

Understanding mothers' decision-making needs for autopsy consent after stillbirth:

Framework analysis of a large survey

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Abstract:

Background: Experiencing stillbirth is devastating and leaves parents searching for causes. Autopsy is the gold standard for investigation, but deciding to consent to this procedure is very difficult for parents. Decision support in the form of clear, consistent and parent-centred information is likely to be helpful. The aims of this study were to understand the influences on parents' decisions about autopsy following stillbirth and to identify attributes of effective decision support that align with parents' needs.

Methods: Framework analysis using the Decision Drivers Model was used to analyse responses from 460 Australian and New Zealand (ANZ) mothers who took part in a multi-country online survey of parents' experiences of stillbirth. The main outcomes examined were factors influencing mothers' decisions to consent to autopsy following stillbirth.

Results: Free-text responses from 454 ANZ mothers referenced autopsy, yielding 1,221 data segments for analysis. The data confirmed the difficult decision autopsy consent entails. Mothers had a strong need for answers coupled with a strong need to protect their baby. Four "decision drivers" were confirmed: preparedness for the decision; parental responsibility; possible consequences; and role of health professionals. Each had the capacity to influence decisions for or against autopsy. Also prominent were the "aftermath" of the decision: receiving the results; and decisional regret or uncertainty.

Conclusions: The influences on decisions about autopsy are diverse and unpredictable. Effective decision support requires a consistent and structured approach that is built on understanding of parents' needs.

Keywords: stillbirth, autopsy, post-mortem, decision-making, bereavement

Introduction

Stillbirth is a highly traumatic event^{1,2} and the difficult decisions that follow add to parents' distress. One of the most difficult of those decisions is if, and how, to investigate cause of death. Autopsy is the gold standard for investigation into unexpected or unexplained deaths³⁻⁵ but agreeing to autopsy can be very difficult at any time, particularly at a time of intense shock and grief^{6,7}. The influences on parents' decision-making about autopsy can be complex and multifaceted^{8,9}, and include the options available, quality of information provided to parents, and staff attitudes about the value of autopsy^{5,10-12}.

Parents need clear and consistent information about their options after stillbirth delivered in a timely and sensitive manner^{8,10} but this is often not their experience¹³. For example, health care professionals can be ill-prepared to engage in discussion about autopsy consent^{11,14} and stress and grief can adversely affect the cognitive abilities of parents¹⁵. Information retention, verbal processing and emotional decision-making can all be impaired by grief¹⁵. Motivators and barriers for autopsy consent have been identified^{6,9,11} but better understanding of the complexity of the factors influencing parents' decisions about autopsy after stillbirth may help to develop appropriate and effective support for decision-making. Horey et al. (2012) identified four "decision drivers" and two "decision aftermath"⁶ that reflect many of the barriers and motivators to consent identified in the wider literature^{16,17}. Decision drivers were influences or reasons to support or oppose autopsy: preparedness for the decision; parental responsibility; concern for consequences; and health professionals⁶. Decision aftermath or consequences included: receiving results; and decision regret or uncertainty⁶. By charting the influences on parents' decisions, the Decision Drivers Model (DDM) offers a practical

approach to thinking about parents' decision-making support needs, which can help address barriers and support parents.

The aim of this research was to apply the DDM to determine its applicability in a large sample of bereaved mothers; and to identify attributes of effective decision support that align with parents' decision-making experiences.

Methods

Open-ended responses from an on-line questionnaire were examined using a framework analysis based on the Decision Drivers Model (DDM) (Table 1). Data were from a large-scale, multi-country web-based survey of bereaved parents for The Lancet Ending Preventable Stillbirths series conducted between December 2015 and February 2016. See Flenady et al. (2016)¹⁸ for the detailed methods. Briefly, the survey was one of three on-line questionnaires designed to elicit responses related to the experience of stillbirth from the perspectives of parents, clinicians and the wider community. Stillbirth support organisations distributed invitations to participate and links to the questionnaire. The intention was to reach a large group of parents and it is not possible to ascertain the actual number of parents who received invitations or the corresponding response rate.

