Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: a cohort study

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Summary

Background Most maternity units have good practice protocols, advising that after stillbirth parents should be encouraged to see and hold their dead infant. Our aim was to assess whether adherence to these protocols is associated with measurably beneficial effects on the psychological health of mother and next-born child. This study forms part of a wider case-control study of the psychological effects of stillbirth.

Methods We identified 65 women in the pregnancy after stillbirth, and enrolled matched controls for 60 of them. Outcome measures included depression, anxiety, and post-traumatic-stress disorder (PTSD) in pregnancy and 1 year after the next birth, and disorganised attachment behaviour in the next-born infant. Comparison variables included seeing and holding the stillborn infant, having a funeral, and keeping mementoes.

Findings Behaviours that promote contact with the stillborn infant were associated with worse outcome. Women who had held their stillborn infant were more depressed than those who only saw the infant, while those who did not see the infant were least likely to be depressed (13 of 33, 39%, vs three of 14, 21%, vs one of 17, 6%; p=0.03). Women who had seen their stillborn infant had greater anxiety (p=0.02) and higher symptoms of PTSD than those who had not (p=0.02), and their next-born infants were more likely to show disorganised attachment behaviour (18 of 43, 42%, vs one of 12, 8%, p=0·04). Having a funeral and keeping mementoes were not associated with further adverse outcomes, but small numbers limited interpretation.

Interpretation Our findings do not support good-practice guidelines, which state that failure to see and hold the dead child could have adverse effects on parents' mourning.

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Introduction

The trauma of stillbirth can have long-term effects on the family. About a fifth of women have prolonged depression,[1,2] and a fifth post-traumatic-stress disorder (PTSD) in the subsequent pregnancy.[3] Other children in the family can also be affected; case reports indicate that these children might be vulnerable to psychological problems possibly related to maternal anxiety,[4–6] and an association between adolescent anxiety disorder and maternal experience of stillbirth has been reported.[7] We have already noted[8] that infants next-born after stillbirth showed a significant increase in disorganisation of attachment behaviour to the mother, mediated not by maternal depression or anxiety, but by a measure of maternal unresolved mourning. This attachment pattern in young children is associated with vulnerability to later adverse psychosocial development,[9] and could be a link in explaining later child disturbance after maternal stillbirth.

The psychosocial management of stillbirth has changed in the past 25 years: where previously the infant was removed to avoid parental distress at the sight of their dead child, parents are now encouraged to see and hold the baby, to dress it as though it were a live child, to hold a funeral, and to keep mementoes.[10] The promotion of these behaviours derives from the view that encouragement of physical contact and creation of memories of the child will facilitate recovery from loss and help avoid pathological sequelae for parents or other children in the family,[11,12] but there has been no systematic outcome assessment to support this practice. Our aim was to examine whether or not these parental behaviours at the time of the stillbirth are associated with beneficial effect on the psychological health of the mother and her next-born child.

Methods

We studied pregnant women, attending one of three district general hospitals, who had no live children and who had previously had spontaneous pregnancy loss after 18 weeks' gestation. Controls were women who were in their first pregnancy and were attending the same antenatal clinics as those who had previously lost a stillborn child. We case-matched controls for age (within 5 years), ethnic origin, and education. All participants were older than age 19 years, had a singleton pregnancy, had a partner, and spoke good English. We excluded women in treatment for physical or mental illness, and those whose stillbirth was a result of an elective termination for abnormality. Because we wanted to include an assessment of the next-born child's development, we identified and enrolled women during the pregnancy subsequent to stillbirth. The local ethics committees approved the study and all participants provided written informed consent.

