



Professionals' practices and views regarding neonatal post mortem – can we improve consent rates by improving training?

DOI:

[10.1159/000496704](https://doi.org/10.1159/000496704)

Document Version

Accepted author manuscript

[Link to publication record in Manchester Research Explorer](#)

Citation for published version (APA):

Spierson, H., Kamupira, S., Storey, C., & Heazell, A. (2019). Professionals' practices and views regarding neonatal post mortem – can we improve consent rates by improving training? *Neonatology*, 115, 314-345.
<https://doi.org/10.1159/000496704>

Published in:

Neonatology

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Neonatology

Manuscript:	NEO-2018-11-3/R1 RESUBMISSION
Title:	Professionals' practices and views regarding neonatal post mortem – can we improve consent rates by improving training?
Authors(s):	Hannah Spierson (Corresponding Author), Susan Kamupira (Co-author), Claire Storey (Co-author), Alexander Heazell (Co-author)
Keywords:	autopsy, consent, counselling, neonatal death, post-mortem
Type:	Brief Report

Professionals' practices and views regarding neonatal post mortem – can we improve consent rates by improving training?

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Short title: Professionals' practices and views relating to post mortem after neonatal death

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Keywords: Autopsy; Consent; Counselling; Post-mortem; Neonatal Death

1. Abstract

Background

In the UK, rates of neonatal post mortem (PM) are low. Consent for post mortem is required and all parents should have the opportunity to discuss whether to have a PM examination of their baby.

Objectives

We aimed to explore neonatal healthcare professionals' experiences, knowledge and views regarding the consent process for post-mortem examination after neonatal death.

Method

An online survey was conducted of neonatal healthcare providers in the UK. Responses were analysed from 103 healthcare professionals, 84 of whom were doctors. The response rate was 11.7% of British Association of Perinatal Medicine (BAPM) members.

Results

Perceived barriers to PM included cultural and religious practices of parents as well as a lack of rapport between parents and professionals. 69.4% of respondents had observed a PM; these professionals had improved satisfaction with their training and confidence in counselling ($P < 0.001$ and $P < 0.001$) but not knowledge of the procedure ($P = 0.77$). Healthcare professionals reported conservative estimates of the likelihood that a PM would identify significant information regarding the cause of death.

Conclusions

Confidence of neonatal staff in counselling could be improved by observing a PM. Training for staff in developing a rapport with parents and addressing emotional distress may also overcome significant barriers to consent for PM.

2. Introduction

A post-mortem (PM) examination may be performed following neonatal death (NND) at parents' request or instruction by a coroner if the cause is unknown or uncertain; in the former situation informed consent is required. In the UK rates of PM following NND have remained constant (29% in 2000, 24% in 2015).^{1,2} The Stillbirth and Neonatal Death charity (Sands) recommend that all parents should have the opportunity to discuss whether to have a PM examination of their baby.¹ We aimed to explore the experiences, knowledge and views of healthcare professionals who counsel parents of PM to identify barriers and facilitators for consent for PM following NND.

3. Materials and Methods

A cross-sectional online survey of UK healthcare professionals who provide care for newborn babies was performed between May 2011 – June 2012. The questionnaire was designed to address questions in 5 main areas: (1) respondents' practice regarding consent for PM; (2) education and support for staff in consent for PM; (3) perceived barriers to PM consent; (4) knowledge about PM; and (5) views about PM. The questionnaire is shown in Appendix S1. The questionnaire was developed in collaboration with parental involvement (CS). Face and content validity was checked by experts in the field, and reliability was established by oral interview of ten respondents after the completion of the survey; the variance between written responses and the interview data was 0.9%. Where appropriate, the questionnaire was amended to ensure clarity. Following Ethics Committee approval (Tameside & Glossop Local Research Ethics Committee, ref. 11/NW/0130), an electronic link to an online survey was sent to members of the British Association of Perinatal Medicine (BAPM) on three occasions over the one year period specified.

4. Results

103 responses were received (a response rate of 11.7%); those who did not work with neonates and did not complete the majority of the questions were excluded, leaving 98 responses for subsequent analysis. Therefore the proportion of BAPM members who responded was 11.7%. Respondents worked in neonatal intensive care (96.9%), high dependency (77.6%) and special care (83.7%). The majority of respondents were doctors (84.8%) most of whom were consultant neonatologists. The remainder were nurses (12.1%) and advanced neonatal nurse practitioners (2.0%). Respondents had a median of 13 years' experience (range 0-32 years). Respondents worked in units with 700-10,000 births per year and 50-1,700 neonatal admissions per year.

