

follow up. Application of the principles of intensive follow up in this common cancer has potentially important financial and resource implications for health services. Although estimation of the cost per life years gained is beyond the scope of this paper, the present study should serve as a basis for economic modelling in future trials. Finally, while wide variation in follow up persists in clinical practice, we believe that clinical guidelines should be revised.

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## Cross sectional survey of parents' experience and views of the postmortem examination

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### Abstract

**Objective** To describe parents' experience and views of the postmortem examination after the loss of a baby.

**Design** Cross sectional survey.

**Setting** Hospital with a dedicated bereavement counselling service, Newcastle upon Tyne.

**Participants** 258 women who had attended a bereavement counselling service at the Royal Victoria Infirmary, Newcastle upon Tyne, on at least one occasion after losing a baby during pregnancy or infancy, between October 1996 and October 2000.

**Method** Self completion postal questionnaire incorporating fixed choice and open ended questions.

**Main outcome measures** Number of respondents who were asked if they would agree to a postmortem examination of their baby, and number who agreed to a postmortem examination; reasons for agreeing and not agreeing to a postmortem examination; quality of explanation received; number who regretted their decision to give or withhold consent for a postmortem examination.

**Results** 166 (64%) respondents completed the questionnaire. Of these, 148 (89%) had been asked to agree to a postmortem examination on their baby and 120/148 of these respondents (81%) agreed, most of whom recognised benefits resulting from the examination. 101/117 (86%) respondents believed the findings had been explained appropriately. Nine (7%) of the 120 respondents who had agreed to a postmortem examination regretted their decision. Of the respondents who refused an examination, four (14%) had regrets about their decision.

**Discussion** Parents viewed the postmortem examination as a useful and necessary tool in helping to discover the reasons why their baby had died. Simplifying the language used to explain findings may further raise parents' understanding of the value of the postmortem examination and ensure that they are satisfied with it. Medical staff involved in consent for postmortem examinations should be fully trained in how to ask for parental consent, the postmortem examination procedure, and how to explain the findings.



Comments from parents in this study can be found on [bmj.com](http://bmj.com)

## Introduction

The uptake, quality, and value of postmortem examinations have been reviewed from the health professional's perspective,<sup>1-7</sup> but literature on the family's views of the perinatal postmortem examination is limited. We asked mothers about their experiences and perceptions of the postmortem examination as part of an evaluation of a hospital based bereavement counselling service.<sup>8</sup> The service is offered to all parents who have experienced a loss in pregnancy or infancy (including miscarriage or termination of pregnancy for antenatally diagnosed abnormality).

## Method

We sent a questionnaire to all mothers resident in the former Northern health region who had attended the bereavement service, in Newcastle upon Tyne, on at least one occasion after losing a baby during pregnancy or infancy, between October 1996 and October 2000. The questionnaire incorporated fixed choice and open ended questions and covered several issues relating to the postmortem examination, demography, and previous obstetric history.

Each woman who had attended was sent a letter, a questionnaire, and a prepaid envelope. All were free to accept or decline the invitation to participate. To maintain confidentiality, no names were written on the questionnaire, although each questionnaire was coded to enable validation of pregnancy outcome. We sent two reminder questionnaires to women who had not yet responded.

### Analysis

Fixed choice questions were analysed by using the statistical package SPSS. Analyses by outcome of pregnancy did not reveal any significant differences; these results are not presented. For some questions, more than one answer could be given.

## Results

### Response rate and outcome of pregnancy

A total of 258 mothers had attended the service. Of these, 166 (64%) completed the questionnaire (age range 17-48 years, mean 32.2 (SD 6.2) years); seven returned it uncompleted, and 18 were returned by the post office; there were 67 non-responders). Analysis is based on 166 questionnaires: among these women there were 33 (19%) miscarriages, 42 (25%) late terminations ( $\geq 16$  weeks), 45 (27%) stillbirths, and 46 (27%) neonatal and post-neonatal deaths.

### Postmortem examination

In all, 148 (89%) respondents said they had been asked to agree to a postmortem examination of their baby. Of these, 104 were asked by a doctor only, 18 by a midwife, four by the bereavement officer, and 12 by a doctor and at least one other health professional. The remaining seven subjects couldn't remember who had asked them. Five respondents did not answer this question; they felt it did not apply to them because their pregnancies had resulted either in a miscarriage or a termination. Of the other 13 respondents who said they had not been asked, one regretted this because she wanted more information about the cause of death, to inform future pregnancies.

One hundred and twenty respondents (120/148, 81%) agreed to a postmortem examination; reasons for agreeing are summarised in table 1.

One hundred and seventeen respondents (97% of mothers agreeing) were later told the findings; 101 (86%) believed that the findings were explained appropriately and 110 (94%) said they were given sufficient time to ask questions. Table 2 shows the responses from parents who did not believe that the findings had been appropriately explained. Respondents' views on how the findings of the postmortem examination were explained are shown on [bmj.com](http://bmj.com).