We screened hospital antenatal case records every 3–4 months, and contacted women by letter inviting them to take part in our study in the third trimester of their pregnancy, when the outcome of the pregnancy was likely to be healthy. Outcome measures were maternal symptoms of depression, anxiety, and PTSD during

pregnancy (assessed in the third trimester) and after 1 year, and disorganisation of attachment behaviour of the next-born child at 12 months. We also computed an overall outcome measure, for which women were rated as having no adverse outcome versus one or more adverse outcomes. Predictor variables included group (index or control) demographic factors, and the parental behaviours promoted by good-practice guidelines. We examined differences between index and control women and infants in the outcome measures, and then explored whether seeing and holding the stillborn infant, having a funeral, and keeping mementoes were associated with improved outcome in the index group.

We used an interviewer-rated demographic questionnaire to gather information about education, employment status of women and their partners, housing, duration of relationship with partner, and current and previous physical and mental health. For index women, we also obtained details of previous pregnancy, confirming gestation at the time of loss, time since the loss, whether the present partner was father of both present and previous babies, whether the mother had seen and held the dead child, had a funeral, attended the funeral, been given mementoes, and whether she felt she had had support from her partner and family.

The Edinburgh postnatal depression scale (EPDS),[13] a ten-item self-report scale developed for postnatal use and validated for use during pregnancy,[14] was used to assess depressive symptoms in the third trimester. The instrument scores from 0 (no symptoms) to 30. For dichotomous analysis, the 14/15 cut-off was used antenatally (as recommended by Murray and Cox[14] because of the high levels of dysphoria in pregnancy). We report data for both continuous and categorical scores.

We used the 20-item Spielberger state anxiety scale (SSA) questionnaire, of the Spielberger state-trait inventory,[15] to assess anxiety at time of testing (state). Each item is scored from 0 (no symptoms) to 4. The average score for a non-clinical, working, female population is 35 (SD 10·6).[15] We used the conventional continuous score, and also report a categorical score with a cut-off of 44/45, which represents the highest scoring 15% of the control group.

We used the 21-item Beck depression inventory (BDI)[16] at 12 months post partum. Each item scores from 0 (no symptoms) to 3. For dichotomous analysis, a conventional cut-off of 10/11 was used.[17] We report for both continuous and categorical scores.

To assess symptoms of PTSD we used the PTSD-1 interview,[18] which shows close correspondence with DSM-III R criteria[19] and provides binary present/absent and continuous severity/frequency outputs on each symptom and the entire syndrome.

Finally, the Strange Situation procedure (SSP)[20] was used to assess infant security of attachment in a 20 min standardised procedure, involving infant and mother in two brief separations and reunions. The procedure is video-recorded and, on the basis of the infant's behaviour throughout the procedure, a score is given for disorganisation of attachment behaviour on a 1 to 9 point scale. A score of more than 5 is the cut-off for the category "Disorganised with respect to attachment".[21] Two masked researchers, of whom one was external and one (PT) internal to the study, rated participants. Inter-rater reliability of the continuous measure of disorganisation was 46% perfect agreement and 79% within one point on the 9-point scale. For discordant classifications the video was reviewed by both researchers together and a classification agreed.

	Stillbirth (n=60)	Control (n=60)	95% CI (difference)	p
Outcome measure				
Third trimester				
EPDS (mean)*	10·8	8·2	0·9 to 4·7	0·004
EPDS >14 (number,%)	17·0 (28%)	4·0 (8%)	8 to 34	0·004
SSA (mean)*	39·8	32·5	3·0 to 11·6	0·001
PTSD	13·0 (21%)	0	11 to 32	<0·001
1 year after birth				
BDI (mean)*	6·0	5·1	–1·2 to 3·0	0·39
BDI >10	10·0 (18%)	4·0 (8%)	–5 to 20	0·18
SSA (mean)*	32·9	32·4	–2·5 to 6·7	0·36
PTSD	2·0 (4%)	1·0 (2%)	–4 to 7	1·00
Disorganised attachment	19·0 (36%)	8·0 (15%)	7 to 36	0·03
Overall poor outcome	39·0 (65%)	23·0 (38%)	8 to 42	0·007

EPDS=Edinburgh postnatal depression scale; SSA=Spielberger state anxiety scale; PTSD=post-traumatic-stress disorder; BDI=Beck depression inventory. *Assessed with paired *t* test. Other analyses by McNemar tests.

