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Decisions to consent for autopsy after stillbirth: Aboriginal and Torres Strait Islander women's experiences

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Abstract

Background: The stillbirth rate for Australian Aboriginal and Torres Strait Islander infants is twice that for non-Indigenous infants. Autopsy is the gold standard for fetal investigation, however, parental consent is low. There is little research investigating the drivers of parents' decision-making for autopsy after stillbirth.

Aims: The current study explored the reasons why Aboriginal and Torres Strait Islander women did or did not give permission to autopsy after stillbirth.

Materials and Methods: Five Aboriginal and/or Torres Strait Islander women participated in semi-structured interviews. Thematic analysis was conducted within a phenomenological framework.

Results: Five themes were identified as reasons for giving permission – to find out why baby died; confirm diagnosis; understand future risk; help others; and doubt about maternal causes. Four themes were identified as reasons for declining permission – not asked in a sensitive manner; not enough time to think; distress about the autopsy procedure; and unwilling to agree. There was a lack of acceptability of the lengthy timeframe for the availability of autopsy results as families usually wait between three and nine months. This lengthy waiting period negatively impacted upon families' health and wellbeing.

Conclusions: It is important for health professionals to understand the factors that parents consider when giving permission for autopsy after stillbirth. It is hoped that an increase in

autopsy rate will enhance the understanding of the causes of stillbirth and ultimately decrease the stillbirth rate for Aboriginal and Torres Strait Islander families.

Introduction

The Perinatal Mortality Rate (PMR) is defined for a given time period as the number of perinatal deaths per 1,000 babies “at least 20 weeks gestation or at least 400 grams birth weight, and neonatal deaths of live born babies within 28 days of birth regardless of gestation or weight”¹. Over the past 30 years, the PMR in Australia has been reduced to almost a quarter of that observed in the 1970’s.² In 2012, the PMR was 8.2 perinatal deaths for every 1,000 births.² To a large extent, the decline in the PMR has been due to a reduction in neonatal mortality, with neonatal deaths declining at a faster rate than the stillbirth rate.^{3, 4, 5} Stillbirths now account for 70% of perinatal deaths.³ In Australia, the stillbirth rate for Aboriginal and/or Torres Strait Islander babies remains over twice the non-Indigenous rate.^{1, 6, 7, 8} It appears that health interventions to date have not narrowed this disparity and the reasons remain to be fully understood. Implementation of a perinatal audit has been shown to reduce stillbirth rates.^{5, 9} Perinatal autopsy is an essential tool in the process of perinatal mortality audit.^{2, 9} While autopsy is the gold standard investigation, parental consent rate remains very low.⁹ For example, in Australia during 2013-2014, only 21.1% of stillbirths were examined by full autopsy⁷.

Parents have reported reasons for consenting to or declining permission for autopsy after neonatal death. For example, a UK study identified factors that supported and deterred consent. Parental consent was given to confirm a diagnosis, to help others, and to understand risks for future pregnancies.¹⁰ Additionally, parents of infants who lived less than a day were much more likely to consent than parents of infants who were three months or older. Parental consent was also more likely provided by parents who felt supported by health professionals in their decision-making. Conversely parents who declined autopsy primarily reported distress about disturbance and disfigurement of the baby, and also having no unanswered questions to be addressed by the autopsy.¹⁰

Australian parental decision-making drivers have also been identified in a secondary analysis of focus groups.¹¹ Factors that supported consent included parents' readiness to decide, a sense of responsibility to find a cause or prevent future stillbirths, gaining peace of mind from results, and the support of health professionals.¹¹ Parents who declined autopsy reported feeling overwhelmed by the situation, wanting to protect the baby from harm, fearing being blamed for the death, and feeling that health professionals were unsupportive.¹¹ While there are similarities between the UK and Australian parents' decision-making, it is unclear whether these reasons are the same for Australian Aboriginal and Torres Strait Islander families. In the context of low parental consent and autopsy rates in Australia, and particularly for Aboriginal and Torres Strait Islander families, it is crucial to understand decision-making for these families in order to deliver culturally sensitive care.

Materials and Methods

This study was conducted in [research site information] is one of the largest non-metropolitan hospitals in Australia. It is the specialist, tertiary referral hospital for all Hospital and Health Services across [research site information]. More than 7.9 % of the [location] Hospital and Health Service resident population is estimated to be of Aboriginal and Torres Strait Islander descent, which is double the 4 % rate for Queensland.¹² A significant percentage of Aboriginal and Torres Strait Islander babies are admitted to this centre with a low birth weight or size for their gestational age.¹³ A chart audit identified 32 Aboriginal and/or Torres Strait Islander women who had experienced stillbirth in the [location] Hospital and Health Service district in a ten-year period (January 2005 – December 2015). Of these women, 12 (37.5%) gave permission for autopsy. As suggested by the project Cultural Advisory Group, potential participants were approached via telephone and, if contactable, were sent a follow-up letter prior to consenting to interview. Multiple attempts

were made to contact all eligible women – 16 women were non-contactable (10 did not answer, 6 with disconnected phones), 3 women had active mental health difficulties and were not approached, 5 women expressed interest in participating but were subsequently uncontactable, 3 women declined, and 5 women agreed to participate in the study.

