

Original Article

Holding a stillborn baby: the view from a specialist perinatal bereavement service

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Background: Stillbirth is a profoundly distressing event. Little evidence exists to guide best practice bereavement care in the perinatal setting.

Aims: To document parents' experiences and outcomes in relation to seeing and holding a stillborn baby at a hospital with a specialist perinatal bereavement service.

Materials and Methods: Prospective cohort study of 26 mothers and 11 fathers who experienced a stillbirth at the Mater Mothers' Hospital, Brisbane from September 2007–December 2008. Mailed self-report questionnaires were completed at 6–8 weeks and 6 and 13 months postloss. Validated measures assessed regret regarding the decision to see and hold the baby, parental grief and mental health.

Results: Of 78 fetal deaths, 26 mothers and 11 fathers participated. Most (20 mothers; 9 fathers) chose to see and hold their stillborn infant. Little regret was reported, irrespective of the decision. For mothers, seeing and holding was associated with higher 'active grief' at 6–8 weeks (mean difference (MD) = 10.5; 95% CI = 3.3–17.8; $P < 0.01$), 6 months (MD = 8.0; 95% CI = 0.6–15.4; $P = 0.03$) and 13 months (MD = 9.9; 95% CI = 1.8–17.9; $P = 0.01$), but not with 'not coping' or 'despair', or mental health. Fathers reported poorer mental health but small numbers mean estimates are imprecise.

Conclusions: More intense grief does not equate with poorer mental health for mothers who choose to see and hold a stillborn infant. Fathers' experiences warrant further study. Supported decision-making is important for bereaved parents, and rigorous evaluation of bereavement care is essential.

Key words: bereavement, delivery of health care, perinatal loss, pregnancy outcome, stillbirth.

Introduction

Each year in Australia almost 3000 families experience the death of a baby before or soon after birth. In 2011, 1748 babies were stillborn (of at least 20 weeks' gestation or with birthweight of at least 400 grams) and 814 babies were born alive but died within the first 28 days of life.¹ Health professionals in maternity settings play a critical role in delivering bereavement care to parents and reducing their risk for longer-term psychological problems² but little evidence exists to guide best practice.^{3,4} This was highlighted in a recent review regarding the psychological outcomes of one aspect of

care: that of encouraging parents to see and hold their stillborn baby.³ The conclusion was that until further evidence is available, parents should be provided 'balanced advice' to assist them to decide whether or not they should see and hold a stillborn infant.

A critical aspect of perinatal bereavement care is supported decision-making.^{2,5} The choice to see and hold their stillborn baby is one of many decisions parents face at a time of overwhelming grief, though only since the 1980s has offering this choice to parents become standard practice. The influence of staff in parental decision-making is well recognised, with 80% of parents not seeing their deceased baby in the late 1980s because staff discouraged them either directly or indirectly.⁶ Studies show mothers who perceive encouragement from staff are more likely to hold their stillborn infant⁷ and often report gratitude to staff who encourage them to see their stillborn baby.⁸

This study documents the experiences and outcomes of seeing and holding a stillborn baby for parents who received care through a specialist perinatal bereavement service. We asked parents about their decisions and any

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associated regret in relation to seeing and holding their stillborn baby and assessed their grief and mental health outcomes over time.

Materials and Methods

The Mater Mothers' Hospital is a large teaching hospital in Brisbane, Queensland with an average annual birth rate of 9500 and a perinatal mortality rate of 11.8/1000 births, reflecting the tertiary nature of care provided.⁹ A dedicated Perinatal Bereavement Support Service provides care and support for families who experience a perinatal death. Staffed by two full-time clinical midwives, one with loss and grief counselling qualifications (PW),

the model of care is based on prevention and early intervention and aims to reduce the development of mental health disorders. Assisting parents in decision-making, promoting attachment, supporting psychological safety and strengths-based counselling are key components of the model. Comprehensive staff education and mentoring contributes to a sound knowledge base and consistent philosophy of care based on guiding principles of compassionate and respectful care, core values of the health service¹⁰ and up-to-date clinical practice guidelines.¹¹