Table 1: **Outcome measures in women who had had a stillbirth and in controls**

Statistical analysis
Inferential tests were two-tailed and a p value of 0·05 was judged significant, since multiple test corrections would have been highly conservative where predictors and dependants are each positively correlated. We assessed significance of continuous variables with *t* tests, because distributions did not differ significantly from Gaussian. Significance for unpaired comparison of categorical variables is from Fisher's exact test and its extension to 3X2 tables and McNemar tests (with exact p values) for paired comparison of proportions. We assessed the effect of time since loss (a possible continuous confounding variable) on continuous dependent variables by analysis of covariance, and the effect of possible categorical confounds by two-way analysis of variance. Selected results are presented with 95% CI:[22] we used the May and Johnson method[23] to identify intervals for paired categorical dependent variables.

Role of the funding source
The sponsors of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report.

	Did not see stillborn infant (n=17)	Saw but did not hold stillborn infant (n=14)	Held stillborn infant (n=34)	p
Adverse outcome				
Third trimester depression (EPDS >14)	1 (6 %)	3 (21%)	13 (39%)	0·03
Third trimester anxiety (SSA >44)	3 (18%)	4 (31%)	13 (45%)	0·17
Post-traumatic-stress disorder	1 (6%)	2 (14%)	10 (30%)	0·13
1 year depression (BDI >10)	2 (15%)	1 (8%)	8 (26%)	0·49
1 year anxiety (SSA >44)	2 (18%)	0	8 (26%)	0·18
Infant attachment disorganised	1 (8%)	5 (42%)	13 (42%)	0·10
Overall adverse outcome (≥1 score above cut-off)	4 (24%)	9 (64%)	27 (79%)	<0·0001

EPDS=Edinburgh postnatal depression scale; SSA=Spielberger state anxiety scale; BDI=Beck depression inventory.

Table 2: **Proportion of women above cut off for adverse outcome in relation to whether they saw, saw and held, or did not see their stillborn infant**

	Saw stillborn infant	Did not see stillborn infant	95% CI	p	Held stillborn infant	Did not hold stillborn infant	95% CI	p
Outcome measure score								
Third trimester depression (EPDS)	11·2 (5·9)	8·8 (3·5)	−0·58 to 5·31	0·051	11·8 (5·7)	9·3 (4·5)	−0·11 to 5·1	0·06
Third trimester anxiety (SSA)	41·3 (11·9)	33·9 (9·5)	0·86 to 13·8	0·02	42·1 (11·4)	36·3 (11·4)	−0·09 to 11·8	0·054
Third trimester PTSD	48·9 (18·2)	41·7 (16·4)	−3·4 to 17·8	0·16	51·8 (18·9)	41·6 (15·2)	1·3 to 19·0	0·02
1 year depression (BDI)	6·9 (6·5)	4·8 (4·0)	−1·7 to 5·9	0·17	7·5 (7·2)	5·0 (3·9)	−0·73 to 5·7	0·11
1 year anxiety (SSA)	32·5 (11·2)	30·6 (9·7)	−5·3 to 9·0	0·57	34·1 (12·2)	29·5 (8·3)	−1·2 to 10·5	0·10
1 year PTSD	40·6 (14·7)	28·3 (10·6)	1·8 to 22·7	0·02	43·2 (14·9)	30·1 (10·3)	5·1 to 21·2	0·002

Data are mean (SD) unless otherwise indicated. EPDS=Edinburgh postnatal depression scale; SSA=Spielberger state anxiety scale; PTSD=post-traumatic-stress disorder; BDI=Beck depression inventory.

