

# Improving uptake of perinatal autopsy

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## **Abstract – 200**

**Purpose of review:** Uptake of perinatal autopsy has declined in the West over the past 30 years, largely due to reduced parental acceptance of a traditional invasive autopsy. Several studies have recently investigated the decline to identify the key factors and how they may be mitigated against.

**Recent findings:** Three main themes were identified that have been found to improve uptake of perinatal autopsy; 1) improved communication, in particular ensuring the consent process was conducted as a conversation with time spent talking through the procedure and allowing time for questions; 2) health professional training to ensure staff discussing autopsy with parents have adequate understanding of the procedure and are able to convey confidence and empathy, and 3) availability of less invasive autopsy, including non-invasive as well as minimally invasive options. These should be offered alongside standard autopsy, which some parents may still prefer.

**Summary:** This review highlights that the discussions that take place, and the options that are available to parents, can profoundly impact whether or not they consent to autopsy investigation. Further research should focus on the impact of offering less invasive options as well as evaluating the training and support materials that have recently been developed.

**Keywords:** perinatal autopsy, perinatal post-mortem, uptake, barriers, facilitators

## **Background**

Of the 2060 babies born in the United Kingdom (UK) every day in 2018, eight babies were stillborn, 515 were miscarried, and there were a further 2131 neonatal deaths (1). Standard perinatal autopsy results in clinically significant findings in 40-70% of cases depending on the type of loss (2) and is the single most useful investigation to establish cause of death (3). The potential value of autopsy for parents is to establish the cause of the loss and provide answers for bereaved parents, help in the grieving process, and provide information regarding the recurrent risk for future pregnancies. It is also a valuable pathology audit and clinical governance tool (3). Despite this, consent rates for perinatal autopsy have dropped significantly in the United Kingdom (UK) (4-6) Western Europe (7, 8) and the USA (9, 10) over the past 30 years. According to recent data, less than half of parents in the UK who have experienced fetal loss, stillbirth, fetal or neonatal death, consent for standard autopsy examination (6). Without an autopsy, many parents are left with no understanding of the cause of their baby's death, and studies have shown that some parents who initially decline, later regret their decision (11, 12).

Research has shown that parents want an autopsy for numerous different reasons. These include: to better understand and process their child's death (13); to understand the risk of recurrence in future pregnancies (14); to advance medical knowledge (15); for 'finality' or 'closure' after the loss (16); and to rule out self-blame (11). A recent systematic review identified a number of reasons for the low uptake of autopsy in the perinatal setting (17). These include parental dislike of the invasiveness of the procedure, wanting to protect the baby from further harm, practical aspects around

transferring the baby to another hospital, poor communication between professionals and parents about the procedure, and an ambivalence about the value of the procedure from health professionals themselves (17). Education and socio-economic status may also play a role (18, 19).

Cultural and religious objections have also been identified as important, particularly in those countries with large Muslim populations (20). Whilst most major religions do not explicitly prohibit autopsy, standard autopsy is not permitted in Islam and Judaism.

For both these religions, cutting and disfigurement of the deceased, and removal of internal organs, tissue and fluids is forbidden, and there is a religious requirement to bury the body as soon as possible (21-24). The only caveat to this is where it is required by law, or would directly save another life (23, 25, 26). As such, uptake amongst these communities tends to be even lower than the general population (27, 28).

A number of studies have been conducted in the last couple of years to explore how uptake of perinatal autopsy might be improved. These have highlighted the importance of three main factors: communication, training and less invasive approaches.

## **Communication**

Communication has been identified as key to improving uptake of perinatal autopsy. Schirmann et al. (29) conducted a large survey study in Australasia which showed that mothers who had experienced stillbirth wanted support and guidance from health professionals that was consistent, factual and detailed. This included information

about autopsy, alternative investigations and their related timelines, where the baby was being kept, how the baby would be cared for during the autopsy, as well as prompt and respectful communication of results.