Mothers and fathers who experienced a stillbirth at the hospital between September 2007 and December 2008 were invited to participate in the study. Parents were

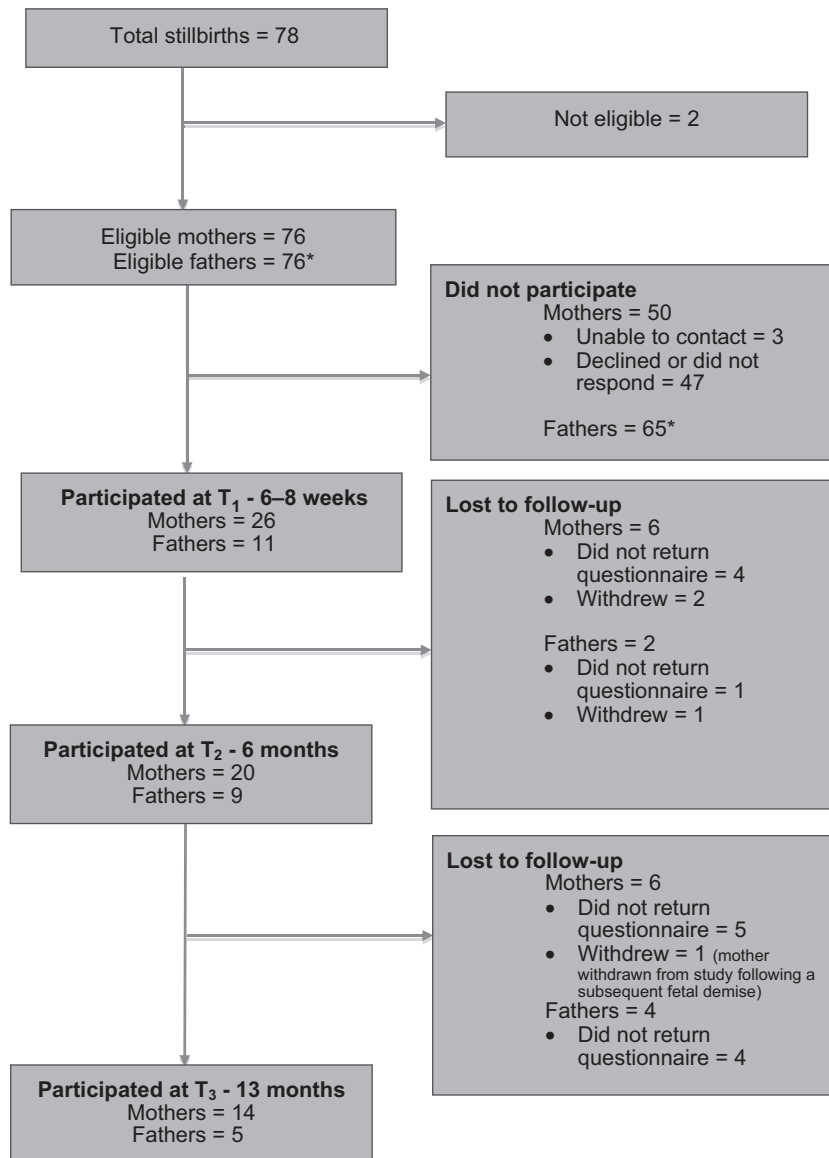


Figure 1 Participant flow and response rates. *The precise number of eligible fathers and their reasons for non-participation is not available as mothers were the unit of recruitment.

excluded if the baby's death had resulted in a formal complaint process or if legal proceedings were pending, if the staff involved in the case considered involvement in research would be psychologically detrimental to the parent(s) or if the mother had died. Ethical clearance was obtained from the Mater Health Services, Human Research Ethics Committee (Ref No. 1111M).

Data on parent decisions, grief, mental health status and regret were collected by mailed survey at 6–8 weeks after the stillbirth, and grief and mental health were assessed again at 6 and 13 months postloss. The measures used were the Decisional Regret Scale (DRS),¹² the Perinatal Grief Scale (PGS)¹³ and the Mental Health Inventory (MHI).¹⁴

The DRS has demonstrated good internal consistency in health-related decision-making. Although not previously used with bereaved parents, it has been used widely in studies of other health-related decisions.¹² The DRS was used at 6–8 weeks postloss to measure parents' perceptions of regret around their decision about seeing and holding their stillborn baby. Five 5-point Likert items ranging from strongly agree to strongly disagree were used, with lower scores indicating less regret.

