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# Decision influences and aftermath: parents, stillbirth and autopsy

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## Abstract

**Background** Stillbirth, among the most distressing experiences an adult may face, is also a time when parents must decide whether an autopsy or other post-mortem examinations will be performed on their infant. Autopsies can reveal information that might help explain stillbirth, yet little is known about how people make this difficult decision.

**Objectives** This study examines the influences on decisions about autopsy after stillbirth among Australian parents.

**Design** The study involved secondary analysis of transcripts of three focus groups using qualitative content analysis.

**Participants and setting** Seventeen parents of 14 stillborn babies participated in consultations around the revision of a perinatal mortality audit guideline.

**Results** Parents shared the decision making. Four decision drivers were identified: parents' preparedness or readiness to make decisions; parental responsibility; concern for possible consequences of an autopsy and the role of health professionals. Each decision driver involved reasons both for and against autopsy. Two decision aftermath were also present: some parents who agreed to an autopsy were dissatisfied with the way the autopsy results were given to them and some parents who did not have an autopsy for their infant expressed some form of regret or uncertainty about the choice they made.

**Conclusions** To make decisions about autopsy after stillbirth, parents need factual information about autopsy procedures, recognition that there might be fear of blame, an environment of trust, and health services and professionals prepared and skilled for difficult conversations.

## Introduction

Stillbirth is among the most distressing experiences an adult may face.[1–4] It is also reasonably common. In high-income countries, stillbirths occur 10 times more frequently than sudden infant deaths[1,5,6] and account for the majority of deaths around childbirth. Stillbirth is also a time when parents are faced with a most difficult decision: should an autopsy or other post-mortem examinations be performed on their infant? Infants who die before birth have different legal status to liveborn babies and the onus for decisions about autopsy for stillborn infants lies with their parents alone.[7]

Knowing the cause of a stillbirth is important to parents.[8,9] and an autopsy offers the best chance to explain why a death occurred.[10,11] However some stillbirths remain unexplained even after autopsy, though these may be reduced to less than one in seven.[10,12] Autopsies can provide information that helps with planning and managing future pregnancies,[13] can change diagnoses,[14] and may help with grief[15] or reassure parents that they were not to blame.[16]

However, perinatal autopsy has a fraught recent history. Practices in England exposed in the enquiry into child cardiac surgery in Bristol Royal Infirmary, particularly organ retention without explicit consent, are attributed to falls in perinatal post-mortem rates in several studies.[17–19] However, similar declines were seen in the previous decade[20] and are attributed to clinicians not routinely offering post-mortem examinations to parents.[21] It can be difficult for health professionals to raise the issue of autopsy after parents experience stillbirth[22] and to find the right way to give appropriate information sensitively.[21–23] A recent survey of lead maternity care providers in public hospitals in Australia and New Zealand found that while the vast majority supported the need to offer all parents high quality autopsy after stillbirth, most felt inadequately skilled to counsel parents about the option of the procedure.[24]

Autopsy rates for stillbirth vary considerably across jurisdictions for other reasons. Different definitions for stillbirth apply internationally making comparison difficult.[5] However, even within the same country, such as in Australia, there can be considerable variability. For example, approximately 50% of stillbirths undergo post-mortem examination in South Australia in 2009[25] compared with 30% in Queensland in the same year[26] and 68.5% in Western Australia for 2005–2007.[27]

There are also considerable variations in practice standards for perinatal post-mortem; clinical guidelines for perinatal mortality have been introduced in several countries to improve quality of post-mortem care and in the conduct of autopsies.[24,28,29] Parents are usually expected to make their decision about an autopsy within 24–48 h of delivery or knowledge of a stillbirth, and autopsies are typically performed within 24–48 h after permission is given. Generally, results are given to the medical practitioner providing care to the woman; however, there are no mandated standards. In Australia, pathology reports should be available within 6 weeks,[30] but staff shortages in some hospitals means that delays of up to 6 months may occur.[26]

Interventions to support people facing other difficult health choices are available but none address the issue of autopsy after stillbirth.[31] The structured approach of purpose-designed decision support tool offers benefits to both parents and health professionals and is likely to be useful. However, before a decision support intervention (DESI) can be developed for parents who experience stillbirth, we need to better understand the process of deliberation involved for parents deciding about autopsy after stillbirth. This is one of the two core components proposed as necessary for the development of a DESI.[32]