Table 3: **Continuous scores on outcome variables in relation to whether mothers held, saw, or did not see their stillborn infant**

Results

We screened 30 000 consecutive case records. 82 of 96 (86%) women who met inclusion criteria agreed to participate. 13 (14%) delivered before the interview date and 69 (72%) had a third trimester interview, of whom 65 (68%) provided useful data. 63 of 83 (76%) control women identified agreed to participate. One delivered before the interview date; 62 (75%) had a third trimester interview, two of whom had been matched to index women who delivered before their interview and who were, therefore, excluded from the study. 60 matched case-control pairs were, therefore, enrolled, and 53 matched pairs were followed up 1 year after delivery. For data that relate only to the stillbirth group, we report on all 65 women in that group (55 at 1 year's follow-up).

The mean age of women who had previously had a stillborn child was 30 years (range 20–46) compared with 29 years (20–43) for controls. 39 (65%) pairs were white and 21 from matched ethnic minorities. Groups were well matched on educational level (35 index women and 36 controls had at least A levels; 25 index and 24 control women had O levels or GCSE, or less; p=1·00). Four case and two control women reported previous physical illness and four case and six control women previous mental illness, which was treated by their family doctor. No women reported psychiatric treatment after the stillbirth. Six reported the stillborn infant had a congenital abnormality, the remainder that the infant was normal. 33 (51%, range 2–11, median 5) women conceived less than 12 months after loss and 32 (49%, 12–180, 23) more than 12 months after loss. Ten women who had had a previous elective termination of pregnancy in addition to the stillbirth showed no significant differences from other cases with respect to baseline characteristics. Although the groups were well matched on other social criteria, they did differ with respect to social disadvantage (unemployment, low income, poor housing), with nine women who had had a stillbirth but no controls having more than one type of disadvantage (p=0·005). We therefore included an assessment of the effect of social disadvantage in the analysis. Of the 65 women who had a stillbirth, 17 (26%) did not see the dead infant, 14 (22%) saw but did not hold the child, and 34 (52%) held the infant.

Table 1 shows the overall outcome results in the stillbirth compared with the control group. Women who had had a stillbirth had significantly greater depression, anxiety, and PTSD in the third trimester of the subsequent pregnancy than their controls, and their infants were significantly more likely to show disorganisation of attachment at age 1 year.

Table 2 shows outcome in relation to whether mothers saw their stillborn child, saw and held the child, or did not see it. Mothers who did not see their stillborn infant had a significantly better outcome for third trimester depression and overall than those who saw, or saw and held, their infant. PTSD was also less frequent, though not significantly so, in individuals who did not see or hold their babies (table 2). Although infant disorganisation of attachment did not differ significantly when compared across all three groups (hold vs see vs neither), infants of mothers who had seen, or seen and held, the stillborn infant were significantly more likely to show disorganised attachment than infants of mothers who had not seen the stillborn infant (p=0·04).

Table 3 shows the results of analysis of continuous scores on outcome variables in relation to whether or not mothers saw or saw and held their stillborn child. All scores were in the direction of a better outcome for women who had not seen or held their stillborn infant than for those who had. Women who saw the infant had significantly higher anxiety and PTSD scores in the third trimester than did those who did not see the child, and had significantly higher PTSD scores 1 year after the subsequent birth. The difference in depression scores in the third trimester was close to significance. Women who had held the infant had significantly higher PTSD scores in the third trimester and 1 year after the subsequent birth than did those who did not hold their infant, and differences in scores for anxiety and depression in the third trimester were narrowly non-significant.

Although having a funeral and keeping mementoes were associated with worse outcomes, most women who had a funeral or kept a memento also saw or held their infant, making a cause-and-effect relation difficult to ascertain. We examined separately the effect of having a funeral and keeping mementoes on those who had held or