Grief was measured using the PGS, a 33-item questionnaire widely used in studies of pregnancy loss.¹³ The PGS has very high internal consistency, reliability and proven convergent validity against measures of mental health, social support and marital satisfaction and has been used longitudinally to demonstrate intensity of grief over time. The instrument provides an overall grief score and three 11-item subscale scores. The 'active grief' subscale includes items such as sadness, missing the baby and crying for the baby. 'Difficulty coping' measures difficulty with normal functioning and dealing with others indicating withdrawal and depression. The 'despair' subscale measures feelings of hopelessness and worthlessness.¹³

The MHI, a 38-item questionnaire measures general population mental well-being.¹⁴ An overall MHI score was calculated, with higher scores indicating better mental health. The MHI was chosen to acknowledge a now widely held view of grief as a 'normal process' not a mental illness and because of its inclusion of 'psychological strengths' which relate to resilience in grief.¹⁵ Socio-economic status was recorded in tertiles using the Socio-economic Index for Advantage at the postcode level.¹⁶ Clinical characteristics, including gestational age and cause of death were obtained from hospital records.

Statistical analysis

Descriptive statistics are presented using means (standard deviations) for continuous data and as frequencies for categorical data. Characteristics of mothers who participated were compared to those who did not using Student's *t*-test (continuous data) and Fisher's exact test (categorical data). To compare the association between the decision to see and hold and grief and mental health at 6–8 week, 6 months and 13 months postloss, we constructed

mixed-effects linear regression models, which accounted for the repeated measures on each parent. Time and decision to hold were entered as main effects, as well as a time-by-decision interaction term. All analyses were conducted on Stata v11.1 (StataCorp, College Station, TX, USA).

Results

Of 78 fetal deaths at the hospital over the 16-month data collection period, 76 mothers were eligible for the study and 26 mothers and 11 fathers (11 paired couples) participated (response rate = 34%). Three mothers were unable to be contacted, 47 declined or did not respond to the invitation to participate. At six months, 20 mothers and nine fathers returned their questionnaires, and at 13 months, there were 14 mothers and five fathers who responded (Fig. 1).

Mothers who participated at 6–8 weeks were similar to nonparticipating mothers in terms of primiparity

Table 1 Participant characteristics of mothers comparing those who held or did not hold their stillborn baby, presented as frequencies

Characteristic	Overall <i>n</i> = 25	Hold <i>n</i> = 19	Not hold <i>n</i> = 6	<i>P</i>
Age (years)				
18–34	16	12	4	1
35+	9	7	2	
Ethnicity				
Caucasian	20	17	3	0.08
Other	5	2	3	
Health cover				
Private	13	10	3	1
Public	12	9	3	
Socio-economic status				
Lower	4	4	0	0.69
Middle	8	6	2	
Upper	13	9	4	
Birth type				
Singleton	18	15	3	0.3
Twin	7	4	3	
Parity				
Primigravida	15	11	4	1
Multigravida	10	8	2	
Gestational age				
≥ 24 wks	11	9	2	0.66
≥ 25 wks	14	10	4	
Cause of death				
Unexplained	8	6	2	0.66
Congenital abnormality	5	2	3	
Spontaneous preterm	5	4	1	
Maternal hypertension	3	3	0	
Specific perinatal conditions	2	2	0	
Perinatal infection	1	1	0	
Fetal growth restriction	1	1	0	

Missing data for one mother who held her stillborn baby.