Relatively little is known about parents' perspectives of autopsy after stillbirth, including their reasons for consenting to or refusing an autopsy. Much of what we do know is inferred from small studies of parents with a broad range of loss, including termination, miscarriage and neonatal death.[9,18,33–35] Motives for autopsy identified in these studies may not always be relevant for stillbirth. For example, consent for autopsy examinations changes according to how long a baby survives after birth, falling in the first week then rising after 3 months of age,[18] or, if parents who have terminated a pregnancy are included by their need to confirm prenatal diagnostic tests.[35]

There are ethical and practical difficulties that limit studies in this area. Parents who have experienced stillbirth are a highly vulnerable group that can be difficult to reach. Secondary analyses are one way to make the most of data already available.[33,34]

This article uses previously collected data from focus groups with bereaved parents to gain greater understanding of parents' deliberations about autopsy after stillbirth.

## Method

This was a secondary analysis of focus group transcripts to generate information on parents' decisions about autopsy and associated issues.[36–39]

The transcripts were produced from recorded sessions undertaken as part of the consultation process in the revision of the perinatal mortality guideline developed by the Perinatal Society of Australia and New Zealand (PSANZ),[40] which aimed to gain insights into parents' experiences of communication around post-mortem investigations, particularly autopsy, to improve existing information for parents. The transcripts were de-identified by the use of pseudonyms.

### Initial data collection

Three focus group sessions were organized by the state-based consumer support group and charity, Stillbirth and Neonatal Death Support in Brisbane (SANDS, Qld)[41] and a national parent-based and research fundraising charity, Stillbirth Foundation Australia[42] in Sydney. These groups were active participants in the development of a perinatal mortality guideline for Australia and New Zealand.

Participants responded to invitations sent through newsletters and email networks. Seventeen parents of 14 stillborn babies (14 women and three men) took part. All men attended with their partner. At least two authors facilitated each session; one had oversight of the PSANZ guideline development and attended all three focus groups (VF), and at least one consumer group member was also present (LC and EM). Each focus group had four to seven participants. They were asked about their experience of stillbirth and the information given to them about the option of autopsy. The sessions, which were held in the usual meeting places of the consumer groups, were conducted in a similar manner to support group meetings; participants told their stories and answered questions from others in the group. The sessions took place in two Australian state capital cities, Brisbane and Sydney, in February 2007. In anticipation of the potential use of the data, written consent was given by all participants for the sessions to be audiotaped, transcribed and published.

### Ethics approval

Ethics approval for this study was given by La Trobe University Human Ethics Committee.

### Data analysis

Transcript data were imported into the NVivo computer-assisted data analysis program.[43] The analysis was concerned with the issues that the parents raised relating to decisions about autopsy. We used qualitative content analysis to answer the practical question of what influenced decisions[36,37] using a summative approach to identify meanings within the content.[38] Two authors (DH and VF) independently created subcategories, which were compared to the original coded meaning units or sets of words with same sense or meaning.[36] The analysis initially focussed on specific manifest content, that is, we looked for particular content in the data relating to: influences on parents' decisions and the impacts of decisions. Identified meaning units were condensed into over-arching themes that described the influences on parents' decisions about autopsy. This stage of the analysis was performed by one author (DH) who initially discussed and revised these findings with a second author (VF), before further consultation with all authors. In particular, the findings were confirmed with the consumer authors (LC and EML), who have spoken about this topic with a wide range of consumers personally affected by stillbirth. The consumer authors also advised on the language to be used. Quotations that typified the identified themes were selected from each transcript before a final selection was made.

## Results

### Participants

Demographic information was limited to information revealed by participants in the transcripts. There was no information about the ages of parents and limited information about employment. All babies were born within the previous 7 years, although precise details were not available for five babies. At least four babies were born in the 18 months prior to the focus groups, and five were born 2–7 years earlier. Seven babies were premature, ranging from 27 to 36 weeks gestation, and at least three were term (37–42 weeks) but there was no information on the gestational age of the remaining four babies in the transcripts. Autopsies were performed on eight of the 14 babies with the cause of death established in only one case (neonatal haemochromatosis). The cause of death was known for two of the six babies who did not have an autopsy; one died as a result of placental abruption and the other because of foetal maternal haemorrhage. The cause of death remained unknown for the remaining 11 babies.