Clinicians' practice in counselling for post mortem

The majority of respondents were experienced in providing information to parents regarding PM with 73.5% reporting that they 'Always' provided information to parents. Respondents who stated they 'Rarely' or 'Never' provided information were most often nurses. Information was most often given in the hours after death (63.4%) but it was also given before baby's death (22.6%), in the minutes after death (11.8%), and in a minority of cases in the days after death (2.2%). Most respondents discussed PM only once (25.8%) or 1-2 times (71.0%) with few discussing it 3 or more times (3.2%). Consent for PM was usually discussed with the mother (98.9%), father (98.9%), with another person on request of the parents (78.7%) and another staff member was often present for support (90.4%). 98.9% of respondents reported providing verbal information and 73.4% provided written materials.

54.6% of professionals surveyed were satisfied or very satisfied with the information available for parents, although 4.1% reported a lack of information materials. Satisfaction with information materials to assist staff who are seeking consent was 49.5%, with a large proportion of respondents choosing 'Neutral' to both these questions. 3.1% reported a lack of information materials for staff.

Perceived barriers to post mortem

The most significantly perceived barriers to PM consent were cultural and religious beliefs of the parents, a lack of rapport between parents and professionals and the emotional distress of parents (Table 1A). Notably, 70.5% of respondents felt that it is insensitive to discuss the option of PM with some parents because they are too distressed. 46.4% of respondents reported that transfer to another hospital for PM was always required and 8.2% that it was sometimes required. However, only 13.6% viewed this as a strong or significant barrier; 90.5% of those surveyed felt a PM was still worthwhile even if transfer was required. 61.5% of professionals agreed or strongly agreed that few parents have regrets following consenting to a PM.

Professionals' knowledge regarding post mortem

Knowledge regarding the PM examination varied; 96.9% of respondents knew that PM requires specific consent for organ retention and 85.7% correctly answering that using fetal tissues for research requires explicit parental consent. However, there was less knowledge of practical issues, with only 52.1% of respondents correctly answering the question about timing of tissue disposal.

Respondents' confidence, satisfaction with the training they had received and knowledge were compared depending upon whether they had witnessed a perinatal PM (Table 1). With regard to knowledge, the timing of disposal of tissues was used as this was answered the least accurately overall. Professionals who had seen a PM had greater confidence in consenting parents and were more satisfied with their training. Only 48.4% of those who had not witnessed a perinatal PM thought it would be helpful to their practice.

Healthcare professionals reported conservative estimates of the likelihood of a PM identifying significant information regarding the cause of death (Figure 1B). The most frequently reported figure was 21-40%, with 16.5% estimating that PM would provide useful information in less than 20% of cases in comparison to a literature review which found neonatal PM changed diagnosis or found additional information in 22-81% of cases.³

5. Discussion

This study identified potential barriers in the consent process for PM following NND. While some may be addressed by additional training and support for neonatal staff, others, such as cultural and religious practice may be less amenable to service developments or training. Interestingly, some findings contrast with published data, a report from 2006 found the most reported barrier was access to a perinatal pathologist.⁴ In addition, respondents here reported providing written information about PM to parents in 73% of cases which is higher than other national perinatal mortality survey data.² Many of the barriers to PM consent identified here are consistent with a related study of obstetricians and midwives, indicating that initiatives to address PM consent may have a more significant impact if they address maternity and neonatal care as a whole.⁵

As the clinical team (rather than pathologists) are usually responsible for consenting for autopsy, their knowledge of the procedure is key to providing accurate information to parents and answering questions. Critically, a national survey of neonatal consultants found 80% had received no formal training in obtaining consent for PM.⁴ Here the benefit of witnessing a PM was associated with greater confidence in counselling parents and better satisfaction with training. In addition to knowledge about the procedure, education regarding PM should also include managing parents' emotional needs and in developing a rapport with parents as these were significant barriers.

Although this national survey of neonatal professionals provides a new perspective, it represents a small proportion of those working in the speciality and the majority of respondents were medical. The low response rate of 11.7% of BAPM members is a limitation although the responses reflect the largely medical membership of the organisation. Further research is needed to report practices of neonatal nurses or dedicated perinatal loss teams who may have a closer relationship with parents and could increase the PM consent rates as well as parents' satisfaction with their decision. In addition, this self-reported sample of professionals would be strengthened by survey of parents to report whether the perceived barriers to PM consent, are reflected in parents' experiences.