Table 2 Decision regret scale item responses: shown as frequencies for 20 mothers and 8 fathers who held (unshaded rows) and 6 mothers and 2 fathers who did not hold (shaded rows) their stillborn baby

DRS item	Mothers (<i>n</i> = 20 who held in unshaded rows; <i>n</i> = 6 who did not hold in shaded rows)			Fathers (<i>n</i> = 8 who held in unshaded rows; <i>n</i> = 2 who did not hold in shaded rows)		
	Strongly agree or agree	Somewhat agree	Disagree or strongly disagree	Strongly agree or agree	Somewhat agree	Disagree or strongly disagree
It was the right decision	20	0	0	7	1	0
	5	1	0	2	0	0
I regret the choice that was made	0	0	20	0	1	7
	0	0	6	0	0	2
I would make the same choice if I had to do it again	20	0	0	8	0	0
	5	0	1	2	0	0
The choice did me a lot of harm	0	3	17	1	0	7
	0	0	6	0	0	2
The decision was a wise one	19	1	0	7	1	0
	5	1	0	2	0	0

Missing data for one father who held his stillborn baby.

Table 3 Perinatal grief scale (PGS) and mental health index (MHI) scores for mothers and fathers who did/did not hold at 6–8 weeks, 6 months and 13 months postloss)

	Hold <i>n</i> ; mean(SD)	Not hold <i>n</i> ; mean(SD)	Difference (95% CI)	<i>P</i>
PGS				
Mothers				
6–8 wks	20; 93.3 (26.3)	6; 69.3 (20.3)	–23.9 (–46.9,–0.9)	0.04
6 mths	14; 84.5 (26.2)	6; 66.7 (27.8)	–16.5 (–40.0,7.0)	0.17
13 mths	9; 76.1 (20.5)	4; 58.0 (4.2)	–26.3 (–52.1,–0.5)	0.05
Fathers				
6–8 wks	9; 82.8 (20.0)	2; 55.0 (26.8)	–27.8 (–59.7,4.2)	0.09
6 mths	6; 76.0 (19.8)	2; 48.5 (20.5)	–30.8 (–63.4,1.9)	0.06
13 mths	3; 64.0 (15.4)	1; 61.0 (–)	–17.4 (–56.,21.7)	0.38
MHI				
Mothers				
6–8 wks	19; 152.5 (34.8)	6; 169.7 (28.0)	17.1 (–15.3,49.6)	0.3
6 mths	10; 170.3 (44.6)	5; 182.4 (40.0)	6.4 (–29.8,42.6)	0.73
13 mths	10; 168. (38.7)	4; 156.0 (26.6)	–10.7 (–49.,27.5)	0.58
Fathers				
6–8 wks	9; 171. (16.1)	2; 213.5 (13.4)	42.4 (13.1,71.6)	<0.01
6 mths	6; 178. (26.9)	2; 216.0 (12.7)	39.7 (9.3,70.1)	0.01
13 mths	4; 175. (12.0)	1; 211.0 (–)	40.3 (–0.1,80.7)	0.05

Missing items: 1 mother did not complete PGS at 13 months; 1 father did not complete PGS at 6 months and 13 months; 1 mother did not complete MHI at 6–8 weeks and 5 did not complete at 6 months; 1 father did not complete MHI at 6 months and 13 months.

(*n* = 15/26 vs 29/52, *P* = 0.81) and whether the participant had private health cover (13/26 vs 17/52, *P* = 0.13) but participants were slightly older [mean (SD) = 32.1(5.5) vs 28.8(6.2) years, *P* = 0.02]. The median gestational age for both participants and nonparticipants was 27 completed weeks. These participant characteristics were not associated with whether or not a woman saw her stillborn baby (Table 1).

All 37 parents reported being provided the opportunity to see and hold their baby: 29 parents (20 mothers, nine fathers) chose to do so and eight parents (six mothers, two fathers) declined.

When asked to reflect on their decision, parents expressed little regret: most considered their decision to be 'wise', and the 'right' one, irrespective of the decision made (Table 2). One mother who did not see and hold her baby reported she would make a different decision if

faced with the same choice again. Three mothers and one father who saw and held their baby agreed or somewhat agreed that their choice did them 'a lot of harm'.

Mothers and fathers who saw and held their baby tended to record higher parental grief (Table 3). There was no statistical difference in terms of mental health between mothers who did or did not see and hold their baby but fathers who did not see and hold had significantly better mental health in all three postloss surveys than those who did.