### Sharing the decision

Parents talked of ‘we’ and ‘our’ in relation to their decisions around an autopsy indicative of joint decision making. In some cases, one partner took the primary responsibility but there consensus was evident:

> Georgina: 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. And then we went away and we talked about it. Should we, would we, the benefits in my time when I could speak about it. It wasn’t just in my face I had to make the decision it was mostly him actually. [Autopsy, 27 weeks]

One couple with different inclinations to autopsy decided against it, but did send the placenta for further post-mortem examination

> Rhonda: I’m from a medical background, so I didn’t mind the idea of an autopsy but [John] didn’t want it and I respected that. [No autopsy, 32 weeks]

### Decision drivers

Four major influences or decision drivers were identified in parents’ considerations of autopsy examination for their stillborn baby: preparedness to make decisions; parental responsibility; possible consequences and the role of health professionals. Each decision driver involved reasons for and against autopsy (see Table 1).

#### *Preparedness to make decisions*

The parents generally agreed that a decision about autopsy was difficult to make. For some parents, autopsy was an obvious choice and accepted it as part of their experience,

**Table 1** Decision drivers: reasons for and against autopsy after stillbirth

| Decision driver | Reason for autopsy | Reason against autopsy |
|---|---|---|
| Preparedness to make decisions | Certain of action to take<br>Confidence with scientific processes | Feeling overwhelmed or unable to take things in |
| Parental responsibility | Obligation to determine what went wrong<br>Consideration of needs of future children | Desire to protect baby from unnecessary harm |
| Possible consequences | Better peace of mind | Fear of blame for outcome |
| Role of health professionals | Supportive of autopsy | Unsupportive of autopsy |

> Carol: in terms of decision, it was just a no brainer …, we just said of course, this is something we wanted to do [Autopsy, 39 weeks gestation]

One reason for this response appeared to be the professional background of participants, which gave them confidence that a scientific process of enquiry would help explain what happened.

> David: I guess it was something, after working in science and so on. [Autopsy, 27 weeks gestation]

> Jane: I'm a social worker and I wanted an answer, so we had an autopsy. [Autopsy, 27 weeks gestation]

Familiarity with autopsy also seemed to help; one participant alluded to their previous experience of autopsy for a family member, another raised television dramas as contributing to their acceptance of the procedure. However, the issue was clearly more difficult for other parents. Some felt overwhelmed, unable to make such a decision or to give consent.

> Phillippa: We're both hazy, because my husband was as emotionally wrecked as I was. It was just too much all at once. [No autopsy, 42 weeks gestation]

### *Parental responsibility*

Parental responsibility was an issue for deliberation. Parents strongly desired to protect their baby from unnecessary harm, yet also felt an obligation to find out what had gone wrong. Concern about the impact of the procedure on the baby was a significant barrier to consent, particularly if some explanation for the death already existed. One father said 'it was a shame to disturb his little body'. This evidently swayed the mother, but she now appeared uncertain,

> Rhonda: And I agreed with it at the time, I thought: Well we have an answer why would we do this and waste resources? But I didn't even think, and I still don't know, what about organ donation? [No autopsy, 32 weeks gestation]

Other parents felt obliged to investigate any potential cause of death thoroughly. The need to know why was described by some as overwhelming, a need to, leave no stone unturned' or 'caring about why he died'.

Another aspect of parental responsibility was the consideration of future pregnancies—particularly the desire to avoid a similar fate for future children. This made autopsy necessary despite reservations about the impact of the process on the parent, which some saw as less important than knowing why.

### *Possible consequences*

Several women spoke of their fear that an autopsy would show that they were somehow to blame for their baby's death.

> Georgina: My biggest fear, and that's what a lot of people would have about it, is "oh shit, I might have done something wrong and now I'm going to be blamed". That was the one thing that was my… what if they find out I ate the wrong food or… because I had to find every reason why this wasn't me, that I didn't cause it and the autopsy would reveal that. So for the whole 8 weeks I had to wait for the results. [Autopsy, 27 weeks gestation]

The dilemma was that an autopsy was necessary to exonerate the mother but there was fear that it would not. One woman admitted that she viewed an autopsy that did not reveal a cause of death positively as she felt it would help her to cope with future pregnancies. However, in this case, the autopsy did explain the death and gave the parents new information to consider when planning for another baby.