6. Statements

6.1 Statement of Ethics

The study protocol has been approved by the Tameside & Glossop Local Research Ethics Committee, ref. 11/NW/0130.

6.2 Disclosure Statement

The authors have no conflicts of interest to declare.

6.3 Funding Sources

This study was funded by Bristol Sands.

6.4 Author Contributions

AH and CS designed the study and collected the data. HS analysed the results. AH, HS and SK interpreted the analysis. HS drafted the manuscript. AH, SK and CS critically appraised the manuscript.

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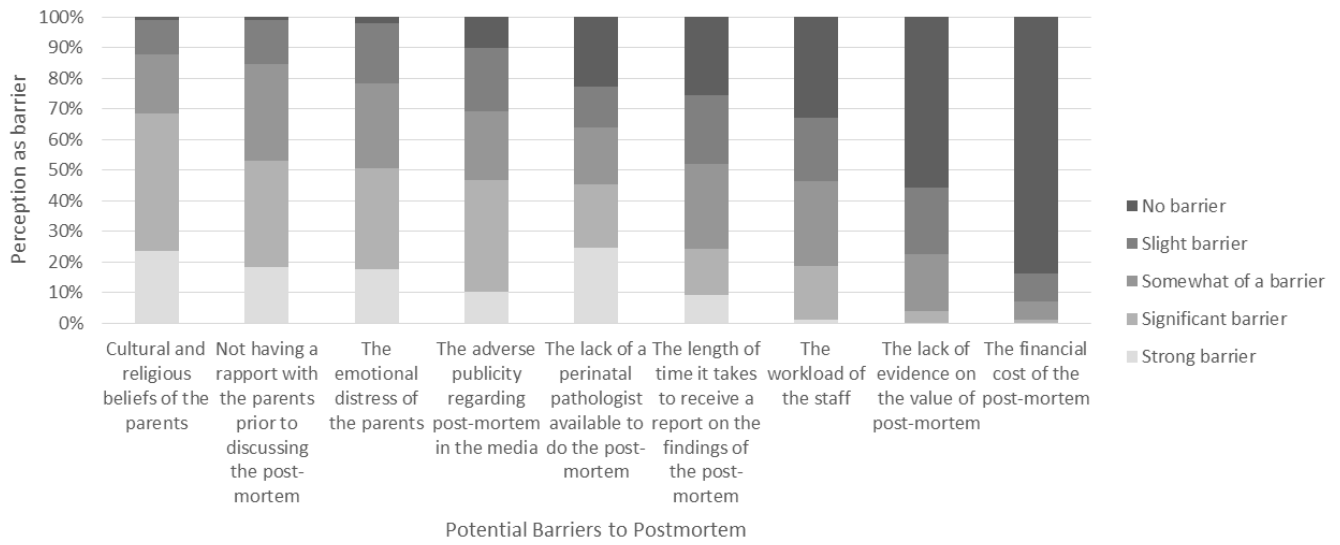
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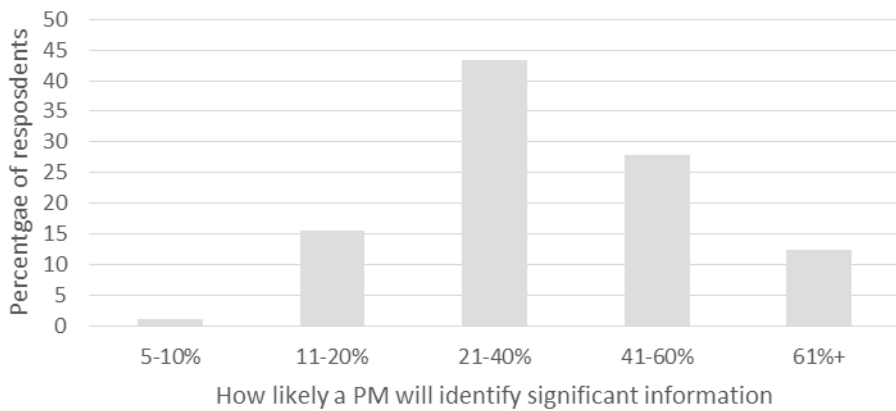
8. Figure Legends

Figure 1: A) Perceived barriers to Post-mortem after neonatal death. B) Perceived likelihood of identifying significant information regarding the cause of death

A



B



The authors would like to thank the editor and reviewers for providing comments on our manuscript. We have responded to the individual comments below.

Reviewer 1 report:

This brief report provides the results of a survey aimed at determining potential barriers to clinicians obtaining consent for post mortems in the event of a neonatal death. The report describes the findings of the survey and provides future direction of research.