Analysis according to the subscales of the PGS indicated a significant difference between participants who held and did not hold on the 'active grief' subscale, with mothers who held their infant demonstrating higher active grief (Table 4). This difference was most pronounced for mothers [mean difference (MD) = 10.5; 95% confidence interval (CI) = 3.3–17.8; $P < 0.01$ at 6–8 weeks, MD = 8.0; 95% CI = 0.6–15.4; $P = 0.03$ at 6 months and MD = 9.9; 95% CI = 1.8–17.9; $P = 0.01$ at 13 months]. The difference between fathers was of a similar magnitude to that of the mothers at 6–8 weeks and 6 months (MD = 12.7; 95% CI = 1.2–24.1; $P = 0.03$ and MD = 13.6; 95% CI = 1.9–25.8; $P = 0.02$, respectively), before attenuating at 13 months

(MD = 3.3; 95% CI = –10.6–17.1; $P = 0.64$). For the despair subscale, scores were comparable at all time points between those who did and did not hold. There is a suggestion fathers who held may have scored more poorly on the not coping subscale, especially at the earlier time periods but, again due to the small number of fathers, the estimates are imprecise and the confidence intervals are wide. The 'did' and 'did not' hold groups were compared in terms of gestational age, cause of death and parity, and no significant between-group differences were identified.

Discussion

Parents who see and hold their stillborn baby may experience a higher intensity of grief but this is not necessarily indicative of mental health disturbance. Mothers who saw and held their baby had higher levels of grief, especially 'active grief', over the course of the study when compared with those who chose not to see their baby. However, the mental health scores of the two groups of mothers did not differ significantly. Fathers presented a different picture but higher levels of grief and poorer mental health for those fathers who saw and held their

Table 4 Comparison of mothers and fathers who did/did not hold their baby in terms of the parental grief scale (PGS) subscales at 6–8 weeks, 6–8 months and 13 months postloss

	Hold <i>n</i> ; mean(SD)	Not hold <i>n</i> ; mean(SD)	Difference (95% CI)	<i>P</i>
PGS: active grief				
Mothers				
6–8 wks	20; 39.9 (7.8)	6; 29.3 (7.4)	–10.5 (–17.8,–3.3)	<0.01
6 mths	14; 35.6 (7.5)	6; 27.5 (10.3)	–8.0 (–15.4,–0.6)	0.03
13 mths	9; 30.9 (5.6)	4; 25.3 (3.3)	–9.9 (–17.9,–1.8)	0.01
Fathers				
6–8 wks	9; 34.7 (6.8)	2; 22.0 (11.3)	–12.7 (–24.1,–1.2)	0.03
6 mths	6; 29.8 (6.3)	2; 18.5 (9.2)	–13.6 (–25.8,–1.9)	0.02
13 mths	3; 23.3 (4.6)	1; 28.0 (–)	–3.3 (–17.1,10.6)	0.64
PGS: not coping				
Mothers				
6–8 wks	20; 28.7 (10.5)	6; 21.8 (7.8)	–7.5 (–16.4,1.5)	0.1
6 mths	14; 25.6 (10.1)	6; 21.2 (10.1)	–3.8 (–13.0,5.4)	0.42
13 mths	9; 24.5 (9.4)	4; 16.0 (2.0)	–10.4 (–20.9,0.7)	0.05
Fathers				
6–8 wks	9; 26.7 (7.2)	2; 14.5 (4.9)	–12.2 (–23.1,–1.2)	0.03
6 mths	6; 25.3 (7.4)	2; 15.5 (6.4)	–10.7 (–21.9,0.5)	0.06
13 mths	3; 22.3 (6.7)	1; 18.0 (–)	–7.5 (–21.2,6.2)	0.28
PGS: despair				
Mothers				
6–8 wks	20; 24.8 (9.6)	6; 18.8 (5.6)	–5.9 (–14.3,2.5)	0.17
6 mths	14; 23.3 (10.0)	6; 18.0 (8.2)	–4.7 (–13.2,3.8)	0.28
13 mths	9; 21.4 (7.9)	4; 16.8 (1.7)	–6.1 (–15.2,3.1)	0.19
Fathers				
6–8 wks	9; 21.4 (7.9)	2; 18.5 (10.6)	–2.9 (–14.9,9.1)	0.63
6 mths	6; 20.8 (7.3)	2; 14.5 (4.9)	–6.4 (–18.8,5.9)	0.31
13 mths	3; 18.3 (5.9)	1; 15.0 (–)	–6.4 (–21.7,8.8)	0.41

