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Bereaved mothers' attitudes regarding autopsy of their stillborn baby

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Abstract

Background—Here we present additional information from the Safe Passage Study, where the effect of alcohol exposure during pregnancy on sudden infant death syndrome and stillbirth was investigated.

Objective—To explore bereaved mothers' attitudes toward obtaining an autopsy on their stillborn baby, and the future implications of consenting or non-consenting to autopsy in retrospect.

Methods—Demographic data was obtained by a questionnaire. A largely qualitative mixed-methods approach was used to meet the aims of the study, using an exploratory and descriptive research design to provide a detailed description of maternal attitudes. A semi-structured questionnaire based on information from literature and reflections on practice was administered during individual interviews.

Results—We interviewed 25 women who had had a recent stillbirth. The time interval between the time of consenting to autopsy and completing this study ranged from 6 to 18 months. Most participants reported that autopsy results provided peace of mind and helped alleviate their feelings of blame. Participants who were unable to comprehend the results reported negative reactions to receiving autopsy results. The majority of participants were of the opinion that they benefited from consenting to autopsy.

Conclusion—Autopsy and the disclosure of its results generally contribute positively to coping following stillbirth.

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For an unfortunate minority, pregnancy ends in bereavement. In the case of a stillbirth, an anticipated joyous birth becomes a tragic death, forcing a mother to deal with the emotions of birth and death simultaneously. There is a great desire for healthcare workers to improve perinatal bereavement care. Obtaining an adequate explanation of the cause of the baby's death can be helpful to parents as they reckon with their loss.^[1] Autopsy in combination with placental examination is the most valuable analysis to identify the cause of stillbirth.^[2]

Stillbirth and neonatal death rates in South Africa (SA) are high. In 2012 - 2013, 32 662 stillbirths and 14 576 early neonatal deaths were recorded in the National Perinatal Problem Identification Programme (PPIP) database from 588 PPIP sites, reflecting a stillbirth rate of 23.1/1 000 and early neonatal death rate of 10.6/1 000.^[3] The number of stillbirths at Stellenbosch University teaching hospitals declined rapidly during the 1960s, but more recently it has declined much more slowly,^[4] in keeping with international trends.^[5] Autopsies and the insights revealed will be critical to further reduction in stillbirth rates.

Understanding the views of parents, and the influences of various cultural and religious beliefs, may contribute to greater enrollment in autopsy.^[6,7] The views of mothers and their families regarding autopsy are essential,^[8] as well as understanding stillbirth in the South African context, and the cultural and socio-economic factors specific to it.^[9] This study was undertaken as an ancillary study to the Safe Passage Study^[10] to explore the experiences of 25 mothers who experienced a stillbirth and were offered autopsy.

Methods

This research was conducted within the Safe Passage Study – PASS (Prenatal Alcohol SIDS Stillbirth) Network at Tygerberg Hospital, Cape Town, SA.^[10] The main aims of the Safe Passage Study are to explore the association of prenatal alcohol exposure with increased risk for SIDS and/or stillbirth. Approval for the research was obtained from the Steering Committee of the Safe Passage Study and the Health Research Ethics Committee at Stellenbosch University (ref. no. 10/09/313).

The objectives of this research were to investigate bereaved mother's attitudes towards autopsy, whether consenting to an autopsy or not, and the significance ascribed to autopsy during the bereavement process. Furthermore, we collected pilot data for future use in studies on how health care personnel could assist mothers during the consent process following a stillbirth.

Purposive sampling techniques were used for this research, recruiting a sample reflecting representative or typical attributes of participants in the Safe Passage Study who had a stillbirth, based upon the judgment of the researcher. Inclusion criteria were bereaved women over 16 years of age with a stillbirth between 6 and 18 months previously. As individuals under the age of eighteen are not allowed to give consent on their own, special approval was obtained from the Health Research Ethics Committee to include them in this study, provided that they were not younger than 16 year. The participants were interviewed from July 2012 to December 2012. Each interview lasted about 45 to 75 minutes. Participants were interviewed after the loss and then more than 6 months later. A mixed-

methods approach with both quantitative and qualitative aspects was employed. Data collection comprised of questionnaires to obtain demographic data and semi-structured one-on-one interviews. Interviews relied upon a set of prepared questions on an interview schedule, but the interview was guided by the schedule rather than dictated by it,^[11] allowing the interviewer to explore the emotional complexity of reported experiences while also assuring that certain specific information was uniformly collected. An exploratory and descriptive research design was used in order to gain a detailed description of the psychosocial implications of stillbirth, with special attention to perceptions on autopsies, including regrets regarding their initial indication or whether autopsy eased the bereavement process.^[12] Further elaboration in answers provided data to understand and describe behaviour reflecting the subjective experience, especially beneficial for such a sensitive topic as autopsy with specific focus on the participants' views of consenting for autopsy, receiving the autopsy results, and their feelings in retrospect.