Table 3 summarises the perceived benefits of consenting to a postmortem examination. The most common stated benefit was that it helped to explain what had happened to the baby (see [bmj.com](http://bmj.com) for parents' comments). However, nine respondents of the 120 agreeing (7%) who had given consent regretted their decision. Seven gave reasons: four felt guilty because the examination had not found anything conclusive, one thought that it had produced more questions than answers, and two respondents felt their baby had gone through enough. A further three had mixed feelings about whether they regretted giving consent.

Twenty eight respondents did not agree to a postmortem examination. The most common reason given, out of a choice of five (see table 4), was that they felt their baby had suffered enough.

Four respondents said they regretted not having the information that the postmortem examination may have provided. One said: "Now, two years later, I would like to know why they died," and another: "an answer may have alleviated the burden of guilt."

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**Table 1** Reasons for agreeing to a postmortem examination (n=244)\*

Reason	No of responses (%)
I wanted more information about what had happened	108 (44)
To help improve medical knowledge and research	59 (24)
It was recommended by the person asking for my consent	40 (16)
I felt a need for "finality" or "closure" after my loss	25 (10)
I wanted to know if future pregnancies would be affected	7 (3)
I needed to know if I'd done anything to cause this to happen	2 (1)
Other	3 (1)

\*166 questionnaires were returned; more than one answer could be given.

**Table 2** Reasons why respondents felt the postmortem examination findings were not explained appropriately.\* 12 out of 16 respondents gave reasons

Reason	No of responses (%)
Type of information given confusing	6 (43)
Language used too complicated	4 (29)
Findings not communicated appropriately	2 (14)
Need further visits or more time to have findings explained	2 (14)
Total	14

\*More than one reason could be given.

**Table 3** Respondents' stated benefits of agreeing to a postmortem examination\*

Reason	No of responses (%)
Postmortem examination helped to explain what had happened	41 (60)
We needed to know whether future pregnancies would be affected	14 (21)
Postmortem examination helped us to come to terms with what had happened	13 (19)
Total	68

\*More than one answer could be given.

**Table 4** Reasons for respondents not consenting to a postmortem examination.\* 27 out of 28 respondents gave reasons

Reason	No of responses (%)
I felt my baby had already "suffered enough"	22 (44)
I did not feel it would help me	13 (26)
I was concerned about the effects of the examination on my baby's appearance	5 (10)
I didn't want my baby cut	3 (6)
I was concerned it might delay funeral arrangements	2 (4)
For religious reasons	0
Other	5 (10)
Total	50

\* More than one reason could be given.

## Discussion

During the time of this study, the late fetal and neonatal postmortem examination rate in the Northern region was 60%.<sup>9</sup> The high postmortem examination rate among respondents reflects, in part, the high proportion of miscarriages and termination of pregnancies for fetal malformation—postmortem examination rates in these groups are generally high.

The perceived benefits of the respondents' agreeing to a postmortem examination for their baby related largely (as expected) to an improved understanding of the circumstances that led to their baby's death and a recognition that this information could be helpful in determining possible implications for future pregnancies. However, many hoped that medical knowledge might be advanced—a finding noted previously.<sup>10 11</sup>

Thirteen comments stated that the findings had helped them come to terms with their loss, removing feelings of guilt by reassuring them that the reasons for proceeding to termination were well founded, or that the baby's problems could not be attributed to their actions. Beckwith concludes that one of the most positive roles of the postmortem examination is "to help alleviate the myriad of false apprehensions on the part of the family."<sup>12</sup> These observations illustrate that families may benefit in ways not foreseen by health professionals and that they should always be asked whether they would like their baby to have a postmortem examination. Other responses indicate that families are not advised appropriately after their baby's death. Of nine who regretted giving consent, four gave as their reason the fact that no "cause" of death had been found—an outcome for which they should have been prepared. Thirteen comments from those refusing consent believed that they would not be helped by the examination. In a recent study by McHaffie and colleagues, no parent regretted their decision to agree (62%) or not agree (38%) to a postmortem examination.<sup>11</sup> This difference may reflect appropriate counselling of parents when health professionals were obtaining consent.

For respondents who did not believe that the findings had been adequately explained, confusion over the explanations offered or use of medical terminology were the most commonly stated reasons. This indicates the importance of interpreting such terminology, explaining medical concepts, and giving the opportunity for families to ask further questions at a later date. Also, the pathologist could be involved more frequently in providing feedback and at the consent stage.

We acknowledge that this is a study of a selected sample of women attending a tertiary centre with a

## What is already known on this topic

Current literature relates mainly to health professionals' views of the postmortem examination

The perceived benefits of having a postmortem examination relate mainly to improving understanding of the circumstances leading to the death of the baby

## What this study adds

Every family should be offered the opportunity for a postmortem examination

The benefits and limitations of the postmortem examination should be explained so that expectations of the outcome are appropriate

Medical concepts and terminology should be fully explained during follow up and families given the opportunity to ask questions at a later date if necessary

dedicated bereavement counselling service, and therefore the views expressed may not be wholly representative of all women suffering a loss. However, the study is particularly relevant in the light of the chief medical officer's recent interim guidance on post-mortem examination,<sup>13</sup> and it confirms the need for all those working in the field to be trained in how to ask for parental consent, the postmortem examination procedure, and how to explain the findings.

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