Missing items: 1 mother did not complete PGS at 13 months; 1 father did not complete PGS at 6 months and 13 months.

baby must be treated cautiously due to the small numbers involved.

This study presents rarely available Australian data that captures prospectively the mental health outcomes of parents following stillbirth. Unlike previous studies, we measured mental health and levels of parental grief rather than pathological states such as depression, anxiety and traumatic grief. Mothers who 'met' their baby had higher levels of sadness, missing the baby and crying, an observation consistent with the close association between grief and attachment. Maternal-infant attachment is a complex process that occurs to establish an enduring affectional bond between mother and infant. Mothers are grieving a relationship with a baby who is real to them and this needs to be acknowledged and supported by care providers.²

The small sample size and high loss to follow-up limit the generalisability of findings but are not unexpected in a study of this type. Mixed-effects statistical models were used, which take advantage of the repeated measurements on the same individuals to weight the data to account for missingness, increasing the statistical power of the analysis. The small number of participants precluded detailed examination of factors such as cultural background or religious beliefs, which may be important determinants of parents' decisions and mental health outcomes. Regret was measured on only one occasion, 6–8 weeks postloss, and whether parents' views changed with time was not assessed. Other studies suggest nearly all parents who see and hold their baby later describe the experience as personally valuable.⁷ Follow-up of parents over an extended period of time, including the next pregnancy, is needed.

Our study did not set out to resolve the contradictory findings that have emerged regarding the practice of parents seeing and holding their stillborn infant but to document outcomes for parents who had received coordinated care from a specialist bereavement service. Consistent with others,^{2,17} our findings show that when parents are supported in their decision-making, most will choose to see and hold their baby. Regardless of their choice, few parents regretted their decision, at least relatively soon after their loss. Parents who choose not to see and hold their stillborn infant, even in a supported care environment, may differ from those who interact with their baby on a range of personal, sociocultural, situational and obstetric characteristics. Some of these factors may also be important determinants of the level of attachment to their infant and the level of grief experienced. For example, cultural norms that strongly discourage talking about or 'worshipping' the deceased, or open displays of emotion or discussion of feelings, as in some Asian cultures¹⁸ may help to explain why better outcomes have sometimes been observed for those who did not spend time with their baby. Similarly, differences in attachment and grief have been noted following the death of one baby of a multiple pregnancy.¹⁹

Parents diagnosed with a fetal death face many complex decisions at a time when their decision-making capacity is

greatly diminished by the shock and devastation of grief. They frequently look to staff to assist or advise in these 'once in a life-time' decisions. A decade of research has attempted to address just one of these decisions, that of whether or not a parent should see and hold their stillborn baby. It is time to move beyond this simplistic question to more meaningful evaluation of the nature and quality of care provided and the context in which parents' decision-making occurs. Compassionate care that provides a deep respect for the deceased or dying infant, balances privacy without isolation and gives informational and emotional support is recommended in caring for all grieving families.^{2,5} Staff need to be well informed about the importance of their role in influencing immediate and longer-term bereavement outcomes, and aware of their own values and reactions to provide impartial care.²⁰ Some maternity units have developed bereavement support programs to address these needs,^{21,22} while the role of a bereavement midwife²³ is gaining credibility in larger maternity hospitals. Both approaches are strongly advocated by parent support groups.²⁰ Rigorous evaluation of approaches to bereavement care is a vital next step in developing best practice and ensuring appropriate care and optimal outcomes for families following stillbirth.

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Conflict of Interest

Patricia Wilson is employed by Mater Health Services as the Coordinator of the Bereavement Support Service, where the study was undertaken. The study was partially funded by the Mater Foundation.

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