The following attitudes were explicitly inquired about, after the loss and 6 months later, to guide the interviews: autopsy beyond consideration owing to religious reasons; autopsy desired although prohibited by religion; autopsy resisted owing to concerns that it cut the baby's body; autopsy worth considering after being informed what an autopsy is and entails; autopsy of no advantage as it would not bring the baby back; acknowledges benefits of autopsy; autopsy benefits the mothers by helping to understand the death of a baby better; autopsy desired for potential benefits to future pregnancies; autopsy not desired because husband/partner is opposed to it and it would influence the relationship negatively; autopsy desired despite partner/husband not approving. A participant could endorse more than one attitude. Participants were also asked to share their perceptions about what had been gained from the autopsy, in retrospect, at the later interview.

Results

Twenty-five participants who had experienced a stillbirth were approached for the study. The ages of the participants ranged from 16 to 39 years. Three mothers were <20 years old, 14 were between 20 and 29 years old, and 8 were between 30 and 39 years old. The majority of the participants (56%) were between 20 and 29 years. The 25 participants had lost 34 previous pregnancies, which included 26 stillbirths, 6 miscarriages, 1 ectopic pregnancy and 1 infant death. Regarding the educational qualifications of the participants, 9 of them had completed Grades 10 - 11, 4 completed Grades 8 - 9 and 4 completed Grade 12. Only 2 participants had tertiary education. Six participants had not completed primary school. Twenty-four (96%) participants lived in dwellings with electricity and 20 (80%) had access to indoor running water. Only 18 (72%) of the participants had a toilet inside their dwelling.

Twenty-one (84%) participants were approached for an autopsy and 18 (85.7%) consented to it. Table 1 summarises the main perceptions about autopsy. The majority of participants (48%) approved an autopsy because the information gained might be helpful in the management of future pregnancies and because it would help them to understand the cause of the stillbirth. Eleven participants (44%) appreciated the benefits of an autopsy, while 10 (40%) participants felt more positive about autopsy after receiving an explanation of the information that would be obtained from the results. Three participants consented to autopsy

although it was against their religious beliefs, and 4 did not consider autopsy for religious reasons. Six (24%) participants were hesitant about requesting an autopsy because they did not want the baby to be cut. There was only a small change in the responses when the same questions were repeated after 6 months. Several participants endorsed more than one perception.

Reactions to the autopsy results included gaining peace of mind (22.2%), providing hope (11.1%), alleviating feelings of guilt (27.8%) and anger towards partner (5.6%) and being unable to understand the results (5.6%). Three participants (16.7%) had not yet received the results of the autopsy at the time of the interview (Table 1).

Discussion

Based on the high rate of consent (87.5%), most of the participants in our study understood the potential advantages of an autopsy, as reflected in Table 1. Nearly half of the participants felt that the information gained from an autopsy would prove beneficial to the management of future pregnancies (48%) or that the findings would help them understand the reasons for the death (48%). There was some resistance owing to cutting of the infant (24%) and religious prohibition of an autopsy (12%). Upon hearing the autopsy results, 72% described the positive consequences of the information gained, including less self-blame and feelings of relief. Mothers who had not received autopsy results had negative feelings about that beyond just the lack of information.

Autopsy can be a difficult topic to approach at the time of acute loss. Previous research has shown that a large majority of those who are asked to provide consent would provide it.^[6] This study had a consent rate for autopsy of 86%, which was similar to that in the cited research. In a review on the effectiveness of interventions to support parents' decisions about autopsy consent after a stillbirth and to determine autopsy rates,^[13] no studies of sufficient rigour were identified, and it was concluded that support for parents making decisions about autopsy after stillbirth must rely on local knowledge, as well as the experience of those involved at the time. A search of 40 websites associated with supporting parents who experience stillbirth also found little reference to, or information about, autopsy. We found little change in the participants' attitudes to autopsy between the initial approach and follow-up at least 6 months later. This would suggest that the likelihood of gaining consent is significant and largely formed at the time of the loss. The most suitable time to obtain consent is soon after labour, depending on the mothers' medical and emotional condition. Forty percent of the mothers interviewed felt that simply being informed of the option and what was likely to be gained led to a positive attitude about it.

