accountability regarding their baby's death were also carried forward to this final free text response in the survey.

> *Reviews do not appear to hold clinicians accountable for their negligence. I work in a similar field and fully understand the implications of such investigations/ reviews. However, in cases such as ours where the negligence is indisputable, there were no tangible outcomes or any real consequences to individuals. I am not unreasonable but extra supervision or training on policy is not enough to ensure the next child's life is saved!*
>
> **Mother of a baby who died after birth, Wales, 2019**

> *We did not agree with the outcome and felt a lot of things were covered up.*
>
> **Mother of a baby who was stillborn, England, 2019**

One parent distinguished between the overall system of care and individuals involved in the review process.

> *Unfortunately, we will never be satisfied as we will never know if our baby would have lived, had we been seen earlier and not kept waiting. Every member of staff has been very caring and approachable, and we appreciate it is not just down to one person, rather the system as a whole which wasn't working properly.*
>
> **Mother of a baby who was stillborn, England, 2019**

It should also be recognised that there are implications for parents where the review has not met the expectation of providing answers to the reason for their baby's death.

> *I think investigations are great to some extent, but sometimes they just prolong the pain even more especially when there are no answers.*
>
> **Mother of a baby who died between 22 and 24 weeks' pregnancy, England, 2019**

Some parents were pleased to see that the review prompted measures to improve future care and outcomes.

> *It was nice to see changes that have been put in place following my son's death and how the hospitals are going to link together better. They picked this up to be a bigger issue than I did, as I feel moving me to the other hospital earlier would not have made a difference on out outcome.*
>
> **Mother of a baby who died after birth, England, 2019**

Overarching themes identified

There were themes identified that cut across all of the free text responses in the survey.

1. Timing

This theme related to the time it took for the investigations to be completed and the review to take place, which often exceeded the time expected and could potentially cause further upset.

The theme also related to the timing of the approach from healthcare professionals informing parents about the review of their baby's death and how this linked to their grief, capacity to process information and the opportunity for meaningful contribution to the review.

Parents may also have had further questions following the review or the consultant meeting and expressed greater satisfaction with the review process where avenues for ongoing contact with those involved in their baby's care remained.

2. Keeping informed and relationships with healthcare professionals involved in review

It was clear that parents found it difficult when they were not kept informed of the progress of the review or its outcome, regardless of how long the process took.

Parents appreciated being informed about the ongoing review and this maintained a level of trust and relationship between them and those that had cared for them or were involved in the review.

3. Unresolved issues for parents

The theme of unresolved issues following review was an issue for a group of parents. This was linked to where parents felt communication was inadequate during the meeting to discuss the review findings, where the letter summarising the review findings was poorly communicated or included mistakes, or where the ongoing progress of the review had not been communicated effectively.

Very occasionally, this also related to an apparent break down in the relationship between parents and those involved in their care, or a distrust that internal reviews are valid. Unresolved issues resulted in parents working harder to find the answers they were seeking (sese theme 5 below).

Conversely, where communication was good, parents were less likely to have unresolved issues.

4. The desire for accountability

Some parents expressed the need for greater accountability from those involved in their care and wanted to know that measures had been put in place to improve care for future parents. This sometimes included questioning whether the internal review process was transparent. A couple of parents said they wanted the hospital to apologise for failures in care.

5. Additional work undertaken by both parents and healthcare professionals

A clear theme throughout the responses was the additional work undertaken by both parents and healthcare professionals over and above the standard review process.

For parents, this related to inadequate communication with those involved in their care or unresolved issues, which caused them to undertake additional work to gain the answers they sought.

For healthcare professionals, this additional work was associated with accessibility, availability and advanced communication skills that enabled parents to access the information they were looking for about their baby's death and their care in a supportive way.

Summary

Parents' responses to the open text questions in the survey illustrated that they would like to be informed about the hospital review of care after their baby's death and to be given the opportunity to ask questions and share their views and concerns about their care so that these can be addressed by the review process.

Missed opportunities to invite parents to contribute their views or questions regarding their care and the care of their baby can result in unresolved issues for parents in the longer term and impact their emotional wellbeing.

There is a need to improve understanding of how to communicate with parents regarding the review of their baby's death in a timely, individualised, and sensitive way. This should include how to resource services to ensure adequate time and attention is given to communicating with parents and how to ensure the training needs for healthcare professionals in advanced communication and bereavement care skills are met.

The ambition must be to ensure parents do not experience poor and insensitive communication, thereby improving the relationship between parents and those involved in their care and minimising the unresolved issues that parents may continue to live with long-term.

[1] Braun, V. and Clarke, V. (2013) Successful qualitative research: a practical guide for beginners. London: SAGE.

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