

Original Research

Consent for paediatric and perinatal postmortem investigations: Implications of less invasive autopsy

L. Judge-Kronis^a, J.C. Hutchinson^{a,b}, N.J. Sebire^{a,b,1}, O.J. Arthurs^{b,c,*}^a Department of Histopathology, Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK^b Institute of Child Health, UCL, London, UK^c Department of Radiology, Great Ormond Street Hospital for Children NHS Foundation Trust, London WC1N 3JH, UK

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ABSTRACT

The majority of perinatal and paediatric deaths do not fall within the jurisdiction of the Coronial medico-legal system; the decision to consent to autopsy is a personal choice, made by parents on behalf of their child in order to better understand the circumstances of their death, to answer specific questions or to improve the process for others. Professionals seeking to obtain informed consent should understand the general autopsy process as well as the complete range of options available, with their advantages and disadvantages for specific clinical scenarios. This article summarises the principles of obtaining consent for perinatal or paediatric autopsy in the UK at the time of publication.

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1. Introduction

In the UK, permission to carry out any aspect of paediatric or perinatal autopsy is usually provided by the parents, unless the case falls within the jurisdiction of Her Majesty's Coroner (or Procurator Fiscal in Scotland) or the Police. The consent process is directed by guidance provided by the Human Tissue Authority (HTA), requiring consent to be obtained from those with a 'qualifying relationship' to the deceased, usually the parents or legal guardians. Consent in this context is not a single 'act' but rather a process that establishes permission to carry out investigations that the parents agree can take place.

Investigation after death should be viewed as a continuation of patient care and a professional service that can be offered to parents. Perinatal autopsy remains the most useful method to understand the cause and mechanisms of death, and changes the provisional antemortem clinical diagnosis in 35–75% of cases [1]. The consent process should offer the parents all suitable and

available options regarding further tests and examinations for their child depending on the medical history and clinical circumstances, and the parents should be given as much information as they require to decide what is best for their child.

Obtaining informed consent from a bereaved parent can be challenging, and parents' perceptions play a pivotal role [2]. Almost twice as many parents who decline any form of postmortem examination, later regret their decision (compared with those who accepted the offer) [3]. Parents' needs include impartial, accessible and objective information delivered by empathic and sensitive caregivers, so that they can make choices consistent with their values [3]. An autopsy forms part of the bereavement process, and can help many bereaved parents reach some "closure". This article aims to outline how to obtain informed consent in a clear and professional manner, with the ultimate aim that the parents feel that their child is receiving the best possible care.

2. Principles of consent

The principles of obtaining consent for perinatal autopsy are:

1. Consent should be obtained by an experienced and appropriately trained professional, who is respectful of the parents' wishes.
2. The parents should be fully informed regarding all options. They should be approached at a suitable time, by a member of the

* Corresponding author at: Great Ormond Street Hospital for Children NHS Foundation Trust, London WC1N 3JH, UK.

E-mail addresses: Lydia.Judge-Kronis@gosh.nhs.uk (L. Judge-Kronis), Ciaran.Hutchinson@gosh.nhs.uk (J.C. Hutchinson), Neil.Sebire@gosh.nhs.uk (N.J. Sebire), owen.arthurs@gosh.nhs.uk (O.J. Arthurs).

¹ Paediatric and Developmental Pathology, Department of Paediatric Pathology, Camelia Botnar Laboratories, Great Ormond Street Hospital for Children NHS Foundation Trust, London WC1N 3JH, UK.

- team they have a rapport with and should not feel pressurized.
3. The parents should understand the specific procedure which they are consenting to, including current practice and any recent developments.
 4. All parties should be made aware of the specific medico-legal framework, under the guidance of the UK Human Tissue Authority (HTA).

The team should manage parental expectations regarding the timescale, process and outcome of the investigation, so that they are realistic. Unfortunately, there is limited published evidence to support the effectiveness of various methods to help parents who have experienced a bereavement decide whether to have further postmortem investigations, and most discussions rely on the ad hoc knowledge and experience of those involved at the time [4].