### *Role of health professionals*

Health professionals, both doctors and midwives, influenced decisions about autopsy in important ways, both to encourage and discourage autopsy as an option. Parents spoke positively of health professionals who encouraged them to consider autopsy. They viewed their input into the decision making as supportive and offering hope. Several participants viewed the behaviour of some health professionals negatively. The parents felt actively discouraged to consider autopsy and expressed suspicion of their care providers' motives. These parents described the information flow as restricted and health professional behaviour as self-protective. One couple went so far as to get their autopsy report from an independent source.

Parents also felt health providers were caught unprepared for stillbirth and that this affected the management of their care. They reported encounters with health professionals who did not share information, who restricted access to additional information or who had poor skills in helping people with grief. One woman believed her doctor was misguided when he explained her situation as a once-a-year occurrence at that hospital as it made her feel 'alien'. Another reported a nurse telling her 'you're just going to have to face it. You're losing your baby'.

Parents also identified helpful behaviours among health professionals. Understanding the importance of the decision to parents was critical to perceptions of helpfulness. Several parents wanted more time to make their decision, and it helped one family that the option of autopsy was raised prior to the birth. Other participants did not have this opportunity but suggested health professionals should raise the issue more than once.

Parents also wanted more guidance from their doctors, and some felt that a doctor was better placed to make the decision. One parent contrasted the difference in shared decision making related to caesarean delivery where doctors are willing to make and guide decisions.

> Ruth: Your doctor makes other decisions for you like "labour is not progressing very well I think you should have a caesarean". They are quite happy to make those decisions and guide you so why is suddenly when things go wrong and its not the outcome that everyone wants everyone backs off and they are not that professional anymore. I don't understand. [No autopsy, 40 weeks gestation]

Another mother felt that while it is necessary to tell parents that an autopsy might not provide an explanation, it was important to give hope that a cause might be found.

### *Decision aftermath*

The decision about an autopsy was not the end of the issue for parents. Decisions have consequences. Two significant decision aftermath were described. Parents who decided to have an autopsy reported poor feedback processes of the autopsy findings. Parents who did not did have an autopsy reported regret about the choice they had made.

Making the decision to consent to autopsy was significant to parents, but several parents who did consent expressed dissatisfaction with the way health professionals gave the autopsy findings to them. One parent described the process as too quick and without any opportunity for appropriate information sharing. She described the experience as 'emotionally overwhelming'. Parents viewed the autopsy report as one way of reconnecting with their baby and felt this particular significance was not understood by health professionals.

> Jane: But for me I was very pleased to have the report. It was like another way of reconnecting with him. You get such a level of detail about your child that you wouldn't get in a different setting. I found it quite comforting…. [Autopsy, 27 weeks gestation]

Parents complained of misinformation, of being given the wrong results and of phone calls not returned.

> Jane: We basically case managed our own way through the system, because we didn't have a good experience of referral or follow-up at all… I was given the wrong results, over the phone, that my baby had no kidneys...when I finally got some information we were told that [baby] had no kidneys. And I thought, "Well how can that be so? We had a 19 week ultrasound, how can you tell me…"…. [Autopsy, 27 weeks gestation]

They expected reporting processes for all post-mortem examinations to be more formal, for the seriousness of the information and its potential impact on them to be recognized:

> Rhonda: I would like to have a formal meeting where everything is looked at. …he was looking in his filing system for it and he said 'I can't find [the pathology report of placenta] now' and I said 'I don't mind waiting' and he said 'oh no no no, I can't find it' and I thought gosh this is so important, just take a bit of time'. [No autopsy, 32 weeks gestation]

Despite these problems and the high proportion of unexplained death, no parent who consented to autopsy expressed regret about their decision in the focus group discussions. This response was typical:

> Claire: Because I'm not asking questions and I don't have the what if. And even though it was unexplained I did everything I could to find out for myself [Autopsy, 31 weeks gestation]

However, some form of regret or uncertainty about the choice made was common among those parents who did not have an autopsy, including realization of a missed opportunity to find a possible explanation for the baby's death. Even those parents with an explanation wondered if an autopsy could have told them more. Parents also raised doubts about other missed possibilities, such as organ donation or research, as part of their need to create some meaning from their loss.

