

Autopsy for stillborn babies: Experiences of parents with communication and information

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Background

Autopsy examination remains the gold standard investigation of stillbirth, but autopsy rates continue to fall in many regions.

Clinicians may feel inadequate to counsel parents about autopsy and be reluctant to add to their burden.

Inappropriate information and poor counselling practices may have psychosocial consequences for bereaved parents. It can increase anxiety and lead to regret about autopsy decisions.

Aims

This pilot study was the first in a series of planned studies that aim to improve counselling and consent procedures for bereaved parents around autopsy examination after stillbirths.

Methods

Pilot data were obtained during the consumer consultation process in the update of the PSANZ Perinatal Mortality Guidelines undertaken by SANDS Queensland and the Stillbirth Foundation in Australia with the PSANZ Perinatal Mortality Group.

Parents who suffered a stillbirth in the previous 12 months were identified through newsletters and by word-of-mouth. There were three focus groups. Sessions lasted 2-3 hours and were taped. Content analysis was undertaken.

Parents talked about their views and experiences of the consent process for autopsy for their stillborn baby.

Results

Seventeen parents (14 mothers and 3 fathers) participated. The majority experienced late gestation stillbirth in the previous 12 months. Most consented to an autopsy and the cause of death remained unknown.

Inability to make an informed decision

The most common issue for parents was their inability to make an informed decision about autopsy due to overwhelming shock and grief. Some parents did not recall any conversation with care providers about the option of autopsy

- ▶ *I don't remember any material about autopsy, we were asked but at that time it was all a blur, there was so much to deal with.*
- ▶ *It was really too soon. It was the next day. But we weren't ready to take in any of the information. We weren't ready to make a decision. We weren't of sound mind.*
- ▶ *I had just had the caesarean and then the next day I had the question put to me so it was too difficult to deal with. We're both hazy, because my husband was as emotionally wrecked as I was. It was just too much all at once.*

Information needs

Parents wanted information that addressed their fears. These mainly concerned mutilation and the loss of time with their baby.

Parents felt it was important to decision-making to understand that autopsy offered a chance to find out more. None could recall being told this.

All parents agreed that, as well as verbal information, written information about an autopsy was important. Eight parents had no recollection being given written information.

- ▶ *Address the fears of the parents - that we don't want to see the baby with stitches. We don't want to see that because we're just coming to terms with that the baby's died and then to see that the baby has been cut open - we don't want to see that. So I don't know whether you can still have the baby bathed...*
- ▶ *Yeah they do need to focus on (benefits of autopsy), especially if the person's going to have more babies, just for prevention. I mean that's a big one - you don't ever want to go through that again so that's number one.*



Results (cont'd)

Reasons for an autopsy

The main reasons parents consented to an autopsy for their baby were the need to know what went wrong and to prevent it happening again.

- ▶ *... because I had to find every reason why this wasn't me, that I didn't cause it and the autopsy would reveal that.*
- ▶ *But, the big thing was he (Doctor) knew I wanted more children so he really drove home that we don't know why this happened and you don't want it happening again so the more information we have is better for you. We can't save this baby but we can save the next.*
- ▶ *Because for me, it was about caring about why he died. That was what motivated me to get an autopsy. So didn't care how it makes me upset, I just want to get to the bottom of why this happened*

Some parents also had altruistic reasons for autopsy - they wanted to help future parents by helping gain more knowledge about the causes of stillbirth.

Fear of blame

Some mothers were anxious an autopsy could lead to them being blamed for their baby's death

- ▶ *... I was a mess - the fear. The fear that it's (autopsy) just going to show me up as the worst mother in the world.*
- ▶ *My biggest fear, and that's what a lot of people would have about it, is 'oh (expletive) I might have done something wrong and now I'm gonna be blamed'. That was the one thing that was my big worry what if they find out I ate the wrong food or...*

Importance of others in the autopsy decision

Many participants felt dependent on the advice of their health care provider in the decision making process.

One mother felt it was the responsibility of the care provider to make the decision on the parents' behalf. She compared it to other emergency-type decisions made in other's best interests (eg emergency caesarean delivery) and felt let down by her care provider.

- ▶ *If he had said to me, I think we should get an autopsy done because we might find, even if it's the smallest thing, we might find something. Then I probably would've said, if you think, you are the professional, you have studied, you should be in control, you lead the way. Don't ask me, I know nothing. You're asking me to make a decision that will impact my future.*

The need to involve others such as grandparents and friends to interpret information was important to parents. Some mothers relied on the fathers to interpret information given to them.

- ▶ *My husband was with me every single minute and he took in all that information, not me. He listened. You need a really strong person with you when those questions are asked about autopsy and he processed it for me.*

Results (cont'd)

Importance of others in the autopsy decision (cont'd)

One mother spoke of feeling vulnerable making the decision for autopsy due to her perception that her care provider lacked objectivity. She would have preferred to discuss the option with a third party. She felt her clinician was concerned about possible clinical error.

- ▶ *I guess my take home message was that because we'd had a bad relationship with my doctor at the end, I didn't want him to be the one to feed me back. I would have really liked an independent person. Because unless you really connect, or there has been some medical negligence, putting that person as you interpreter of what happened, is like a wolf reporting back to you. I ended up going to (hospital) and meeting up with the pathologist.*

Feelings about the autopsy decision

Parents who did not have an autopsy expressed regret or doubt about their decision. No parent who consented to autopsy expressed these feelings. Some parents said the autopsy, even when it did not reveal a cause for the death, helped them.

- ▶ *I don't remember being asked for an autopsy at all. .. But I'll never know. I have regrets...*
- ▶ *...having an autopsy is not going to bring it back. You know I just wanted to leave it be and then I had hospital staff encourage me to choose to have an autopsy and I'm really glad that I did now. Even though it was unexplained and I knew there was a chance that was going to happen, I went on and I've had another baby. It's made it easier to move forward I think.*

Staff ability to provide appropriate care

Parents frequently raised concerns about clinical staff not able to cope with the event of stillbirth.

- ▶ *But I think they (staff) were also very stunned. That week they had 3 stillbirths. So I think the staff were reeling quite a bit.*

Parents commented that many staff do not understand how parents respond to the loss of a child or know how to provide basic care or compassion.

Parents suggested health care providers learn specialist communication skills to care for parents after a stillbirth suggesting the need for "Stillbirth accreditation"

- ▶ *But you've got to think that anyone working in the medical profession would have some experience in their working life of death? And grief? It sort of comes from the territory? So why aren't they...it would be one of the lessons you learn.*
- ▶ *Mum 1. Could there be like for social workers for instance a stillbirth accreditation so that only they can talk to people who have a stillbirth*
Mum 2: There should be the same for midwives and the same for obstetricians
Mum 1. ...Stillbirth accreditation..... how good is that!

Conclusion

These focus groups identified a number of key factors about autopsy consent for further study.

On the basis of these findings, a wide scale survey of parents, midwives and doctors is planned. The survey will inform the development of an intervention to improve communication about the option of autopsy. It is envisaged that a decision aid for autopsy consent will form part of this intervention. Further details are available on the ISA website <http://www.stillbirthalliance.org/> under Research / ongoing

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