Lewis et al. (30) conducted qualitative analysis on free-text survey responses from bereaved parents as well as interviews with bereaved parents, parent advocates and health professionals, to explore the factors that act as facilitators or barriers to autopsy. Their findings revealed that parents were more likely to consent to autopsy if consent was conducted as a conversation with time spent talking through the procedure and allowing time for questions, if specialist staff conveyed confidence and empathy and were open and honest, and if there was reassurance that the baby would be treated with dignity and respect. Through that work they identified a series of 'decisional drivers', that were particularly important for those parents that were initially undecided or ambivalent about autopsy. These were: the initial approach; whether or not there was time for adjustment and deliberation; the discussion about the procedure; and the formal consent process. The way in which these moments were managed by healthcare staff significantly impacted whether or not parents consented to autopsy. For example, there were examples of healthcare staff briefly mentioning autopsy as a "tick-box" exercise rather than a core component of ongoing care, which was more likely to result in parents declining. They made a series of recommendations for practice when discussing autopsy with bereaved parents including routinely approaching everyone, providing written materials from leading support charities, and presenting autopsy as a core component of the ongoing care of the baby (Figure 1).

## Training

A number of studies have flagged up the importance of training in order to address some of the current barriers to uptake. Spierson et al. (31) explored neonatal healthcare professionals' experiences, knowledge, and views regarding the consent process for autopsy examination after neonatal death through an online survey. Of the respondents, 69.4% had observed an autopsy, and those professionals had greater confidence in consenting parents and were more satisfied with their training. Whilst that study is limited by a low response rate, it does highlight the value of observing the procedure. They concluded that in addition to knowledge about the procedure, education regarding autopsy should also include managing parents' emotional needs and developing a rapport with parents, as these were identified as significant barriers.

The findings from that study echo the findings of an audit conducted in a large teaching hospital in Ireland. Despite 64% of neonatal health professionals saying that they had discussed perinatal autopsy with a mother, self-reported levels of understanding of autopsy were found to be low with just 10% reporting 'excellent understanding' (32). These audit results highlight the need for further education among all staff working with bereaved families. Following that study, education sessions were arranged in the hospital for key healthcare professionals to clarify the procedure for perinatal autopsy. Education and training needs were also identified in a mixed-methods study looking at reasons behind low autopsy acceptance after stillbirth in a disadvantaged district in France (18), where only 39% of families agreed to an autopsy. The importance of training to ensure healthcare professionals understand the value of carrying out

autopsies, and developing policies to improve communication, were suggested to improve uptake.

### **Less invasive autopsy**

Traditional standard autopsy, based on dissection, has remained largely unchanged for hundreds of years. However, a number of less invasive techniques have been developed in recent years in an attempt to improve uptake rates and reduce concerns around the invasiveness of the procedure (33). One promising approach is the use of cross-sectional imaging techniques, in particular magnetic resonance imaging (MRI), which can also be used to guide further tissue-sampling techniques (34-37).

Several imaging modalities are becoming important in different contexts, for example the use of post mortem magnetic resonance imaging (MRI) in larger fetuses, post mortem ultrasound and micro-CT techniques in smaller fetuses, and post mortem CT in childhood deaths (38). The majority of trials report diagnostic accuracy of >75%, particularly for MRI, and are currently used as an adjunct to conventional autopsy to provide pre-autopsy imaging data. More recent advances in laparoscopic and image-guided approaches now mean that tissue can be acquired from the body without the cosmetic disfigurement of a standard autopsy (39, 40). These developments should encourage highly accurate imaging as the first step in autopsy, with parents advised about the possible subsequent need for tissue sampling in their particular instance, regarding tissue abnormalities that have been identified or the absence thereof. A “normal” post mortem imaging examination allows clinicians to focus investigations towards the mother or placenta, rather than the baby, but the psychological “value” of

a normal imaging examination is yet to be fully assessed. Understanding the limitations of these techniques, such as natural limits of resolution with smaller fetuses (41) or the effect that maceration has on diagnostic accuracy (42, 43), will further inform a patient-centred / tailored approach.