> Ruth: We didn't have an autopsy. So you have to live with that unfortunately.... [No autopsy, 40 weeks gestation]

> Phillippa: It's all about finding why this has happened and if there's any possible way we can do that and we missed that opportunity and you can't get that back. You still have the guilt anyway. ... There was the guilt anyway, but if we could at least try narrow it down. Whether they could have answered that question: why he died, we don't know. But at least... [No autopsy, 42 weeks gestation]

## Discussion

This study showed that the deliberations about autopsy after stillbirth are complex and that difficult health decisions are not stand-alone events. The four key issues appeared to drive parents' decisions had dual natures and different levels of importance to the decision makers. We have not found this previously articulated in the literature. The dual nature of the decision drivers meant there were reasons to both support and oppose autopsy. These emotionally laden decisions create difficult decision environments where internal conflicts were largely unavoidable. There was some evidence of recognition heuristic,[44] where parents looked for decisions or information familiar to them in making their choice but it was beyond the scope of this study to determine how any individual decision theory applied to individuals. These decisions were also made by couples, which is an aspect of decision making that is yet to be addressed in the development of decision support interventions.[45,46]

Another important finding from this study is that health decisions were recognized to be not stand-alone events. There were anticipated consequences (such as reporting back autopsy findings), which were reported to be handled poorly, and unanticipated consequences (such as parents' regrets about decisions not taken), which were not considered.

Findings were consistent with studies involving parents considering autopsy following neonatal death and with a recent study in the United Kingdom. Specifically, the role of health professionals was important[18,33], and future decision supports in this area should possibly consider their use in face-to-face encounters with health professionals rather than as autonomous interventions.[45] The decision about autopsy was not independent of future decisions, and parents wanted information that might affect future pregnancies.[18] Parents did not consent to autopsy just to discover new information; they also consented to rule out possible causes, including personal and professional negligence.[18,33] Like other studies, concern about unnecessary harm was also given as a reason for refusal.[18] However, unlike other studies, parents in this study did not raise altruistic reasons, such as helping prevent stillbirths happening for others or research and teaching, as the basis of their consent.[18,33,35] This may be because, unlike other studies, participants in this study were not expressly asked about this.

The absence of formality in the process of sharing autopsy results was unexpected and unseemly to parents who felt the significance of their decision was not understood by health professionals who were possibly more focussed on the autopsy findings. It is consistent with the recognition that structured processes appear to help people through difficult decision making. Breeze *et al.*[47] found that the process of completing a survey on their decision making about autopsy helped parents to feel better about the decision that they had made. This augurs well for the benefits that a decision support intervention could offer parents.

Our study found that only parents who had not agreed to autopsy expressed regret. While this may be a consequence of selection bias, the finding is consistent with other studies, such as the survey to assess satisfaction with post-mortem examination among Australian women with different types of pregnancy loss, which also identified regret more commonly among those who did not consent to autopsy.[48] A larger survey in the UK of 166 women with pregnancy loss also found a higher rate of decision regret among those who refused autopsy, but again results were not reported separately for stillbirth.[49]

This study involves a hard-to-reach population, whose views are rarely heard, and there are several limitations. Similar to other studies,[33,34] this was a secondary analysis. Parents were not asked directly about the reasons for their decisions about autopsy; rather, these were derived from the latent content in the transcripts of focus group discussions. This means that we could not determine how well current decision models applied. It also might mean that important reasons were not raised or were overlooked in the analysis. However, the discussions focussed on communication of the option of autopsy, and themes were consistent across all the focus groups. It is highly likely that parents will raise issues important to them in discussions around such a critical subject. The second main limitation to this study is that there were relatively few participants, and they are unlikely to be representative of all parents experiencing stillbirth. Participants were involved with parent groups, which gave them opportunities to tell their story and become familiar with it, in ways that others parents of stillbirth might not. The process of reflection through story telling can change how people see their experience; they might reframe events, such as the reasons for their actions, to fit the narrative they tell themselves and others.[50] Participants were also self-selected, which may have attracted people with particular issues they wanted to be aired. The study relies on transcripts from focus groups, not interviews with individuals, which is also likely to have affected the type of data available for analysis. This could have both positive and negative affects, as the presence of others may influence the information disclosed. Some people may have felt inhibited or unduly influenced by other stories, but they may also have been more willing to talk about issues because they shared the experience of stillbirth with those in the group. Group members also questioned each other, which revealed new information.

