Effectiveness of bereavement interventions in neonatal intensive care: A review of the evidence

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KEYWORDS
Neonatal intensive care; Bereavement care; Bereaved parents; Grief; Effectiveness

Summary
The provision of bereavement care is an important part of neonatal intensive care. This systematic review of the effectiveness of interventions to support families and facilitate emotional adjustment following the death of a baby suggests that, while these are largely appreciated by parents who have participated in research, there has been little rigorous evaluation of their effectiveness. This review reflects on possible reasons for this; for example: NICU-led bereavement care is changing, the effectiveness of bereavement care is difficult to measure, concepts of effectiveness are not static, and ethical concerns complicate experimental research. Bereavement interventions are compassion-led and generally considered to be beneficial. New research questions and new methodological challenges are discussed with reference to two examples of evolving practice: bereavement photography and the use of ritual. Future research using innovative and sensitive RCTs and consensus amongst relevant stakeholders is suggested.

Introduction
In many Western societies the death of a child is a rare event, mostly occurring in hospital, and usually in an intensive care setting.1 When babies die in neonatal intensive care units (NICUs), parents experience events and an environment that differ in important ways from those associated with other types of bereavement, such as the death of a spouse. Some aspects of death in the NICU are very context-specific, and the associated experiences can differ even from other forms of parental bereavement that occur in relatively similar circumstances. Unlike parents experiencing earlier perinatal losses, those bereaved in a NICU have a period preceding death during which they may engage with their child as a born and living individual. Unlike parents of older children who die in paediatric intensive care, most have no opportunity to experience home life with their child. Experiences associated with the NICU setting and the opportunities and limitations that it generates, shape and contextualise the bereavement interventions available to parents. There have been calls for research on the effectiveness of bereavement interventions more generally in the paediatric field,2–5 but we suggest that NICU-led bereavement interventions warrant investigation in their own right.
Objectives

The aim of this review is to consider systematically the evidential base for the effectiveness of bereavement interventions or packages of care for parents around the time of and following the death of a baby in a NICU. We reflect on the nature of this evidence, identify gaps in the literature, and make suggestions for further research.

Methods

Studies evaluating any specific NICU-led intervention or package of care designed to improve the level of support or psychological well-being of bereaved parents and other family members, measuring any outcomes, were considered. A hierarchy of study designs to assess effectiveness was distinguished, ranging from randomized controlled trials (RCTs), non-randomized controlled studies, and studies without controls. Qualitative or broadly descriptive studies were also included for their insights into parental views of the effectiveness of bereavement interventions.

Full details of the search strategy are available from the authors. In brief, appropriate electronic databases were searched on keywords including bereavement, bereaved, grief, end of life, withdrawal, infant, newborn, child, baby, neonate, neonatal, paediatric, intensive care, critical care, parent, sibling and family. Although studies involving only miscarriage, termination of pregnancy, or stillbirths were excluded, studies which considered the broad range of perinatal bereavement including death within the first month of life were included in the review. Reference lists of studies, reviews and guidelines for professionals were checked for additional studies. Given that there were very few quantitative studies, no statistical analysis was conducted.

Results

The searches yielded 1588 citations. Although few concentrated exclusively on NICU parents, 109 full papers were evaluated in depth, including six previous reviews2–7; 21 studies1,8–27 met the inclusion criteria and are briefly summarized in Tables 1 and 2. Of the 21 studies, 14 were conducted in the US6–11,13,14,17–19,21,24–27 and seven in Europe.1,12,15,16,20,22,23 One was an RCT12 four were cohort studies with non-randomized controls10,14,16,21 one with historical controls,14 one was a longitudinal case series,19 and 15 were qualitative or broadly descriptive studies.8,9,11,13,15,17,18,20,22–27 The 21 studies focused either on specific interventions or on broad packages of care.

Evaluation of specific interventions (n = 7 studies)

Bereavement support groups or counselling

Of the four studies that investigated the impact of support groups or counselling, one was an RCT12 in which mothers were randomly allocated to receive planned support and counselling, or to receive routine hospital care immediately following stillbirth or early neonatal death. At 6 months there was a lower rate of psychiatric disorder (measured by the General Health Questionnaire) and less anxiety and depression (Leeds Scale) in the support and counselling group, but by 14 months these differences were no longer statistically significant. Similarly, a cohort study with non-randomized controls16 found that parents whose baby died in an NICU or after sudden infant death syndrome (SIDS) in the first year of life who received counselling experienced significantly less anxiety at 1 and 13 months post-bereavement (State-Trait Anxiety Inventory) than those who had not received counselling. They did however experience significantly more intrusive thoughts at 1 month (Impact of Event Scale) and more bodily symptoms at 13 months (Bodily Symptom Scale) than the non-counselling group. These findings contrast with those of another non-randomized study which found no difference in grief reactions (Hogan Grief Reaction Checklist) between parents who had and had not attended a support group.21