Interviews were conducted by an Aboriginal midwife and an Aboriginal researcher with participants at a location of their choice and were guided by open-ended questions. Questions were developed in consultation with the Cultural Advisory Group to ensure cultural sensitivity. Women were asked about whether they were approached to gain permission to autopsy and about the factors they took into consideration when making that decision. A yarning, informal interview style was used.¹⁴ Informed consent was obtained both verbally and in writing prior to the interviews and audio recorded with permission. Data was analysed within a phenomenological framework^{15, 16} using thematic analysis.¹⁷

Five women participated in semi-structured interviews of up to 60 minutes - four women identified as Aboriginal women and one identified as an Aboriginal and Torres Strait Islander woman. Three women were primigravida. At the time of the stillbirth, the women's ages ranged from 17 – 39 years, while their ages ranged from 26 – 45 years at the time of the interview. Of the four women who were offered an autopsy, three accepted and one declined. One woman who delivered at a hospital outside of [location] was not offered an autopsy, however accepted alternative investigations. Of the four women who were offered autopsies after stillbirth, midwives approached two women while doctors approached two women.

Ethics approval for this study was obtained from the Queensland Health Research Ethics Committee (15/QTHS/91).

Results

Not all women were approached to provide consent for autopsy. For those women who were approached, below outlines the factors that influenced their decision-making regarding declining or giving permission for autopsy, and also the acceptability and impact of the waiting periods upon health and wellbeing.

Reasons for giving permission to autopsy

Five themes were identified that drove decisions to give permission to autopsy: 1) *finding out why the baby died*; 2) *confirm diagnosis*; 3) *understand future risk*; 4) *doubt about maternal causes: did my body cause this?*; and 5) *to help others* (see Figure 1).

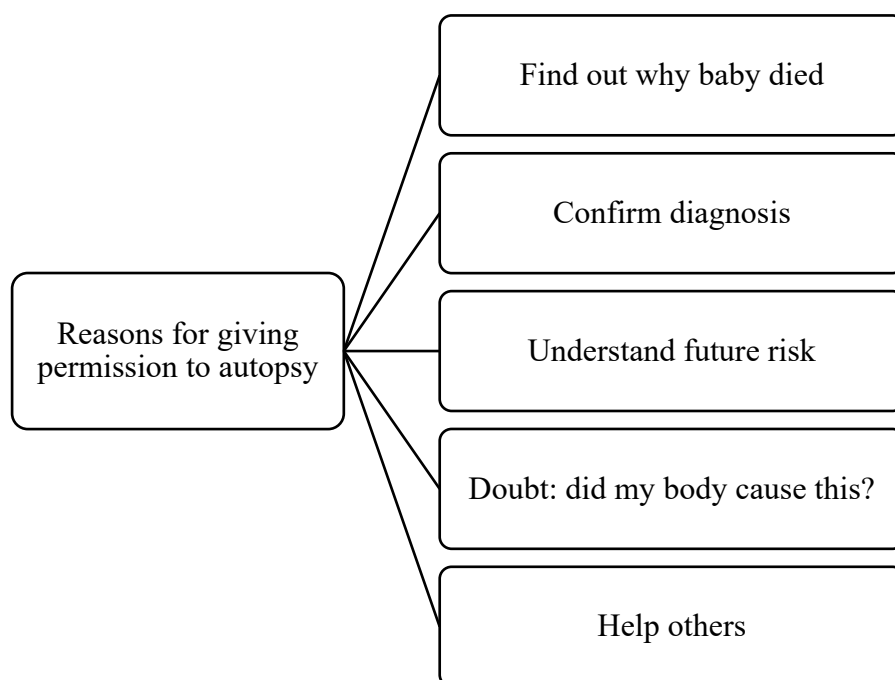


Figure 1. Reasons women and families gave permission for autopsy.

The women reported several reasons for giving permission to autopsy after stillbirth. For one woman, she wanted to confirm the diagnosis and to understand future risks. She stated that she provided permission to autopsy because “I definitely wanted to know that what

was said, was what it was...[and] so I knew my likelihood of it happening again” [P3]. Other families did not have a diagnosis prior to the stillbirth. For these families, providing permission to autopsy was a way to find out why baby had died. For example, one woman stated that

it wasn't until a few days later. We had processed what had happened...we agreed to [autopsy] just because at the time of it all happening we didn't know what had happened. Going for – sending her for an autopsy would just – it was a step towards trying to find out what happened.” [P1].