Despite its limitations, this study does offer insight into the deliberation processes in the difficult decision of autopsy made by parents after stillbirth, which will be important in the development of decision support interventions. The study gives some indication of the information important to parents in making this decision and the range of emotions at play. Providing factual information about autopsy procedures and recognizing that women might be worried that they are to blame for their baby's death might help address fears. Women in this study spoke of obsessing about their behaviours and suggested quite high levels of stress while waiting for autopsy results. The majority of parents in this study consented to autopsy, but it is possible that fear of blame might be a significant deterrent among those who did not.

Second, an environment of trust is needed to facilitate the process of decision making and consent. Many parents wanted health professionals to help them with their decision making but they need to feel confident that any transparent procedures that exist are in their best interests and that issues are not obscured to protect possible incompetence among health professionals. Loss of trust in health professionals can be a significant impediment to informed decision making. This study showed that while many parents found health professionals to be supportive, others did not. Parents responded differently to their decision role, and some felt that care providers lacked objectivity and would have preferred to discuss options with a third party. This option was not made available to any of them. These issues suggest an appropriate decision support intervention would offer tangible benefits to health professionals and their relationships with those they care for at this difficult time.

The third observation is that greater care is needed when giving autopsy results to families. On the basis of the parents' narrations, greater care would mean a variety of processes ranging from issuance of the correct report to the correct parents, being acknowledged in a timely manner but allowing sufficient time for parents to respond to information contained in the reports, and acknowledging the gravity with which parents felt about their loss. Even autopsy examinations that are unable to explain the cause of death contain information precious to parents. The management of these and potentially other processes following an autopsy seem to be important and should be considered in the adoption of any decision support intervention into routine care.

Finally, health services and professionals need to be prepared for difficult conversations with parents. Unfortunately, stillbirths are not uncommon, but care providers seemed unprepared to care for parents when such unexpected events occur.[8,34] Parents' decisions about autopsy after stillbirth are likely to be influenced by their background, experiences and values,[51] but all parents should be given information about their options. Advice given with authority and sensitivity will support them.[52,53] This further supports the need for a decision support intervention for decision making about autopsy after stillbirth.

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## References

1 Cacciatore J, Schnebly S, Froen JF. The effects of social support on maternal anxiety and depression after stillbirth. *Health and Social Care in the Community*, 2009; **17:** 167–176.

2 Frøen JF, Cacciatore J, McClure EM *et al*. Stillbirths: why they matter. *Lancet*, 2011; **377:** 1353–1366.

3 Sutan R, Amin RM, Ariffin KB, Teng TZ, Kamal MF, Rusli RZ. Psychosocial impact of mothers with perinatal loss and its contributing factors: an insight. *Journal of Zhejiang University, Science, B*, 2010; **11:** 209–217.

4 Gausia K, Moran AC, Ali M, Ryder D, Fisher C, Koblinsky M. Psychological and social consequences among mothers suffering from perinatal loss: perspective from a low income country. *BMC Public Health*, 2011; **11:** 451.

5 Frøen JF, Gordijn SJ, Abdel-Aleem H *et al*. Making stillbirths count, making numbers talk – Issues in data collection for stillbirths. *BMC Pregnancy and Childbirth*, 2009; **9:** 58–74.

6 Smith GC, Fretts RC. Stillbirth. *Lancet*, 2007; **370:** 1715–1725.

7 Gould S. Are perinatal deaths adequately scrutinised? *Archives of Disease in Childhood Fetal and Neonatal Edition*, 2011; **96:** F241–F242.

8 Gold KJ. Navigating care after a baby dies: a systematic review of parent experiences with health providers. *Journal of Perinatology*, 2007; **27:** 230–237.

9 Samuelsson M, Rådestad I, Segesten K. A waste of life: fathers' experience of losing a child before birth. *Birth*, 2001; **28:** 124–130.

