

ORIGINAL ARTICLE

Bereaved parents' experience of care and follow-up after stillbirth in Sydney hospitals

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Background: Despite stillbirth being identified as one of the most traumatic events a woman can experience, there is a lack of evidence on which to inform best practice in hospital and follow-up care.

Aims: The aim of this study was to identify which strategies are most valued by parents regarding care following stillbirth in order to improve the support and management of grieving families.

Method: Mixed methods questionnaires were sent to bereaved participants of the Sydney Stillbirth Study. Questionnaires included a combination of fixed and open-ended responses regarding two critical areas: the participant's hospital stay and their follow-up care. We analysed the qualitative data using thematic analysis.

Results: Of the 103 women who experienced a stillbirth, 36 responded to the questionnaire. Responders were more likely to have private obstetric care (odds ratio (OR) 4.7, 95% CI 1.7–12.7) and be tertiary educated (OR 6.2, 95% CI 2.3–16.8). Three key themes relating to hospital management of stillbirth were identified: the emotional response to grief, the educational importance of being guided through the grief process, and the environmental aspects of adequate time and appropriate physical space. Families preferred not to be seen in an antenatal setting for follow-up.

Conclusions: Simple key components of care including a sensitive and respectful approach, offering guidance as to creating memories, and arranging follow-up care in a quiet and private environment are valued by families experiencing a stillbirth. Incorporating these into practice is achievable and could benefit both families and caregivers.

KEYWORDS

Australia, bereavement care, parents' view, stillbirth

INTRODUCTION

The global burden of stillbirth has gained considerable international attention in recent years following the publication of two major series in the *Lancet* in 2011 and 2016 and a global call to action.^{1,2} Subsequently there has been improved description of the epidemiology, better understanding of the risk factors, and

increased interest in the subsequent impact on bereaved families. Despite this, there remains limited evidence around both the provision and evaluation of best practice care following stillbirth.

Giving birth to a dead infant is possibly the most traumatic experience a woman can undergo. It affects partner relationships, subsequent pregnancies, surviving and subsequent children, career, friendships and healthcare providers.^{3–5} A Cochrane

review examining the effect of psychological support interventions following stillbirth reported no randomised controlled trials on which to inform evidenced-based care.⁶ However, three small qualitative studies from the UK,⁷ the USA⁸ and Sweden⁹ examined parents' views of their care following stillbirth. As well, two systematic reviews assessed the impact of contact with the stillborn infant¹⁰ and experimental interventions for women after stillbirth.¹¹ All emphasised the need for further research in order to understand how best to implement effective care following stillbirth. In general, research shows that positive interpersonal relationships and strong social support are inversely related with grief intensity, suggesting that these interventions may improve psychological outcomes associated with stillbirth.^{12,13}

In Australia, the importance of psychological and psychosocial support is included in an education program aimed at health professionals to increase uptake of the Perinatal Society of Australia and New Zealand (PSANZ) perinatal mortality guidelines.^{14,15} Initial evaluation of the program found increased knowledge and confidence of the participants to implement the guidelines.^{15,16} However, whether this has changed clinical practice has not been assessed. Only one study has evaluated the effectiveness of the PSANZ guidelines from the perspectives of bereaved parents¹⁷ and recommended that health professionals seek feedback from parents as to how they can improve the support provided. No studies in Australia have evaluated parents' views of their follow-up care after discharge.

The aim of this study was to describe the experience of care received by bereaved parents after stillbirth in Sydney hospitals during their hospital stay, following discharge and through to their follow-up visit, from January 2006 to December 2011.