Similarly, permission to autopsy was provided to address the doubt about whether the mother's body had caused the stillbirth. For example, one woman stated that “was it something wrong with my body...but there was no explanation on that” [P4]. One woman reported that the information from an autopsy could help others in the future. She stated that she gave permission “so I could help somebody else who's going through the same thing” [P3].

Reasons for declining autopsy

Four themes were identified that negatively impacted upon the decision to provide consent to autopsy: 1) *not asked in a culturally sensitive manner*; 2) *not enough time to think about giving permission*; 3) *distress re the autopsy procedure*; and 4) *nothing could make me agree* (see Figure 2.)

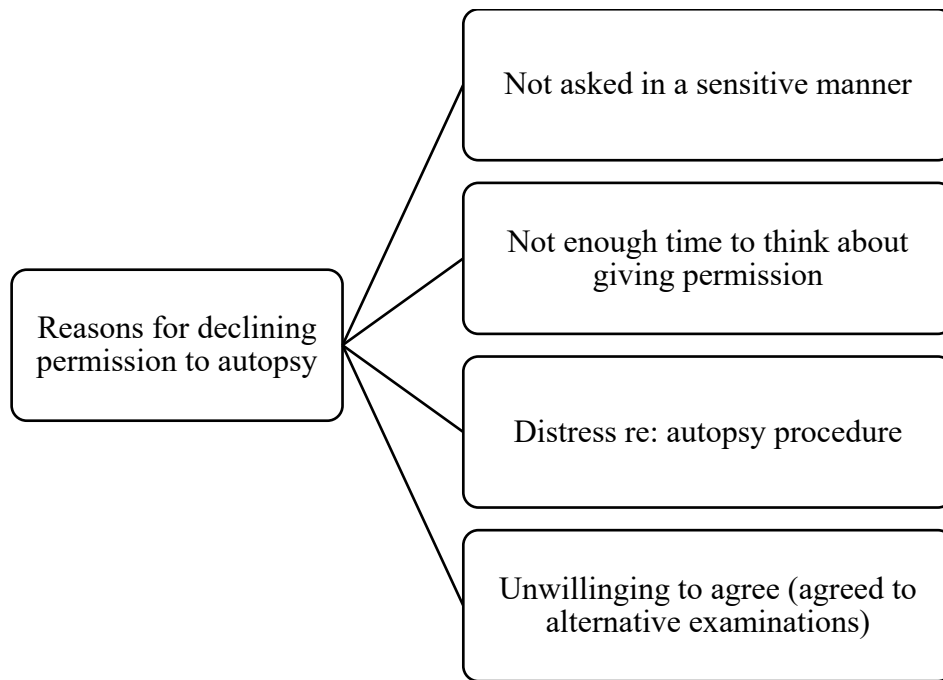


Figure 2. Reasons women and families declined permission for autopsy.

A woman reported that even though her husband had consented to the autopsy, she did not have enough time to think about giving permission after the trauma of experiencing stillbirth. She stated that “at the time, [the request to autopsy] was all just a quick five minute [discussion after the birth], so if it was explained beforehand, I would have just said yes anyway, you know, to what’s, what’s going on [request for stillbirth]” [P4]. This woman went on to report that she was not asked in a sensitive manner and that this impacted upon her ability to make an informed decision. When asked whether she would have agreed if she were asked ‘properly’, she stated “yeah” [P4]. While this woman did not elaborate on how to be asked ‘properly’, she reported feeling alone after the stillbirth:

It's strange with Indigenous ladies or, you know Indigenous ladies full stop, because it's very hard because of the up-growing that you have and to ask for something like that [counselling], it's - yeah. And you don't know, yeah, that you're going through that, yeah went into a shell by myself [P4].

Another woman reported that she declined an autopsy due to distress thinking about the autopsy procedure, including the dissection of her child. She stated that “I opted not to do it, I think...I didn’t want them cutting up my baby” [P5]. When asked if hospital staff could have further supported a decision to give permission, one woman simply stated “no” [P5]. However, even though this woman declined an autopsy, she wanted an alternative examination to know why the stillbirth had occurred and “opted for an MRI scan and a blood test only” [P5]. It is also important to note, that for women experiencing this distress, it may be difficult for staff to support a decision to provide permission for autopsy.