Fixed and open-ended questions covered parents' experiences in pregnancy, around stillbirth, and over the longer-term. The responses to 16 open-ended questions asking about post-mortem examinations and about care after stillbirth were analysed for this study (Appendix 1).

Mothers residing in Australia or New Zealand who reported a stillbirth after 20 weeks' gestation were included. This gestational limit is consistent with the definition of stillbirth used in both countries. Male respondents were excluded due to low response rates and mothers with a loss earlier than 20 weeks were also excluded (Figure 1).

Descriptive analyses were conducted using SPSS (version 24.0) to examine key characteristics of participants including: mother's age; country of residence; educational level; length of time since stillbirth; and whether or not an autopsy had been conducted.

The Framework Method¹⁹ was used to analyse the open-ended responses. This form of directed thematic analysis offers a flexible approach to analysing and structuring qualitative data and is widely used in health care and policy research²⁰. Framework analysis is a multi-stage, iterative method that combines inductive and deductive analysis, enables use of a pre-existing framework and allows for adaptations if new concepts emerge¹⁹⁻²¹.

The analysis was led by three authors (AS, DH and FB) with the other authors providing multidisciplinary insight, contributions to discussions, refinement of the analytical framework and interpretation of codes. This included confirmation of the initial and subsequent analyses.

In the first stage of analysis, all open-ended responses were read, re-read and searched for all references to autopsy, post-mortem, investigations, testing, results, information required to make decisions and communication of information. All relevant, in-scope data were transferred to an Excel spreadsheet. A subset of these data were examined independently by three authors (AS, FB and VF), where data were considered case-by-case and relevant responses coded onto the DDM matrix. This process was used to determine the 'goodness of fit' of the DDM framework and to identify and resolve any areas of ambiguity or disagreement. This process was continued through the full dataset by two authors independently (AS and FB).

The mapping of the data in this way provided a structured representation of the dataset, a visual means of identifying patterns, and an audit trail. During mapping and interpretation, patterns and connections within and between themes and participants were explored to gain

deeper understanding. With these refinements new insights emerged that modified the original model to take account of the findings from the dataset (Table 2).

Permission was granted by the International Stillbirth Alliance (ISA) Steering Committee to allow the analysis of the Australian and New Zealand data of the Parents Survey. ISA ethics approval was granted by the Mater Health Services Human Research Ethics Committee on 29th 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, Behavioural Research Ethics Board on 22nd December 2014 (Ref #H14-02784). (Vancouver, Canada).

Results

Of the 4182 respondents to the international parent survey, 460 were mothers from Australia and New Zealand that reported a stillbirth with a gestational age of at least 20 weeks. All 460 of these participants answered the demographic section of the survey in full; 416 were from Australia (90%) and 44 from New Zealand (10%). Half of the Australian and New Zealand mothers were aged 30-39 years (49.8%), 43.3% had undergraduate degrees, and most were in paid work (37.6% full-time and 31.5% part-time). Two-thirds of the 460 included women experienced their index stillbirth within the previous 5 years (67.6%) and more than two in five experienced stillbirth between 30-37 weeks gestation (41.3%). Women in Australia and New Zealand were comparable on most demographic items, although New Zealand women were more likely to be younger ($p = 0.03$) and to have experienced stillbirth more recently ($p = 0.002$) than women in Australia. Overall, participants were older and more highly educated than the wider population of women experiencing stillbirth in Australia.²²

Just over half the included mothers (53.9%) reported that autopsy was performed on their baby. A small number of mothers were unsure about this (2.2%) or did not answer (0.2%). This is slightly higher than the 42% reported in Australia in 2011-12²² and New Zealand in 2014²³. Rates of autopsy in the survey did not differ between the two countries or between the key characteristics examined (Appendix 2).