Reilly-Smorrowksi and colleagues asked parents directly for their views of a support group programme, attended by approximately half of the bereaved parents in their centre.24 Questionnaires completed at the end of each 12-week period of support consistently suggested that parents viewed the support groups as very helpful, particularly as an aid to learning to tolerate their grief. No comparisons were made between parents who did and did not attend the support groups.

Giving information on parental grief

Two studies described and assessed methods of informing newly bereaved parents about parental grief and the coping strategies that they might employ.

A small cohort study using non-randomized controls investigated the impact of telephone follow-up by a physician.10 Around the time of death a physician spoke to parents in person or by telephone. The physician explained some of the problems commonly experienced by bereaved parents and gave advice on topics such as sources of strength and support, talking to siblings, and organizing funerals. A follow-up telephone call approximately 1 week later repeated this information, reviewed post-mortem findings, and offered the opportunity to discuss the cause of death. Parents were encouraged to contact the physician with any further questions. At a later interview (9–27 weeks post-bereavement), 18 parents who had received a follow-up telephone call reported significantly fewer grief-related problems, particularly loneliness and depression, guilt feelings, questions about heredity, and concerns about the cause of death, compared to the 11 parents who were not called.

A survey investigated the impact of sending a book to parents a few days to several weeks post-bereavement.13 The book covered topics such as funeral arrangements, marital strain, reactions of others, effects on the couple’s physical and emotional relationships, siblings, religious issues, guilt, learning to have fun again, and getting on with life. It was accompanied by a letter extending the NICU staff’s sympathies and encouraging parents to call with any problems or if they wished to review the baby’s illness and death. The letter also reviewed the nature of grief and the problems some families might experience. In a questionnaire, most respondents indicated that the book was helpful and suggested continuation of the project.
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<tr>
<td>Rowe</td>
<td>1978</td>
<td>US — single university hospital</td>
<td>To examine how effectively information about the baby’s death was transmitted to parents by the physicians at a perinatal referral centre</td>
<td>Morbid grief reactions, level of understanding, degree of satisfaction, sources of support and information</td>
<td>Mothers (perinatal death)</td>
<td>Not a specific intervention</td>
<td>Qualitative study — interviews conducted 10–22 months after the death</td>
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<td>Cohen</td>
<td>1978</td>
<td>US — single university hospital</td>
<td>Aim not stated</td>
<td>Parents’ views on viewing the body of their dead baby</td>
<td>Mothers (perinatal death)</td>
<td>Not a specific intervention</td>
<td>Descriptive study — interviews at a perinatal bereavement clinic around 1 month after the death</td>
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<td>Schreiner</td>
<td>1979</td>
<td>US — single tertiary hospital</td>
<td>To examine the outcome of a physician telephone call to parents approximately 1 week after the death of their baby</td>
<td>Persistence and severity of nine different grief-related problems</td>
<td>Families* (death in a NICU)</td>
<td>Telephone call from a neonatologist 3–19 days after death</td>
<td>Non-randomized study comparing parents who received a telephone call with those who did not. Semi-structured interviews conducted 2–3 months after the death to assess outcome</td>
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<td>Mahan</td>
<td>1981</td>
<td>US — single university hospital</td>
<td>To evaluate methods of helping families through the birth, illness and death of their baby and to see if the staff’s ideas of parental support systems concur with the feelings of those affected by care practices</td>
<td>Parents’ views about the care they received</td>
<td>Sets of parents (death in a NICU)</td>
<td>Not a specific intervention</td>
<td>Qualitative study — postal questionnaires sent to mothers and fathers (time since the death not reported). Effect on response of socioeconomic status, whether mother or father answered, and parental age examined</td>
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<td>Forrest</td>
<td>1982</td>
<td>UK — single university hospital</td>
<td>To test the hypothesis that psychological recovery from stillbirth or early neonatal death (death of the baby within the first 7 days after birth) is enhanced by a planned programme of support and counselling</td>
<td>Psychological recovery at 6 and 14 months</td>
<td>Mothers (perinatal death)</td>
<td>Planned support and counselling</td>