### **Parental views on less invasive approaches**

Recent studies have highlighted that less invasive methods of autopsy are likely to improve uptake in the perinatal setting (19). In a mixed-methods study comprising 850 surveys and 20 interviews with parents who had experienced perinatal loss, over 90% of participants indicated that they would consent to some form of less invasive autopsy if it were available. Overall, 54% would consent to standard autopsy, 74% would consent to a minimally invasive autopsy which included imaging as well as tissue biopsy, and 77% of participants would consent to a non-invasive autopsy involving imaging only. Qualitative findings suggested that parents valued a non-invasive autopsy because the lack of any incisions allowed the baby to 'rest in peace' and put parents more 'at ease' consenting the procedure. Parents valued a minimally invasive approach because it enabled tissue samples to be taken without requiring large incisions to the body. Interestingly, 8% of participants would still choose standard autopsy over less invasive procedures, primarily because it was associated with 'taking all steps possible', and potentially gave 'the best chance of determining the cause of death'. This highlights the importance of offering parents a choice around autopsy.



Less invasive procedures have also been shown to be more acceptable, and therefore potentially increase uptake rates, amongst parents from the Muslim or Jewish faith. In a qualitative study comprising interviews with religious leaders and parents from the Muslim and Jewish community in the UK, a non-invasive approach was perceived as being religiously permissible because it did not require incisions or interference with the body (44). A minimally invasive autopsy was less acceptable than a non-invasive approach as it still required incisions to the body, although in those circumstances where it was required by law it was more acceptable than a standard autopsy. During focus group discussions with community members, the majority of participants indicated they would potentially consent to a non-invasive approach if the body could be returned for burial within 24 hours, or if a family had experienced multiple fetal/pregnancy losses and the information gained might be useful in future pregnancies. A minimally invasive approach was less acceptable than a non-invasive approach, but around half of participants said they may consent to this.

High acceptability of less invasive approaches to perinatal autopsy has also been found in studies in countries with large Muslim populations. In a qualitative study conducted in Pakistan, parents and religious leaders recognised the need for less invasive autopsy in cases where couples had experienced multiple stillbirths, neonatal deaths and miscarriages, provided that the deceased is respected and buried as soon as possible and parents are counselled appropriately (45).

## **Conclusion**

The loss of a baby is an exceptionally difficult and challenging time for parents. Women who have experienced miscarriage, stillbirth or neonatal death have been found to experience depression, anxiety and post-traumatic stress disorder as a result, which can have a long term effect on their mental health, as well as attachment disorders with their current or future children (1, 46-48). A significant amount of research has been conducted in the past couple of years to examine the current barriers and facilitators to parental consent for perinatal autopsy. This review highlights that the discussions that take place during that time, and the options that are available, can impact whether or not parents consent to an autopsy investigation.

A great deal of work has been conducted recently to improve the communication and training health professionals receive, as well as the support available for parents making decisions about autopsy. This has included animations created with parents to dispel some of the myths surrounding autopsy and to ensure parents have clear and accurate information (49), training videos specifically to support staff breaking bad news as well as to have discussions around autopsy examination (50), training for health professionals around consenting for autopsy from the new National Bereavement Pathway (51) and training for health professionals to better understand and meet the needs of bereaved parents (52). Such resources are important to ensuring more consistent and high-quality discussions which may in turn improve uptake rates in this setting. Further research to understand the impact of recently developed resources, as well as research to understand the impact of offering less invasive autopsy to parents, is vital to improve our understanding of the current

barriers and drivers for consenting to perinatal autopsy. This is where our collective efforts should now be focused.

### **Key points**

- Communication around autopsy is key, and can improve uptake of perinatal autopsy, when delivered sensitively, at an appropriate time, and with confidence and knowledge of the procedure.
- Training should be provided to all healthcare staff talking to parents about autopsy investigation to ensure they have sufficient knowledge about the procedure, and are equipped to manage parents' emotional needs.
- Less invasive methods of autopsy investigation are likely to improve uptake, and address concerns about the invasiveness of standard autopsy, which is particularly important for some religious groups, but further research will evaluate whether improved uptake occurs in practice.