The abstract reflects the findings of the survey. It would be beneficial to add the proportion of respondents to the methods.

We have added the proportion of respondents to the methods section of the abstract.

Introduction - the Royal College of Pathologists also supports the need for perinatal autopsies and provides a guideline for perinatal autopsy. This could potentially be an additional reference to the introduction.

The most relevant guideline from the Royal College of Pathologists, 'G168 Guidelines on autopsy practice - Neonatal death' is still under consultation and has not yet been published fully. We have therefore not added this reference at present.

Methods - the survey appears to have been available for responses for 12 months (May 2011 - June 2012)- this would be unusual. Can this be clarified and the number of times the email was sent out to potential respondents.

This detail has been clarified in the methods section.

Results - as with all surveys knowing the denominator is important to know whether the responses are representative of the community being surveyed or a small proportion and therefore not representative. How many members of the BAPM are there to know what proportion responded to the survey eg 20% or 80% respondents. What is the makeup of BAPM - proportion medical, nursing etc

We have added this information to the results section. As the response rate is comparatively low we have added this as a limitation of this study.

Discussion - while this is a brief report further recognition of the limitation of a survey is required, especially depending upon the proportion of respondents. Another possible research question for the future is whether there are dedicated perinatal loss teams that discuss PM with families following a perinatal loss along with later follow-up and whether this would improve PM consent rates and parent/family satisfaction.

We have added a statement regarding the low response rate in the discussion and have added this additional research question.

Reviewer 2 report:

This is an interesting study which addresses healthcare professional experience, knowledge and views regarding the consent process for post-mortem examination after neonatal death. Historically there has been a relatively poor uptake of post mortem within this group and this study highlights the areas which may account for this.

I think it might be worth amending the title to draw out specifically the issue relating to training to improve access to the data.

We have updated the title to reflect this.

In my view it merits publication as it provides insight into the barriers for seeking consent. It was concerning that 70% felt it insensitive to discuss the option of PM with some parents because of distress and I wondered it might be worth analysing this further, was this more or less likely to occur if the carer knew the parents well.

Unfortunately we do not have the data to analyse this point further.

I think it highlights the need for specific training in the taking of consent and the need for a better understanding of the role of the PM in allowing parents to gain the best insight into the death of their child. It again highlights the relative shortage of pathologists and the need for transfer to specialist centres for autopsy.

1 ~~Neonatal post mortem~~ – Professionals’ practices and views regarding neonatal post mortem – can
2 we improve consent rates by improving training?

Formateret: Nummerering: Fortløbende

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16 *Corresponding Author

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23 Tel: 0161 276 6857.

24 hannahspierson@gmail.com.

25 **Keywords:** Autopsy; Consent; Counselling; Post-mortem; Neonatal Death

26 **1. Abstract**

27 Background

28 In the UK, rates of neonatal post mortem (PM) are low. Consent for post mortem is required and all
29 parents should have the opportunity to discuss whether to have a PM examination of their baby.

30 Objectives

31 We aimed to explore neonatal healthcare professionals' experiences, knowledge and views
32 regarding the consent process for post-mortem examination after neonatal death.

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34 An online survey was conducted of neonatal healthcare providers in the UK. Responses were
35 analysed from 103 healthcare professionals, 84 of whom were doctors. The response rate was 11.7%
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38 Perceived barriers to PM included cultural and religious practices of parents as well as a lack of
39 rapport between parents and professionals. 69.4% of respondents had observed a PM; these
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41 and $P < 0.001$) but not knowledge of the procedure ($P = 0.77$). Healthcare professionals reported
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45 Confidence of neonatal staff in counselling could be improved by observing a PM. Training for staff
46 in developing a rapport with parents and addressing emotional distress may also overcome
47 significant barriers to consent for PM.

48 A post-mortem (PM) examination may be performed following neonatal death (NND) at parents'
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150 6.4 Author Contributions

151 AH and CS designed the study and collected the data. HS analysed the results.

152 AH, HS and SK interpreted the analysis. HS drafted the manuscript. AH, SK and CS critically

153 appraised the manuscript.

154 7. References

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172

173 8. Figure Legends

174 **Figure 1:** A) Perceived barriers to Post-mortem after neonatal death. B) Perceived likelihood of
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Submission Statement

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NEONATAL POSTMORTEM - PROFESSIONALS PRACTICES AND VIEWS

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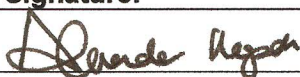
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