The motivations for an autopsy were largely to gain an explanation for the reasons for the stillbirth. No mother spoke about contributions to science, but they were concerned about the relevance of the loss to their future pregnancies. This was also in accord with other research,^[6] which found that the mothers desired more information about what had happened, 'finality' or 'closure' after the loss and a determination of whether future pregnancies would be affected. Our sample expressed little desire to improve medical knowledge or to reduce

the risk to others in the future,^[14] although these areas were not explicitly addressed in the methodology.

Twelve percent of our participants complained that they had not received any written results. This is in line with unsatisfactory experiences in the 25% of parents in the largest study on the views of parents and healthcare workers on perinatal autopsy.^[15] In our study, verbal feedback was given to most of the participants in a supportive environment. There seems to be a place for written feedback in addition to the verbal feedback, especially in low-income countries where telephonic communication and transport are difficult. Other research has found the difficulty of inadequate explanation of findings,^[6,16] which is likely to reverse any benefits to a family's coping. However, research has shown that parents not consenting to autopsy are approximately twice as likely to regret their decision compared with those who decided to have the autopsy performed. Autopsy therefore has a high value and is one way to assist parents' efforts to find eventual closure.^[6,15]

Little information on attitudes to autopsy from other African countries could be found. One study addressed knowledge, attitude and perceptions of doctors and relatives of the deceased on autopsy.^[17] A close correlation was found between the level of education of the relatives and their knowledge of autopsy. The main factor influencing refusal of autopsy was fear of mutilation of the body, as expressed by doctors relatives. This was found in the reports of some mothers in this study. According to doctors, religious beliefs were the second most common reason for refusing autopsy, but were rated fifth by relatives. It is interesting that, despite the low levels of education of participants in this study, 85.7% of those approached consented to autopsy. Likely reasons for this is that the background knowledge of the population on autopsy was higher and that the approach in obtaining consent for autopsy was highly successful.^[18]

Although we obtained a high consent rate for autopsy, there is still room for improvement. Our interviews found a fear of disfiguring or mutilating the body of the infant, as described above. Although this is understandable, more attention could be given to explaining the process of autopsy and the respect with which tissues are handled. Some participants whose resistance to autopsy was based upon this objection later regretted not consenting to autopsy. In general we experienced a lack of knowledge in mothers, fathers and close family members. Our findings confirm that of another study in a low-income country on the knowledge, attitudes and perceptions of relatives of diseased patients and doctors. [17]

Conclusions

Obtaining consent for autopsy soon after a sudden loss, and in participants with severe socioeconomic challenges, is difficult. There is a lack knowledge and understanding and many preconceived ideas exist. Among the mothers who were approached for autopsy following stillbirth, we found high levels of consent and a desire to have an autopsy performed when its potential advantages were explained. We found little difference between the perceptions and attitudes of mothers when the request for autopsy was made compared with those obtained at least 6 months later. The majority of mothers saw a benefit to autopsy and found that, once the results were shared, it contributed in a helpful way. There is a great

need for all healthcare workers to inform communities about autopsy in general, and speak confidently of its advantages under specific circumstances.

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Table 1

Theme of reaction upon hearing the autopsy results

Subthemes	Categories	Narratives	n (%)
Peace of mind	Relief	'It made me feel at peace.'	4 (22.2)
Hope		'We took the positive out of it, which is that our baby was completely normally formed, it was only the lungs that were underdeveloped.'	
		'It brought me some peace and gave me hope that I still can carry a baby full term.'	2 (11.1)
		'My first question to the professor when he phoned me with the results was if I will be able to fall pregnant again.'	
Normal Blame	Alleviated feelings of blame	'I acted normal. I can't remember the results anymore.'	2 (11.1)
		'I was blaming myself throughout the first few weeks, but the autopsy really just explained to me what really happened, things that weren't spoken to me when I left the hospital.'	5 (27.8)
Anger	Towards partner	'I blamed myself but now I feel more at peace.'	
		'They told me I had an infection and my baby passed away from this. I was very angry towards my partner.'	1 (5.6)
Unable to comprehend	Struggling to understand	'I didn't understand the results so well.'	1 (5.6)
No results yet	Non-acknowledgement of feelings	'I haven't received any written results yet and feel it is my right to have these results.'	3 (16.7)