3. Consenting to care after death

3.1. General considerations

All parents should be offered the opportunity to discuss having a postmortem examination of their baby, in order to make an informed choice. Even when prepared with a good understanding of the available options, the process of taking consent for post-mortem investigations is not easy, since each family's concerns and priorities may differ. However, several questions that should be considered in all cases are: Should the police or HM Coroner be involved (as this may take precedence over parental choice)? Is consent necessary for the procedure to be performed? When should the consenting process begin? Are there any particular circumstances that will affect the timing of any conversations? Where will the discussion occur and who should lead this? Is an interpreter required? When will the different parts of the procedure be carried out? What are the time scales relevant for this child? Which research projects are currently available? Where is stored material kept? What happens if the parents change their mind?

3.2. Who should ask for consent?

Seeking informed consent for autopsy should be viewed by the clinical team as a continuation of care around end of life issues, to help explain what will happen to their baby/child following the death (Fig. 1). The primary consent taker should have adequate knowledge of all aspects of the options available to parents. Ideally, they will be someone from the end of life of clinical care teams, such as bereavement midwife, who is trained to obtain consent. Such staff should be experienced in postmortem work and end of life issues. It is useful if they have themselves witnessed various types of post-mortem examinations, although they are not expected to be adept at carrying one out [3]. Although taking consent as part of a team can be an effective way to work with parents, someone familiar to the family may be able to highlight particular parental needs and better detect non-verbal communication during the process. A named professional to contact can also be useful for future questions the family may have. Conversely, parents may ask questions outside of the area of expertise and knowledge of any individual team member, medical or otherwise, and other team members should be available if required.

Staff should have received recent training on bereavement, although access to such training may be variable. They should be familiar with the local postmortem practices and procedures for their institution, the written information that is given to parents, as well as several online booklets available through charities such as the Stillbirth and Neonatal Death Charity (Sands) [5–9].

There are many choices for parents to make, and medical professionals may feel that they know what would be of most benefit to the parents, but the importance of objectivity and impartiality in the process cannot be overstated. Some healthcare professionals may suggest that a post-mortem examination is not necessary, as the cause of death is adequate [10,11]. In such circumstances, the quality of the information given to parents by healthcare professionals, as well as the personal beliefs of the consent taker, have been identified as potential barriers to some parents consenting to a post-mortem [3,12,13]. Professional staff training may help to remove these barriers.

Assurance of continuity of care often contributes to the decision to consent to autopsy. It is of utmost importance to most

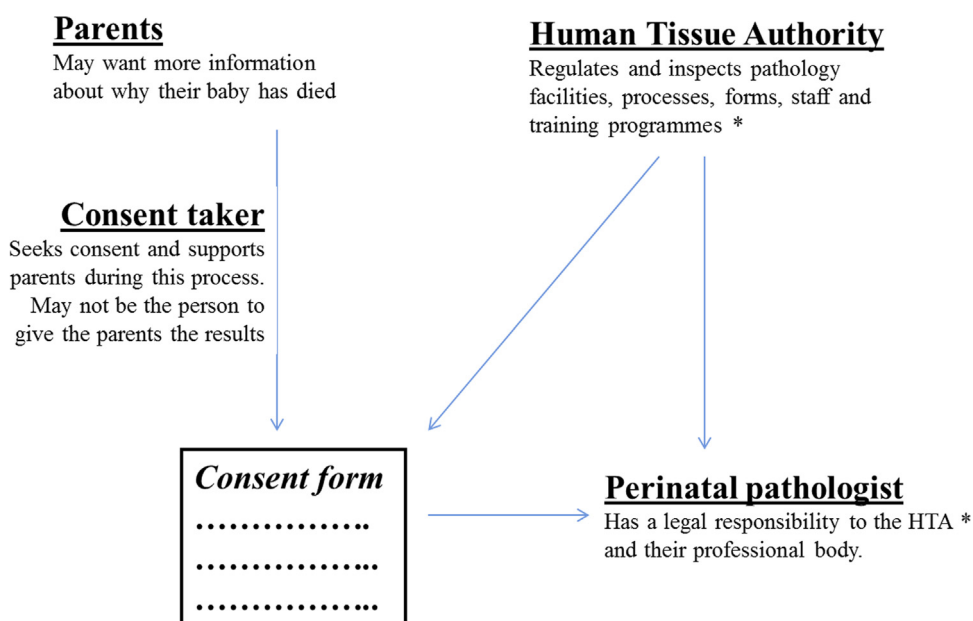


Fig. 1. Consent for a perinatal post-mortem examination. *The HTA regulates facilities in England, Wales and Northern Ireland. This is done by a separate body in Scotland. Reproduced with permission from Sands [9].

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