MATERIALS AND METHODS

We conducted a cross-sectional survey of all bereaved families who participated in the Sydney Stillbirth Study. The Sydney Stillbirth Study was a population-based, matched case-control study investigating modifiable risk factors for late pregnancy stillbirth (from 32 weeks gestation), between January 2006 and December 2011. All seven tertiary maternity centres in metropolitan Sydney were included plus the two largest private hospitals and one district hospital. Services for follow up and community support varied across the sites; however, they all offered at least one follow-up appointment. Detailed methods have been previously published,¹⁸ along with a follow-up study assessing the acceptability and anxiety associated with participating in stillbirth research.¹⁹

Data collection

In February 2012, questionnaires with a cover letter and a stamped, return-addressed envelope were posted to bereaved participants of the Sydney Stillbirth Study. Individual study numbers from the

Sydney Stillbirth Study were used to link all participant's birth and demographic data which was entered in a password-protected database. Participants were identified only by the study number. At least two attempts were made to contact non-responders by phone and/or email. Participants were given the option of completing the questionnaire by phone.

The questionnaire was designed with multidisciplinary input from clinicians and researchers with expertise in qualitative research methodology, and pilot tested by relevant clinicians, bereaved parents and perinatal epidemiologists. Open and closed-ended questions assessed participant satisfaction and experience with their hospital and follow-up care. Closed-ended questions used a five-point Likert scale ranging from Strongly Disagree to Strongly Agree with opportunities to comment on each of the questions, along with open-ended questions relating to what was most or least helpful during their hospital stay. Questions about follow-up care related to home visits, community support, and follow-up appointments, specifically: location and timing of appointments, attendance of hospital personnel, content of, and overall satisfaction with, the clinical interaction (Appendix S1).

Analysis

Quantitative data are presented using descriptive statistics. Differences between characteristics of responders and non-responders were compared using χ^2 test for differences between proportions. Data were analysed using SPSS Version 21 (IBM SPSS Statistics, 2012 IBM Corp., Armonk, NY, USA). Responses using the five-point Likert scale were categorised into 'Strongly Agree/Agree', 'Neutral', and 'Strongly Disagree/Disagree'. Text responses to open-ended questions were analysed using thematic analysis²⁰ by the three authors. The process included: familiarisation with the data, independently coding the data using the study objectives and emergent themes and developing a framework by clustering themes together to best explain the data. Discussion between the researchers continued until there was a consensus of themes. Quotations that directly related to the identified themes or the aims of this study were identified.

Ethics approval was given by the Northern Sydney Local Health District Human Research Ethics Committee (Study ID: 0605-081M).

RESULTS

Of the 103 bereaved women who were sent the questionnaire, 36 (35%) were returned. Six envelopes were returned unopened stamped with 'address unknown'. Telephone follow-up resulted in 17 disconnected numbers and two women who declined participation. Interpreters were not available for three non-English speakers. Another 16 questionnaires were resent at the participant's request with four subsequently completed. The remainder were unable to be contacted after two phone and/or email

TABLE 1 Maternal characteristics of responders versus non-responders to survey

Maternal characteristics	Responders, n = 36 (%)	Non-responders, n = 67%	P-value
<i>Maternal age</i>			
<35	23 (63.9)	50 (74.6)	0.479
35–39	10 (27.8)	12 (17.9)	
≥40	3 (8.3)	5 (7.5)	
<i>Primiparous</i>	16 (44.4)	37 (55.2)	0.297
<i>Private care</i>	14 (38.9)	8 (11.9)	0.001*
<i>Term</i>	23 (63.9)	41 (61.2)	0.788
<i>Not in paid work</i>	2 (5.6)	24 (35.8)	0.001*
<i>Living with partner</i>	36 (100)	55 (82.1)	0.007*
<i>Smoking</i>	1 (2.8)	9 (13.4)	0.159
<i>Adverse social</i>	1 (2.8)	11 (16.4)	0.053
<i>Tertiary education</i>	30 (83.3)	30 (44.8)	<0.001*
<i>Born overseas</i>	14 (38.9)	37 (55.2)	0.114

*Significant.

attempts. Final data included participants from each of the nine sites except one, from which none of the three recruited women responded.