The maximum number of possible responses to 16 open text questions from 460 respondents was 7,360. In total there were 4,791 open text responses (65% of possible open text responses) with 1,221 of these in-scope (25.5% of all open text responses) provided by 454 mothers (98.7%).

Overall, the analysis confirmed the presence, and dual nature, of four major decision drivers (influences) and two decision aftermath (repercussions) identified in the DDM, and expanded the elements of two drivers: legacy was an additional positive influence; and acknowledgement of parenthood was included in parental responsibility.

Decision driver 1: Preparedness for the decision

The immense difficulty of autopsy consent after stillbirth was strongly confirmed;

Making the decision to have or not have an autopsy performed on your unborn dead baby is so incredibly difficult. Yes, you want as much information as possible, but you also want to protect that baby in any way you can. [Consented 3825]

Mothers deliberated with varying levels of certainty about the action to take. For some the choice was clear, either for autopsy *because all other tests gave no answers - so an autopsy was the next step in trying to get some answers* [Consented 26069]; or against: *it wasn't going to change the fact that she was gone.* [Declined 2888]. Others struggled, feeling overwhelmed

and lacking guidance with *no info to base a decision on ... I don't know, it [the decision] was just what came out of my mouth* [Declined 9368].

The joint nature of the decision was evident and sometimes involved negotiation: *my husband and I felt differently and these decisions were a compromise* [Declined 7140]. At times the decision appeared largely taken out of mothers' hands, being *talked into it by doctors and family* [Consented 2967] or being *told to [while] I was in immense grief and extremely vulnerable* [Consented 4493].

Autopsy was a clear choice for parents driven by a quest to find the reason for their baby's death. Occasionally this resolve was strengthened by a parent's professional background but scientific knowledge could also be overridden by other considerations as in the following instances: *I come from a scientific background. Before he was born I thought I would have an autopsy. But it shocked me after he was born I felt so incredibly strongly that I did not want his body to be interfered with* [Declined 7405].

Mothers who did not proceed with autopsy fell into three main groups: those who believed the reason for death was already known; those who thought nothing would be gained; and those who were deeply averse to the procedure of autopsy. Most wanted answers, but this need was outweighed by views that autopsy was unnecessary or strong feelings against autopsy. Some cited personal beliefs, religious or cultural reasons: *It was a personal belief choice. My husband and I simply didn't want to have the procedure done on our son.*

[Declined 6801], but many more were steadfast in their opposition and unable to contemplate "putting their baby through it".

Decision driver 2: Parental responsibility

Parental responsibility involved cognitive and emotional aspects. There was an obligation as parents to find out what had gone wrong and to obtain factual information for themselves, for

their baby, and for future children. Emotionally, the desire to protect their baby from further harm was strong as was the desire *to be a good mother* [Consented 9104].

For some mothers this meant leaving their baby's body intact ...*complete, innocent and perfect as he was* [Declined 7314]; for others this meant proceeding with autopsy as *we owed it to our little man* [Consented 3872]. Parental responsibility weighed heavy ... *I found it incredibly hard knowing that I signed the consent form knowing exactly what they would do to him* [Consented 7104].

A pervasive theme, not present in the DDM, was acknowledgement of parenthood. This manifested in desires to engage in parenting activities, to have opportunities to form or strengthen their emotional attachment with their baby, and to be recognised as the baby's parent. Parents wanted to spend time with their baby but sometimes felt pressured to "*hand the baby over*" [Consented 7554].

Regardless of the decision, care and respect of the baby mattered greatly. Mothers wanted to know where their baby was and to be assured that their baby would be cared for: *It felt just the same worry as if I was sending a live child off to somewhere I didn't know the location of* [Declined 25646].