	Age (<30 years or ⩾30 years)	Social disadvantage (present or absent)	Ethnic origin (white or ethnic minority)	Education (⩾A levels or no A levels)	Saw stillborn infant (yes or no)	Held stillborn infant (yes or no)	Funeral (yes or no)	Kept memento (yes or no)
Outcome measure score								
Third trimester depression (EPDS)	0·01	0·16	−0·02	0·02	−0·28*	−0·26*	−0·14	−0·14
Third trimester anxiety (SSA)	−0·07	0·33*	−0·10	−0·14	−0·23	−0·21	−0·17	−0·09
Third trimester PTSD	−0·08	0·12	0	0·15	−0·19	−0·20	−0·14	−0·06
1 year depression (BDI)	1·51	−1·04	−1·04	−1·74	−0·06	−0·14	−0·07	−0·07
1 year anxiety (SSA)	−0·09	0·03	−0·04	−0·08	−0·02	−0·17	−0·12	−0·04
Infant disorganisation	0·08	0·09	−0·13	−0·11	−0·34*	−0·14	−0·13	−0·25
Overall	−0·06	0·24	−0·16	−0·11	−0·51*	−0·37*	−0·36*	−0·39*

Data are proportion difference between exposed and unexposed. EPDS=Edinburgh postnatal depression scale; SSA=Spielberger state anxiety scale; PTSD=post-traumatic-stress disorder; BDI=Beck depression inventory; Overall=presence of any negative outcome across the six possible outcome criteria. *p<0·05.

Table 4: **Relation between categorical dependent variables and predictors for mothers who have had a stillborn child**

not held the stillborn infant. For those who had held the baby (34), having a funeral made no difference to outcome: 13 (56%) of the 25 who had a funeral, and five (56%) of the nine who did not have a funeral, had one or more adverse outcomes. All but one of those who had held the infant kept a memento. This one woman had a good outcome, but no conclusions can be drawn. For those who did not see the baby (17), having a funeral (four) and keeping mementoes (three) made no obvious difference to outcome, but numbers are so small that analysis is not useful. The only demographic variable significantly associated with outcome was social disadvantage (table 4).

We have already reported[2,3] an association between conception within a year of stillbirth and anxiety, depression, and PTSD in the subsequent pregnancy. We therefore tested the joint effect of time since loss and seeing and holding the dead infant with analysis of covariance. This factor had no effect on the significance of any associations reported except for third trimester depression, in which instance the association with seeing and holding the dead infant became narrowly non-significant (p=0·06). We also tested the joint effect of social disadvantage and seeing and holding the dead infant with two way analysis of variance and, again, the only effect was that the association with third trimester depression and seeing the dead infant became narrowly non-significant (p=0·06).

Discussion

In 1985, the Royal College of Obstetricians and Gynaecologists in the UK published guidelines, recommending that after a stillbirth "staff should create an atmosphere which encourages parents to see and hold their baby [...] Parents may need to be informed that if they do not see their baby they may regret it as it could make mourning more difficult".[10] Our findings do not accord with these guildelines, and instead suggest that mothers who elected not to see and hold their stillborn infant had a better outcome than did those who did see and hold the infant. Women who did not see or hold their child had significantly lower depression in the subsequent pregnancy, and had less symptoms of anxiety and PTSD. The next-born infants of women who had seen their dead infant were more likely to show disorganisation of attachment behaviour than were infants of women who had not seen the dead baby. None of these findings was explained by time since loss. Although having a funeral and keeping mementoes do not seem to confer any benefit in terms of the outcome measures we studied, they do not add significantly to the degree of pathology, and much larger numbers would be needed to tease apart these associations.

Usual practice after stillbirth, until the 1970s, was to remove the dead child before the parents had seen it, with the well-intentioned wish to protect them from distress. However, parents also complained that staff avoided them, failed to acknowledge the severity of their loss, and resisted allowing them to talk about the death. The first clinician in the UK to call for a change in management was Lewis.[11,12] Lewis asked that parents be treated with greater understanding and openness, but also suggested that long-term problems were caused by parents suppressing their grief and not having contact with their dead child. The evidence for this position came from clinical accounts of parents who had been treated for psychological problems after the loss.[24,25] Despite the absence of epidemiological evidence, the next two decades saw an explosion of articles, books, and seminars, lending support to the proposed changes, with a parallel appearance of protocols of good practice in labour wards.