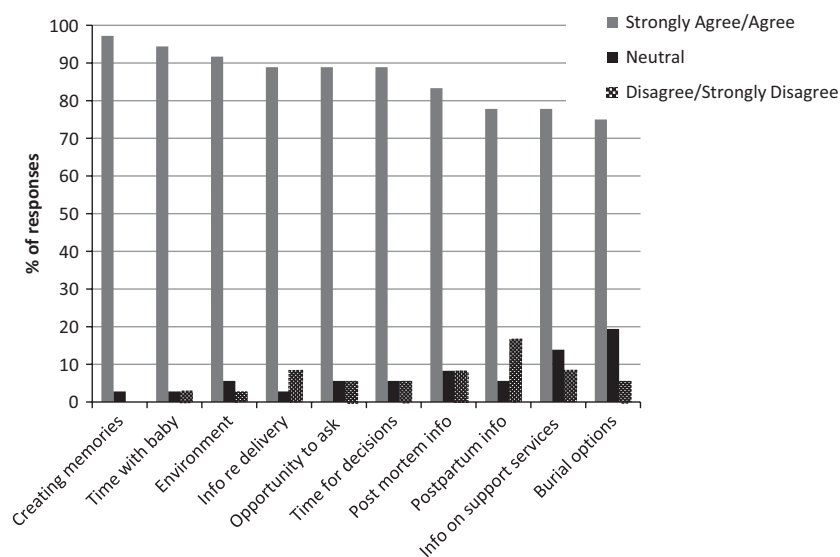
Characteristics of respondents

Socio-demographic differences between women who participated in this follow-up study compared to those who did not respond are shown in Table 1. The women who responded to the questionnaire were significantly more likely to have been receiving private care (38.9% vs 11.9%; $P = 0.001$), co-habiting with a partner at the time of delivery (100% vs 82.1%; $P < 0.01$) and tertiary educated (83.3% vs 44.8%; $P < 0.001$). Non-responders were more likely to not be in paid work (5.6% vs 35.8%; $P = 0.001$). There was no significant difference between the two groups in regards to age, parity, gestation and country of birth.¹⁸ There was also no significant

difference in time from stillbirth to completion of survey between the responders and non-responders (30.08 months, SD 16.3 vs 29.63 months, SD 17.1; $P > 0.05$).

Hospital stay

Almost all participants strongly agreed/agreed that they were satisfied with their hospital care and management regarding information they received about delivery (32/36), opportunities to ask questions (32/36), time to make decisions (32/36), time spent with their baby (34/36), hospital environment (33/36), and support in creating tangible memories of their deceased infant (35/36). Slightly fewer women were satisfied with the post mortem information received (30/36). There was less satisfaction with information received on physical health and recovery (27/36), support services (27/36) and burial options (28/36) (Fig. 1).

**FIGURE 1** Satisfaction with hospital care.

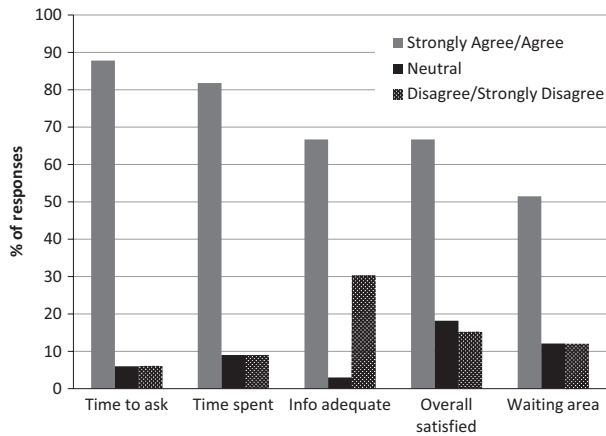


FIGURE 2 Satisfaction with follow-up care.

The majority of participants who completed the survey had consented to a post mortem examination of their baby (28/36). Reasons for declining an autopsy at the time of the loss included: being afraid of what the baby would look like, cultural and/or religious beliefs, wanting to limit the number of people who touched the baby, anxiety about more trauma or disrespect to the baby and advice that it would not be helpful. We found that responders were significantly more likely than non-responders to have consented to an autopsy (OR 3.5, 95% CI 1.4–8.5).