Lack of acceptability of waiting time for results of autopsy

Women reported that the waiting period for results of the autopsy was unacceptable. The desired timeframe was reported to be “a week...or two at the latest” [P4]. One woman reported that was informed that the timeframe would be ‘a few weeks, four or five weeks’ [P1], however this was not adhered to and the results were delivered three months after the stillbirth. For another family, it was nine months before the results were delivered. This woman reported that “it was probably only a week or two until she came back to [home town]. But the results I didn’t get until nine months later” [P3]. When asked if this was acceptable, the woman emphatically replied “no way” [P3]. She went on to explain that “the autopsy took two weeks. Honestly, it would have been nice to have answers then. But it would have been nice at least a month. Nine months later, I rang a couple of times and they were like no, we don’t have anything yet” [P3].

Negative impact of lengthy timeframe for receiving autopsy results

The women reported that waiting for the results negatively impacted upon their health and wellbeing. The woman who waited nine months for the results reported that “you get in

quite a dark place waiting to hear back” [P4]. A woman who reported waiting three months for results reported that

we were at a standstill. It wasn’t...even after her funeral, it’s not like it made it better or it made it easier. It was just that closure, just puts you in a different mind frame. Even then, so waiting for [the results] and having her sent away for that autopsy, you were just at a standstill. You had to wait” [P3].

Discussion

Aboriginal and Torres Strait Islander women in this study identified reasons to consent or decline autopsy after stillbirth. Consent was provided by families where complications were not expected and they wanted to find out why their baby had died¹¹, and also to confirm a prior diagnosis.¹⁰ Similarly, families consented to autopsy to understand potential risks in future pregnancies.^{10, 11} Women in the current study also reported giving permission for autopsy to reduce doubt about the possibility maternal causation factors. Similarly, others have found that women consented even though they were fearful of the autopsy results. They did so, in order to rule out maternal causation and to reduce potential blame.¹¹ It is important for health professionals to support women to reassure them during this stressful time.

In this study, parents reported factors that influenced the decision to decline an autopsy. Parents reported not included not having enough time to think about their decision at the time of the stillbirth. This reason was also reported by other parents who felt unprepared and overwhelmed by the situation.¹¹ Women also reported not being approached and asked about autopsy in a sensitive manner. A sensitive approach by health professionals included being sure to include both parents in the decision-making, together with providing enough

time after the stillbirth for parents to be able to provide informed consent. This factor is similar to others who have noted the negative impact of unsupportive health professionals during this time.^{10, 11} It is important for health professionals include both parents where possible and to manage the timing of information to support parental decision-making.

Parents in the current study also reported feeling distressed when thinking about the autopsy procedure. As others have also found^{10, 11}, parents reported a need to protect the baby from further harm, including disfigurement and dismemberment. This reason was a primary driver of the decision to decline autopsy. It may be difficult to address this concern as some parents reported that they were unwilling to ever provide consent. While autopsy may be the gold standard for understanding stillbirth, it is important for health professionals to note that, despite their best professional efforts, some families will not agree.

Although the majority of the women in this study gave permission for autopsy, there were negative consequences in terms of waiting periods for results and health and wellbeing. The women reported that the waiting time was unacceptable. The earliest results were one month after the stillbirth, while the longest period was nine months. The delay in receiving results had a negative impact upon women's health and wellbeing, with women particularly reporting distress, and symptoms of depression and anxiety. It is incumbent upon health professionals to provide a reasonable and accurate indication of the length of time for the return of results. This may be difficult in a regional tertiary hospital where the nearest neonatal pathologist is 1600 kilometres away. Further, it is critical to inform parents that results may be inconclusive. Given that women have reported difficulties in remembering discussions and conversations at the time of the stillbirth, it may be prudent for written information to be provided in families. Follow-up of families by mental health professionals in the interim period may also help to ameliorate distress and enhance wellbeing.

A limitation of the current study is the low number of women who were interviewed. However, one-on-one interviews allowed women more time to consider their experiences and thus deeper insight into their experiences. Further, women were able to recall vivid memories of their experiences even in the context of the passing of several years. Such vivid memory recall is not unexpected given the traumatic experience of stillbirth.¹⁸ Therefore, results of this study offer early insights that specifically focus upon Aboriginal and Torres Strait Islander women's decision making.

The decision to provide permission to autopsy after stillbirth is complex. The families in the current study identified push and pull factors that influenced their decisions. This information will assist health professionals to support parents and families to make informed decisions about autopsy and potentially increase the perinatal autopsy rate. Of particular note are the cross-cultural similarities in decision-making processes identified across previous research and the current study. Policy and practice guidelines for health professionals who support Aboriginal and Torres Strait Islander women and families should be updated to reflect these similarities. This study provides early support for these similarities. However, this study also highlighted the need to be supported 'properly'. Cultural implications of this factor warrants further investigation and could be used to further update the clinical practice guidelines. It is hoped that an increase in autopsy rate will enhance the understanding of the causes of stillbirth and thus help to decrease the stillbirth rate for Aboriginal and Torres Strait Islander families.

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