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## Bullets and annotations

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Lewis C, Riddington M, Hill M, et al. Availability of Less Invasive Prenatal, Perinatal and Paediatric Autopsy will Improve Uptake Rates; A Mixed Methods Study with Bereaved Parents. BJOG : an international journal of obstetrics and gynaecology. 2019;126(6).

*This is the largest UK study comprising 859 survey responses and 20 interviews with bereaved parents exploring parental views, preferences and hypothetical uptake of less invasive autopsy. The findings suggest the potential for a significant overall increase, which could be as high as 90%, if less invasive methods were available.*

Sauvegrain P, Carayol M, Piedvache A, et al. Low autopsy acceptance after stillbirth in a disadvantaged French district: a mixed methods study. BMC Pregnancy Childbirth. 2019;19(1):117.

*Mixed-methods study conducted in a disadvantaged district in France which shows that the proportion of women accepting an autopsy was lower than previous estimates of autopsy acceptance from studies in France, suggesting that socio-economic factors may impact autopsy uptake.*

Lewis C, Riddington M, Hill M, et al. "The communication and support from the health professional is incredibly important": A qualitative study exploring the processes and practices that support parental decision-making about postmortem examination Prenatal diagnosis. 2019;39(13).

*Mixed-methods qualitative study which highlights the various factors found to impact on whether or not women consent to autopsy. A number of recommendations are made regarding 'good practice'.*

Spieron H, Kamupira S, Storey C, et al. Professionals' Practices and Views regarding Neonatal Postmortem: Can We Improve Consent Rates by Improving Training? Neonatology. 2019;115(4):341-5.

*Online survey of neonatal healthcare providers in the UK which underscores the importance of observing an autopsy for staff who are discussing the procedure with parents as it improved satisfaction with their and confidence in the procedure*

Cullen S, Mooney E, Casey B, et al. An audit of healthcare professionals' knowledge regarding perinatal autopsy. Ir J Med Sci. 2019;188(2):583-5.

*Audit of healthcare professionals' knowledge which shows that healthcare professionals who discuss autopsy with parents find the conversation difficult and self-report levels of understand are low.*

Hutchinson JC, Shelmerdine SC, Lewis C, et al. Minimally invasive perinatal and pediatric autopsy with laparoscopically assisted tissue sampling: feasibility and experience of the MinImAL procedure. Ultrasound in obstetrics & gynecology : the official journal of the International Society of Ultrasound in Obstetrics and Gynecology. 2019;54(5):661-9.

*Minimally invasive autopsy with laparoscopically (MinImAL) assisted sampling provided good histological yield from major organs with minimal cosmetic damage in 103 unselected fetal, neonatal or paediatric deaths. The "unexplained" rate in stillbirths and intrauterine fetal deaths that underwent MinImAL autopsy was not significantly different from that following standard autopsy.*

Shelmerdine SC, Hutchinson JC, Ward L, et al. Feasibility of INTACT (INcisionless TArgeted Core Tissue) biopsy procedure for perinatal autopsy. *Ultrasound in obstetrics & gynecology : the official journal of the International Society of Ultrasound in Obstetrics and Gynecology*. 2020;55(5):667-75.

*Needle biopsy of organs via the umbilical cord, performed under ultrasound guidance, gave an overall biopsy success rate of over 75%. This novel technique offers the ideal combination of an imaging-led autopsy with organ sampling for parents who decline the conventional invasive approach.*

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Schirmann A, Boyle FM, Horey D, et al. Understanding mothers' decision-making needs for autopsy consent after stillbirth: Framework analysis of a large survey. *Birth (Berkeley, Calif)*. 2018;45(3):255-62.

*Analysis of qualitative survey responses which found four “decision drivers”, each of which have the capacity to influence decisions for or against autopsy: preparedness for the decision; parental responsibility; possible consequences; and role of health professionals. The findings are a first step in designing a support tool that can assist both parents and health care providers to navigate the difficult conversations and decisions that follow stillbirth.*

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