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Bereaved parents and maternity hospital perinatal death reviews: a respectful and collaborative process is needed

The death of a baby is devastating for parents, families and staff involved. The standard of bereavement care that families receive around the time of pregnancy or early infant loss has a significant impact on their psychological recovery. Our research highlighted that consistent, individualised bereavement care is essential; it facilitates a seamless transition for bereaved families–from diagnosis through the hospital stay to discharge and follow-up–allowing them to focus on their baby, their bereavement and their family's wellbeing. Our analysis of inquiry reports emphasised the need for experienced and skilled staff to always be available to: provide immediate support to bereaved families as appropriate, and assist families in understanding and processing information around the time of their loss. Our research findings also showed that, for the parents, open, honest communication with staff, as well as having a key hospital contact, is essential. Involving bereaved parents in their baby's care and in the maternity hospital perinatal death review can help parents process their bereavement and plan for the future.[1]

What do we already know?

Bereaved families value kind and compassionate interactions with hospital staff around the time of the death of their baby. Lack of information or explanations may exacerbate feelings of anger and frustration.[2] Individualised continuity of care allows the parents to focus on their baby, and address all questions or concerns to one person.[2]

What is …

Perinatal death (or mortality): The death of a fetus which is born weighing ≥500g or at 24 or more weeks of pregnancy (stillbirth), or the death of a live-born infant within the first 7 days of life (early neonatal death) or within the first 28 days of life (neonatal death).

Perinatal death reviews: *Local adverse incident reviews* are carried out by hospitals into unexpected events to identify any modifiable contributory factors. *Perinatal death reviews* are carried out after a perinatal death in maternity hospitals, to gather all the information on events relevant to the death, identify contributory factors and cause of death, and to recommend changes to prevent future deaths in maternity hospitals by identifying and addressing modifiable risk factors.[3] Including the patient and/or family's perspective and knowledge in this review can offer significant insight to the care received.[4]

What did we do?

We conducted two studies to understand this issue further:

Analyses of ten published inquiry reports related to Irish maternity services to describe the impact of, and identify issues with bereavement care provided to families around the time of pregnancy and/or early infant loss.

Interviews with bereaved parents in Ireland, to understand how they experienced the review process and how they feel this process may be improved. The study also assessed bereaved parents' perception of how they may be appropriately involved in the maternity hospital perinatal death review in ways that benefit them and the review process itself.

What did we find?

From the findings in the inquiry reports:

- Bereavement care was not consistently individualised or respectful, resulting in additional feelings of anger and upset.
- Clear communication of complex issues, in a manner that is understandable to bereaved families, did not always happen.
- It was recommended that experienced and skilled staff should always be available to provide immediate support to bereaved families as appropriate, and assist families in understanding and processing information around the time of their loss.

From the interview findings, parents expressed the need and a wish for:

- Open, honest communication with staff
- Having a key hospital contact.
- Opportunity to provide feedback on their experience and be included in the review of their baby's death, in a way that was sensitive to their needs and the hospital's schedule.
- A respectful, flexible system that allows bereaved parents' involvement in their baby's perinatal death review and is beneficial to parents and the review itself is needed.

> "I was always kept informed. It is so important. **An informed approach is a fair approach** and that needs to be taken with bereaved parents. This is the death of a child, it is an ongoing process and all you are doing is sitting at home waiting for some sort of information.

> And the information that is received and **the information that is given to bereaved parents, it is not enough**. It is not okay to just send a one sentence email to say, yes they are still working on it.

> Just ask parents would you like to provide any further information. I don't know… giving a form would work or, you know, give people just an opportunity**, at least ask them at some point, would you like to give any more information?** Do you have any other information that you'd like to have included in anything?"

How could bereavement care and perinatal death reviews be improved in Ireland?

- The involvement of parents in reviews needs to be carefully considered and resourced, as poorly managed engagement has the potential to cause more hurt.
- Development of an information booklet explaining the different aspects of the review process (i.e., key contact, supports available, ways to provide feedback, timelines and possible outcomes including results and reports) to complement existing information given to parents.
- All the relevant clinical staff, should be involved in perinatal death review.
- A shift from a blame-culture is needed to a focus on achieving best practice through collaboration and implementation of review recommendations.
- Standardisation of the local perinatal death review processes at a national level would alleviate discrepancies in reviews and experienced by parents.
- Regular training sessions for all staff should form part of standardised practices in Irish maternity hospitals/units.

Further information

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