Decision driver 3: Possible consequences

Mothers considered possible consequences of their decision, both positive and negative. That autopsy might contribute to better peace of mind was important. Self-blame and preventability featured heavily. While the DDM identified fear of blame as a concern and possible reason for not proceeding with autopsy, this was only weakly manifest in this dataset. However, concern and potential self-blame were prominent in mothers' comments, whether women consented *I did feel some anxiety about them finding the reason was because of something I did* [Consented 2702], or declined autopsy *I wanted to know if there*

was anything I could have done to prevent it from happening [Declined 3830]. Some, but not all, women who expressed such concerns proceeded with autopsy to find out, but no mother who declined autopsy directly linked their reasons to this concern.

Legacy, not present in the DDM, was an important benefit of autopsy for some mothers. It included the desire to give their baby's death 'purpose' or 'meaning' by contributing to wider knowledge about stillbirth and its causes and to helping others avoid similar loss: *I also wanted the possibility that any information learned from her autopsy might prevent loss for someone else sometime in the future. I wanted her to have a 'purpose'*. [Consented 6623]

Decision driver 4: Role of health professionals

The influence of health professionals on parents' decisions was evident with many examples of supportive or unsupportive practice related to autopsy. HCPs actively encouraged and supported parents to give consent: *it was suggested by our obstetrician as a way to discover exactly why our baby died* [Consented 6013]. Others discouraged parents actively *I was told I couldn't have one* [Declined 7559], or implicitly through cues that conveyed lack of support for autopsy: *we were advised that sometimes autopsies do not give reasons anyway and just cause more grief* [Declined 3075]. In other instances parents received no support or guidance or information was poorly communicated in terms of tone and/or timing, for example: *the doctor was really horrible with explaining the autopsy ... she went into great detail about what and how they would do it, right in front of me while I was holding my baby and it made me sick to my stomach* [Declined 7546].

Aftermath

The autopsy decision has consequences that may be unanticipated and ongoing. Both DDM aftermath were confirmed; issues around communication of results were present for those

who agreed to autopsy and regret or uncertainty about decisions were present for those who agreed to autopsy and for those who did not.

Unfavourable comments about the timeliness and communication of results were common and health care providers often failed to appreciate the significance and meaning of results for parents: *it took a year for me to get the autopsy results* [Consented 6809]; *I did not have an appointment to find out the results. They were posted to my house and I had to google what it all meant* [Consented 7557].

Some mothers expressed lingering doubts, uncertainty or regret about their decision. For those who had declined autopsy, regret often surfaced in relation to subsequent pregnancies, although it was not inevitable among this group: *there was no answer they could give us that would change the fact that he was dead. We have since had another child and never regretted not knowing what caused his death* [Declined 9338].

For those who consented to autopsy, expressions of uncertainty centred on not getting answers. Even when prepared for this possibility, disappointment and frustration often ran deep: *Unfortunately there was no cause that could be found which was really hard to take* [Consented 4583]

For mothers who expressed regret, regardless of the decision, the absence of support in decision-making and/or lack of information was a common thread: *I was pushed into it I didn't want it* [Consented 3908]; *I feel I was discouraged and I'm deeply regretful of this* [Declined 17840].

Discussion

Decisions about autopsy were very difficult for parents who experienced stillbirth and many factors influenced parents' deliberations. Both cognitive and emotional aspects were present at a time when critical decisions were required quickly, with potential to produce high levels

of internal conflict. Information and guidance to support decision-making was often absent. The quest for answers and desire to protect their baby were almost universal considerations; other considerations varied in their degree of influence and in whether they contributed to decision-making. Some mothers were certain of their decision but many felt overwhelmed or uninformed. Ongoing regret or uncertainty about autopsy decisions was relatively common.

The Decision Drivers Model proved robust in accounting for the perspectives of a large group of mothers who completed an online survey. Minor modifications were made to the original model. These included expansion of the Parental responsibility decision driver to incorporate two additional themes (“acknowledgement of parenthood” and “legacy”) that were prominent in mothers’ responses. The Preparedness for the decision driver was modified to reflect a decision-making spectrum where mothers were in favour, against or uncertain about autopsy for their baby. The modifications add fresh insights and deeper understanding of the decision-making process while also confirming the diversity and dual nature of decision drivers. The interrelatedness of decision drivers and their ability to work in concert or against each other was evident. This helps to explain why the decision can be so difficult for parents to make and for care providers to predict.