Satisfaction with caregivers was generally high. Our results show that 33/36 participants reported they strongly agreed/agreed that family members provided a great deal of help and support. Most participants were also satisfied with the care they received from midwives/nurses (31/36) and social workers (29/36). Doctors were viewed as less supportive than midwives/nurses (27/36). Friends and pastoral care services showed the lowest degree of satisfaction (23/36 and 14/36 respectively) and the highest degree of neutral/not applicable (10/36 and 19/36).

Follow-up care

More than half of the bereaved families received a home visit by a midwife or social worker subsequent to discharge (27/35). Free text responses suggested that two of these visits were extremely unhelpful: one visitor was unaware that the baby had died, and one misdiagnosed a postpartum complication. Of the seven women who did not receive a home visit, three indicated that they would have accepted this service if offered and four did not want the service. One participant could not remember whether or not she received a home visit.

Most participants (33/36) received follow-up care by a clinician on average 6.5 weeks following their stillbirth. The location of the follow-up visit was important and varied. Only half (17/33) agreed/strongly agreed that the waiting area for their appointment was appropriate (Fig. 2). Antenatal clinics were the least favoured location, where responders reported being 'surrounded by pregnant women and children'. Private rooms, general practitioner

TABLE 2 Items discussed during follow-up visit

Item	Discussed, n = 35
Blood results	28
Future pregnancy	28
Placenta results	23
Post mortem results	20
General health	17
Bereavement support	15
Community support	8
Referral	4
Other	4

(GP) clinics or Maternal Fetal Medicine units were favoured by responders as being quiet and secluded. During the follow-up visit most of the appointment was spent discussing the clinical results with less discussion on bereavement, community support and on-going referral (Table 2). Overall, 22/33 participants agreed/strongly agreed that they were satisfied with their follow-up visit. Components of the visit most responders were satisfied with included opportunities for them to ask questions (29/33) and adequate time spent with the clinician (27/33). However, only 22/33 of the participants stated they agreed/strongly agreed that the information they received was adequate (Fig. 2).

Almost all of the families accessed at least one form of community bereavement service following their stillbirth (34/36). For half of them, this was in the form of a social worker organised by the hospital. Other sources of community support were The Stillbirth Foundation, Sids&Kids, Bears of Hope, and SANDS (Stillbirth and Newborn Death Support). Some women accessed more than one service and the majority felt they benefitted from the support (32/34). Two participants who did not access these services stated they received enough support from family and friends and/or written material and did not feel additional care was needed.

Qualitative results

Open field text responses provided insight into what bereaved parents consider important aspects of care after stillbirth. Three major themes were identified: the emotional response to grief, the educational importance of being guided through the grief process, and the environmental aspects of adequate time and appropriate physical space (Fig. 3). There was considerable overlap between the identified themes, indicating that several components of one theme may at times be synonymous with another. Therefore, an overriding meta-theme was identified: the importance of an integrated support system for bereaved families after infant loss.

The emotional response of bereaved families to their loss was evidenced by their description of the care they received and caregivers' attitudes, both positive and negative. Responders reported appreciating staff who demonstrated integrity, honesty, empathy,