10 Flenady V, Middleton P, Smith GC *et al*. Stillbirth: the way forward in high-income countries. *The Lancet*, 2011; **377:** 1703–1717.

11 Gordijn SJ, Erwich JJ, Khong TY. Value of the perinatal autopsy: critique. *Pediatric and Developmental Pathology*, 2002; **5:** 480–488.

12 Dickinson JE. The continuing dilemma of stillbirth. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 2011; **51:** 1–2.

13 Robson SJ, Leader LR, Bennett MJ, Dear KB. Do women's perceptions of care at the time of unexplained stillbirth influence their wishes for management in subsequent pregnancy? An Internet-based empirical study *Journal of Obstetrics and Gynaecology Research*, 2010; **36:** 108–114.

14 Wagner CL, Goldstein M, Conradi SE. Changing a diagnosis: the importance of neonatal autopsy. *Journal of Perinatology*, 2005; **25:** 69–71.

15 Sullivan J, Monagle P. Bereaved parents' perceptions of the autopsy examination of their child. *Pediatrics*, 2011; **127:** e1013–e1020.

16 Flenady V, Silver RM, Incerpi M *et al*. Essential diagnostic workup of stillbirths. In: Facchinetti F, Dekker G, Baronciani DB, Saade G (eds) *Stillbirth: Understanding and Management*. London: Informa Healthcare, 2009: 71–90.
17 Khong TY, Arbuckle SM. Perinatal pathology in Australia after Alder Hey. *Journal of Paediatrics and Child Health*, 2002; **38:** 409–411.
18 McHaffie HE, Fowlie PW, Hume R, Laing IA, Lloyd DJ, Lyon AJ. Consent to autopsy for neonates. *Archives of Disease in Childhood Fetal and Neonatal Edition*, 2001; **85:** F4–F7.
19 Adappa R, Paranjothy S, Roberts Z, Cartlidge PH. Perinatal and infant autopsy. *Archives of Disease in Childhood Fetal and Neonatal Edition*, 2007; **92:** F49–F50.
20 Brodlie M, Laing IA, Keeling JW, McKenzie KJ. Ten years of neonatal autopsies in tertiary referral centre: retrospective study. *British Medical Journal*, 2002; **324:** 761–763.
21 Rose C, Evans M, Tooley J. Falling rates of perinatal postmortem examination: are we to blame? *Archives of Disease in Childhood Fetal and Neonatal Edition*, 2006; **91:** F465.
22 Khong TY. Improving perinatal autopsy rates: who is counseling bereaved parents for autopsy consent? *Birth*, 1997; **24:** 55–57.
23 Snowdon C, Elbourne DR, Garcia J. Perinatal pathology in the context of a clinical trial: attitudes of neonatologists and pathologists. *Archives of Disease in Childhood Fetal and Neonatal Edition*, 2004; **89:** F204–F207.
24 Flenady V, Mahomed K, Ellwood D *et al*. Uptake of the Perinatal Society of Australia and New Zealand perinatal mortality audit guideline. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 2010; **50:** 138–143.
25 Maternal Perinatal and Infant Mortality Committee. *Maternal, Perinatal and Infant Mortality in South Australia 2009*. Adelaide, SA: SA Health, 2011.
26 Humphrey M. *Queensland Maternal and Perinatal Quality Council Report 2011. Maternal and Perinatal Mortality and Morbidity in Queensland*. Brisbane, Qld: Queensland Health, 2011.
27 Perinatal and Infant Mortality Committee of Western Australia. *The 13th Report of the Perinatal and Infant Mortality Committee of Western Australia for Deaths in the Triennium 2005–07*. Perth: Department of Health Western Australia, 2010.
28 American College Obstetricians Gynecologists. ACOG Practice Bulletin No. 102: management of stillbirth. *Obstetrics and Gynecology*, 2009; **113:** 748–761.
29 Maternal-Fetal Medicine Committee, Clinical Practice Obstetrics Committee, Leduc L *et al*. Stillbirth and bereavement: guidelines for stillbirth investigation. *Journal of Obstetrics and Gynaecology Canada*, 2006; **28:** 540–552.
30 National Pathology Accreditation Advisory Council. *Requirements for the Facilities and Operations of Mortuaries*, 2nd edn. Canberra: Australian Government Department of Health and Ageing, 2009.
31 Stacey D, Bennett CL, Barry MJ *et al*. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*, 2011; **10:** 1–213. Article number CD001431.
32 Elwyn G, Miron-Shatz T. Deliberation before determination: the definition and evaluation of good decision making. *Health Expectations*, 2009; **13:** 139–147.
33 Snowdon C, Elbourne DR, Garcia J. Perinatal pathology in the context of a clinical trial: attitudes of bereaved parents. *Archives of Disease in Childhood Fetal and Neonatal Edition*, 2004; **89:** F208–F211.
34 Hunt K, France E, Ziebland S, Field K, Wyke S. ‘My brain couldn’t move from planning a birth to planning a funeral’: a qualitative study of parents’ experiences f decisions after ending a pregnancy for fetal abnormality. *International Journal of Nursing Studies*, 2009; **46:** 1111–1121.
35 Breeze ACG, Statham H, Hackett GA, Jessop FA, Lees CA. Perinatal postmortems: what is important to parents and how do they decide? *Birth*, 2012; **39:** 57–64.
36 Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 2004; **24:** 105–112.
37 Cohen DJ, Crabtree BF. Evaluative criteria for qualitative research in health care: controversies and recommendations. *Annals Family Medicine*, 2008; **6:** 331–339.
38 Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qualitative Health Research*, 2005; **15:** 1277–1288.
39 Patton MQ. *Qualitative Research and Evaluation Methods*, 3rd edn. Thousand Oaks, CA: Sage, 2002.
40 Flenady V, King J, Charles A *et al*. *PSANZ Clinical Practice Guideline for Perinatal Mortality Version 2.2. 2*, 2nd edn. Brisbane, Qld: PSANZ, 2009.
41 SANDS (Qld) Inc. *SANDS (Qld) Inc Stillbirth and Neonatal Death Support Queensland Incorporated including Miscarriage Support*. Brisbane: SANDS (Qld) Inc., 2010.
42 Stillbirth Foundation Australia Inc. *Stillbirth Foundation Australia. Little feet taking big steps ...to reduce stillbirth*. Sydney: Stillbirth Foundation Australia Inc., 2011.
43 QSR NVivo. *NVivo 8*. 2009.
44 Elwyn G, Stiel M, Durand MA, Boivin J. The design of patient decision support interventions: addressing