Consistent with other research⁸ parents wanted ‘consistent, factual and detailed information’ that was clear and timely. Caregivers must be mindful of the level of detail they provide and their verbal and non-verbal communication during autopsy discussions, but it is clear that parents want information about their options.

From a practical standpoint, parents need to know likely timelines, and the impact of decisions on these timelines, including recognition that for parents, those impacts extend well beyond the point of decision-making. Other practical information relates to baby’s care and opportunities to spend time with, and parent, their baby. Mothers want assurance that their

baby is being treated with kindness and respect, in the same way as living infants. Mothers want to be treated in the same way as mothers who have given birth to a live baby. Such treatment extends to the prompt and respectful communication of examination results, and where possible include a follow-up appointment with the clinician for specific review of findings of any investigations. This aspect of care was identified as in need of improvement in the survey

Although decision-making can be viewed as a point-in-time event, decisions are also processes, sometimes with long lasting consequences. Informing parents about longer-term consequences of decisions, that may not be apparent at the time, may help to reduce future decisional regret. Some mothers who chose not to have an autopsy regretted their decision in the context of future pregnancies.

Our large sample of survey responses is both a strength and a limitation. Survey data from 460 respondents provided a wider picture of women's experiences than would have been gained through in-depth interviews with a smaller sample. , however, we could not explore responses and their meanings beyond the words provided in open-text boxes. Framework analysis enabled exploration and expansion of an existing model derived from focus group data. The present study involved a larger, and broader, cross-section of mothers . although the representativeness of the sample is uncertain. The women were recruited mainly through parent organisations in Australia and New Zealand and chose to complete an online survey. These women were more highly educated than mothers of stillborn infants in the wider population. As with all retrospective survey designs the potential for recall bias needs to be acknowledged. Support for autopsy decision-making is integral to care after stillbirth and minimisation of regret is an important care outcome. A recent systematic review²⁴ found decisional conflict, limited information, and less involvement in decision-making predicted patient regret about medical decisions. The findings of the systematic review, coupled with

our finding that mothers who expressed regret or uncertainty (regardless of their decision) often raised concerns about limited information and decision-making autonomy, adds to calls to create environments and tools that support informative discussions with parents about autopsy^{9,11}.

Barriers to consent for autopsy identified in previous studies^{9,11,25} were confirmed in this study. Our findings help move beyond the description of barriers to understanding their role in decision-making. This signifies a shift from ‘what parents are saying’ to identifying implementable actions that support parents in practical, structured and auditable ways. In recognising the diversity and dual nature of decision influences, the DDM underlines the importance of tailored information.

The proliferation of decision support tools in some areas of health care corresponds with growing recognition of the benefits of shared decision-making^{26,27}. Presenting benefits, harms and uncertainties in structured formats enables consideration of these in relation to personal values and preferences²⁸, can increase patients’ knowledge of their options, and can reduce decisional conflict and the likelihood of later regret^{24,29}.

Improving care after stillbirth is a global challenge³⁰. Our findings reflect the experiences of mothers in Australia and New Zealand, but there is reason to expect generalizability to other high-income settings where similar barriers, shortcomings in care and lack of practical guidance and training for clinicians have been identified^{8,9,11,31}. Better care requires the development and testing of evidence-based interventions, including for autopsy decision-making. Taken together, these findings can be translated to a number of core attributes of parent-centred practice (Box 1) to inform the development of a decision support tool suitable for adaption and implementation in different settings.

Conclusion

Supporting parents in autopsy decision-making is an essential but challenging part of quality care after stillbirth. The support offered to parents when deciding about autopsy is an area that requires great care and consideration. Our findings are a first step in designing a support tool that can assist both parents and health care providers navigate the difficult conversations and decisions that follow stillbirth.

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