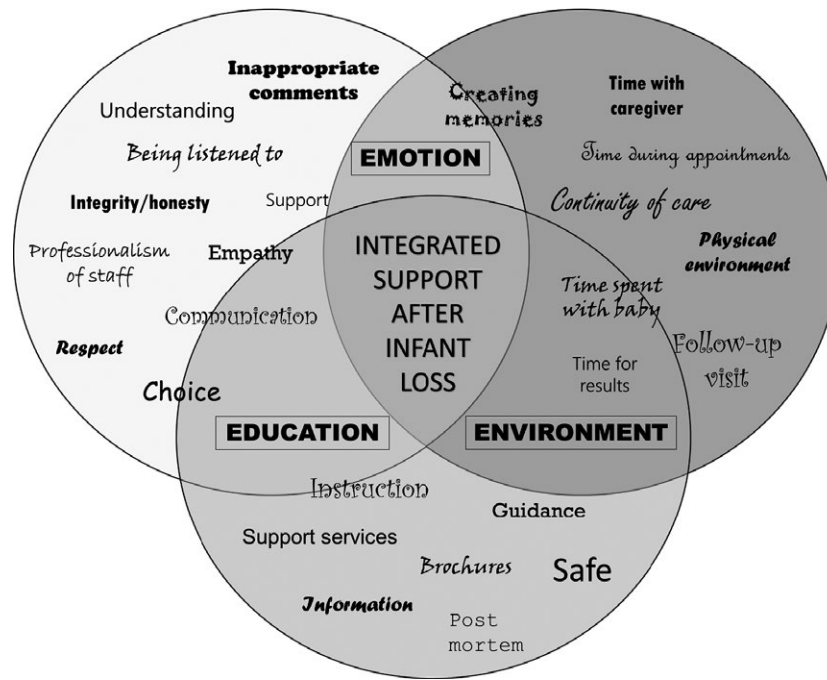


FIGURE 3 Thematic analysis of qualitative responses. [Colour figure can be viewed at wileyonlinelibrary.com]

good listening skills, respect, professionalism and an understanding of their grief. Staff who were obviously uncomfortable with the situation, took control, or made 'inappropriate' comments led to women feeling disempowered, belittled and misunderstood (Table 3).

The second theme identified was that of education. 'Guidance' was a word frequently used by the majority of participants. They felt they had such a short period of time to create a lifetime of memories, but needed guidance as to how to create those memories. Many stated there were not enough educational options given to them at such a critical time, such as verbal discussions, written information and sufficient opportunity to ask questions. More information about health care after delivery and support services for themselves and their partners would be appreciated (Table 3).

The third main theme identified was the importance of the 'environment', including both the physical environment and adequate time spent with their babies and caregivers. A private room away from the sound of newborn infants was important, but needed to be balanced against feeling isolated by staff. Continuity of care was also an important aspect of the hospital environment. Time spent waiting for doctors, appointments or results, were viewed negatively along with an inappropriate environment for the follow-up visit. Waiting in areas with pregnant women and/or crying babies was very distressing to bereaved parents (Table 3).

DISCUSSION

Our results indicate that initial management of stillbirth in the hospital environment shortly before and after birth was generally

viewed as sensitive and appropriate by the majority of participants. There was less satisfaction with follow-up care after discharge, suggesting that while considerable attention has been focused on supporting families around the time of birth of a stillborn infant, less emphasis has been placed on follow-up care.

Parents valued continuity of care both during their hospital stay and after discharge. Qualitative comments highlighted key issues that were valuable to parents at both time points: the emotional response to grief, the importance of being educated about the grief process, and the environmental aspects of adequate time and appropriate physical space.

Participant responses in our study are consistent with other literature on bereavement care and support our main themes highlighting the value of emotional support and sensitive care,¹³ the necessity of receiving structured information and guidance²¹ and the importance of a suitable environment.²² Two recently published systematic reviews evaluating care for families experiencing stillbirth also support our results, particularly in regards to care and support around the time of the birth.^{23,24} However, there is limited evidence to support best practice in management of follow-up care.

In Australia, clinical practice guidelines and education have focused on in-hospital management and investigation of stillbirth.¹⁴ Our study provides valuable insight into the significance of follow-up care after discharge in a suitable environment where all aspects of a family's physical and emotional health are discussed. Our results indicate that community bereavement services are not routinely discussed in follow-up visits despite being highly valued when accessed by parents. Similarly, caregivers viewed as highly supportive (eg nurses/midwives/social workers) should be