the theory-practice gap. *Journal of Evaluation in Clinical Practice*, 2011; **17:** 565–574.

45 Elwyn G, Frosch D, Volandes AE, Edwards A, Montori VM. Investing in deliberation: a definition and classification of decision support interventions for people facing difficult health decisions. *Medical Decision Making*, 2010; **30:** 701–711.

46 Han PKJ, Klein WMP, Arora NK. Varieties of uncertainty in health care: a conceptual taxonomy. *Medical Decision Making*, 2011; **31:** 828–838.

47 Breeze AC, Statham H, Hackett GA, Jessop FA, Lees CC. Attitudes to perinatal postmortem: parental views about research participation. *Journal of Medical Ethics*, 2011; **37:** 364–367.

48 Rahman HA, Khong TY. Perinatal and infant postmortem examination. Survey of women's reactions to perinatal necropsy. *British Medical Journal*, 1995; **310:** 870–871.

49 Rankin J, Wright C, Lind T. Cross sectional survey of parents' experience and views of the postmortem examination. *British Medical Journal*, 2002; **324:** 816–818.

50 Frank A. *The Wounded Storyteller—Body, Illness, and Ethics*. Chicago, IL: University of Chicago Press, 1995.

51 Smith SK, Dixon A, Trevena L, Nutbeam D, McCaffery KJ. Exploring patient involvement in healthcare decision making across different education and functional health literacy groups. *Social Science & Medicine*, 2009; **69:** 805–1812.

52 Bourne S, Lewis E. Perinatal bereavement. *British Medical Journal*, 1991; **302:** 1167–1168.

53 Fox R, Pillai M, Porter H, Gill G. The management of late fetal death: a guide to comprehensive care. *British Journal of Obstetrics & Gynaecology*, 1997; **104:** 4–10.