It is instructive to examine the historical context in which demands for change in management took place. Before World War II, maternal mortality was about one in 200 births, until blood transfusion and antibiotics became widely available in the 1930s and 1940s. Increasingly effective intervention became a driving force for the active medical management of childbirth in subsequent decades, and hospital births in the UK rose from 15% of all births in 1927 to 95% in 1974. Stillbirths fell from 28 per 1000 births in 1948 to 12 per 1000 in 1969 and five per 1000 in 1996, and doctors believed that a somewhat impersonal but technically effective service was a small price to pay for a live mother and infant. However, in the backlash against this perceived utilitarian approach, women argued that survival and sensitivity might not be alternatives, and demanded more control over their experience.[26,27] This situation was the backdrop to the enthusiastic adoption of the new practices, which invited parental involvement and thus fell neatly into the movement to reduce medical paternalism.

Even now, evidence for the effectiveness of the protocols is limited. Results of a retrospective study[28] suggest that there was higher anxiety 3 years from stillbirth when the mother reported she was not allowed as much time with the dead child as she wished, and when she did not have a memento. However, the number of women in this Scandinavian study who did not see their infant was too small to use as comparison. Holding the stillborn child did not correlate with greater or less anxiety or depression 2 years[29] and 3 years[30] after the stillbirth, nor was a correlation seen between number of interventions and grief or coping 2 years later.[29] If satisfaction with care is the outcome measure, more satisfied parents were contacted after the loss by a social worker, and were given explanatory material, kept a memento of the infant, and held a memorial service.[29] Most parents now elect to see, and many to hold, their stillborn infant,[30,31] but this represents current fashion: a generation ago parents said that seeing the infant would be harmful.[32]

Parents in our study had various reasons for seeing, holding, or not seeing their stillborn infant. Some stated their wish not to see the baby, and staff accepted this wish, usually saying that parents could change their minds if they wanted. Others were persuaded: "I didn't really want to hold him but they said it would be better for me." Our overall impression, however, was that most mothers were shocked and had no clear plan of how to manage the situation: they simply went along with whatever was expected of them. Our figures indicate that some parents who saw and held their infant did not have adverse outcomes, and perhaps the experience was useful for them. However, we speculate that sometimes, rather than creating memories which help the recovery process,[11] seeing and holding the dead infant further traumatises a woman who is already intensely distressed and physically exhausted. Furthermore, we noted that some women are left with images that haunt them afterwards.[3,8] Mothers who elected not to see their stillborn infant might have been especially confident women who were able to firmly say what they wanted. However, there was a hierarchy of poor outcome, with those who both saw and held the infant doing worse than those who only saw it, who in turn did worse than those who did neither. We would have to postulate a parallel hierarchy of psychological robustness with those who only saw their infant being intermediate. This seems a less likely explanation for the global increase in psychological problems than that for

some women seeing and holding the infant is a traumatising experience.

Staff are also shocked and upset when there is a stillbirth. Inexperienced staff might feel at a loss to know what to say or do, and perhaps the protocol gives them reassurance that there is a "right" way to manage the situation. We suspect that the protocol might sometimes be rigidly used to reduce staff anxiety, rather than to fulfil the intention of those who devised it of offering more sensitive care of parents.

Unavoidably ours could not be a randomised study and, although there is no obvious difference on baseline variables, parents who did not see and hold their infant might be different from those who wished or agreed to do so. Our control group was not a perfect match: the stillbirth mothers had had previous experience of childbirth, whereas the controls were having a first pregnancy and first child. Ideally we should have had a second control group of women in their second pregnancy. Furthermore, our numbers are small. Finally, as in any study, there is always the possibility that a variable that we have not thought of could account for the findings.

We believe that when parents have a stillbirth, their wishes about psychosocial management should be respected. Our results suggests there is no justification for telling parents that not seeing their dead baby could make mourning more difficult, and that those who are reluctant to see and hold their child should not be encouraged to do so. We hope that our findings will stimulate further debate and research in this area.

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