TABLE 3 Qualitative themes: quotes from parents

Emotion	Education	Environment
<i>In the previous 6 weeks from 34 weeks I had told the birth centre midwives of my concerns over baby's size and dates and movements and no further investigation was done. They just wrote 'well' or similar on my yellow card and rushed me out of the room. I didn't feel I was listened to. (S014)</i>	<i>I now realise that extra guidance about what I could do with my baby would've been appreciated, for example, bath/dress her, walk with her in the garden, take more photos, have hand/foot casts taken, open her eyes, etc.! These are things chronically grieving parents do not think to do – they need guidance. (S088)</i>	<i>We were given a private room for recovery which was quiet and away from healthy newborns. The midwives checked up on us frequently during this time. (S078)</i>
<i>Very honest, real discussions about my options. (S075)</i>	<i>I wish I'd known there was (financial) support plans for counselling services...(and) more relationship focused support/info available (including) support for bereaved fathers. (S042)</i>	<i>My room was near the nurse's ward and I could hear all the conversations about my situation. (S007)</i>
<i>I loved to hear people/staff referring to my son with his name. (S103)</i>	<i>We were not given enough advice about where to seek support or any follow-up care. (S047)</i>	<i>On follow up I waited a long time in an inappropriate area and then reviewed by a Jnr who asked 'What was I there for?' (S025)</i>
<i>One midwife explained she was late to come and check on me because she was 'busy doing the REAL baby thing' – that comment was beyond hurtful. (S057)</i>	<i>The hospital staff didn't properly explain options available to us... Communication should be verbal and clear about what options there are, especially those that are time critical. (S102)</i>	<i>I hated dealing with so many carers in the stage after delivery. I found it very disorientating in my shock, because of constant change of faces and people...(S047)</i>
<i>Only came once. Said they would come back but didn't. (S071)</i>	<i>Perhaps a small booklet could be provided as you never get this time again. (S025)</i>	<i>The autopsy results took months and months to come through due to understaffing...Even knowing no obvious cause is better than worrying if I was the cause of death. (S003)</i>

included as key members of the team involved in decision-making, support and follow-up care. Supporting bereaved families to access professional groups, and encouraging participation of family or friends, midwives and/or social workers to attend follow-up appointments may have a significant impact on satisfaction with care and long-term grief outcomes.

Strengths and limitations

The strengths of our study include utilising a mixed methods approach as many studies evaluating parents' responses use either qualitative or quantitative data only. All participants experienced a stillbirth in late pregnancy, therefore this study compared grief responses at similar gestations.⁵ Furthermore, this is the only Australian study to specifically evaluate follow-up care after discharge from hospital in addition to care around the time of loss. The average time from stillbirth to completion of the survey was relatively short (2.5 years) as compared to other studies collecting data up to 9,²⁵ 11⁷ and 18²² years after the stillbirth occurred.

A limitation of the study is the small sample size which may make the results less generalisable. However, this is not a single site study and includes responses from eight of the nine maternity centres. A 35% response rate is not dissimilar to other studies using postal questionnaires²² and is consistent with that achieved within the Auckland Stillbirth Study.²⁶ This may be partly due to the fact that women are highly mobile in the perinatal period.²⁷ With respect to the qualitative data, we reached saturation of themes very early in the data collection period. Socio-economic

differences showing the non-responders were more socially disadvantaged than the responders are consistent with previous literature.²⁸ This may explain why those who responded tended to be more actively involved in their care, as indicated by the high autopsy rate among the responders and a high number of women who accessed community bereavement support after discharge. However, despite this, there remained a substantial number of negative responses, reflective of the issues of care which could be improved and should be generalisable across all socio-economic groups. Finally, the results show a clear difference in satisfaction with care in hospital around the time of birth compared with care after discharge. Despite the small sample size, the themes generated are consistent with other recently published larger surveys,²⁵ are specific to late pregnancy stillbirth care in Australia and are also consistent with key messages generated from a recent review on provision of effective and meaningful care after stillbirth.²³ The fact that our results precede those of the larger studies is an important consideration, reflecting the need for expedited changes in clinical practice.

CONCLUSIONS

The effect of bereavement care on the response to grief cannot be underestimated. There are several simple and key components of hospital care and follow-up relating to emotional support, education and environment that are valued by families experiencing a stillbirth. Improvements in follow-up care based on these

components could substantially improve parents' overall satisfaction with care. Implementing these strategies should be attainable, and may have a substantial impact on the long-term health outcomes of bereaved individuals following stillbirth.

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SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

Appendix S1. Follow-up questionnaire for bereaved participants of Sydney Stillbirth Study.