<td>RCT — mothers randomly allocated immediately after the death/stillbirth to either planned support and counselling or to routine hospital care. Interviews conducted at 6 and 14 months to assess the outcome using the General Health Questionnaire and Leeds scales</td>
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<tr>
<td>Mahan</td>
<td>1983</td>
<td>US — single university hospital</td>
<td>Not specifically stated</td>
<td>Parents’ views on the value of being sent a book, The Bereaved Parent</td>
<td>Parents (death in a NICU)</td>
<td>Bibliotherapy — book sent a few days to several weeks after the death</td>
<td>Descriptive study — postal questionnaire sent to mothers and fathers approximately 5–6 months after the death</td>
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<tr>
<td>Harmon</td>
<td>1984</td>
<td>US — single regional transport NICU</td>
<td>To describe the reactions of mothers whose baby had died in a regional transport NICU</td>
<td>Maternal grieving and family functioning; mothers’ impressions of interventions and staff involvement during their baby’s hospitalization and following death</td>
<td>Married mothers (death in a NICU)</td>
<td>A neonatal hospice programme</td>
<td>Non-randomized comparison (using historical controls) comparing the impact of a neonatal hospice programme on mothers before and after its implementation — telephone interviews conducted 3–9 months after the death</td>
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<td>White</td>
<td>1984</td>
<td>UK — single hospital</td>
<td>To examine whether various objectives to establish normal grieving were being achieved and if they accorded with parents wishes</td>
<td>Parents’ views about their care; grief response</td>
<td>Families* (perinatal death)</td>
<td>Not a specific intervention</td>
<td>Descriptive study — interviews conducted 2–13 months after the death. Grief response assessed using the Leeds scale</td>
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<td>Dyregrov</td>
<td>1991</td>
<td>Norway — single hospital</td>
<td>To examine the grief reactions of mothers and fathers during the first year of bereavement</td>
<td>Grief response</td>
<td>Families* (death in a NICU or following SIDS)</td>
<td>Grief counselling (although this was not the main aim of study)</td>
<td>Non-randomized comparison of families who did and did not receive grief counselling. Postal questionnaires sent to parents at 1, 6 and 13 months after the death to assess outcome using: Impact of Event Scale; Goldberg General Health Questionnaire; State-Trait Anxiety Inventory; Bodily Symptom Scale; Beck Depression Inventory</td>
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<tr>
<td>Calhoun</td>
<td>1994</td>
<td>US — bereavement support group</td>
<td>To evaluate parents’ perceptions of the nursing interventions in the initial stages of grief from neonatal loss</td>
<td>Perceived helpfulness of interventions</td>
<td>Parents (perinatal death)</td>
<td>Not a specific intervention</td>
<td>Descriptive study — questionnaires distributed to members of a support group during group meetings (time since the death not reported)</td>
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<td>Harper</td>
<td>1994</td>
<td>US — bereavement support group</td>
<td>To investigate the relationship between recommended physician treatments and parent satisfaction following the death of a baby and to determine which physician behaviours are perceived by parents as most helpful</td>
<td>Relationships between satisfaction with care, ‘degree of occurrence continuum’ and ‘perceived helpfulness scale’</td>
<td>Parents (perinatal death)</td>
<td>Seven categories of physician actions</td>
<td>Case series study — parents referred to SHARE (a bereaved parents’ support group) completed questionnaires 2–60 months after the death: Ware’s Short Form Patient Satisfaction Questionnaire measured satisfaction; 34-item questionnaire developed by investigators to assess degree to which physician actions occurred (‘degree of occurrence continuum’) and perceived helpfulness</td>
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<tr>
<td>Author</td>
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<td>Setting</td>
<td>Purpose</td>
<td>Interventions/Measurements</td>
<td>Participants</td>
<td>Study Design/Method</td>
<td>Additional Information</td>
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<tr>
<td>Lasker</td>
<td>1994</td>
<td>US — five hospitals</td>
<td>To evaluate parents’ responses to specific interventions and to assess parents’ overall satisfaction with the care they received at the time of their loss</td>
<td>Whether intervention was experienced; level of satisfaction; value of interventions; grief response</td>
<td>Parents (perinatal death)</td>
<td>Longitudinal case series — interviews conducted with parents approximately 2 months and 1 and 2 years after the death. Perinatal Grief Scale used to measure grief response. Relationships between experience of a given intervention and parents’ satisfaction with their general care, satisfaction with specific intervention, and grief outcomes examined</td>
<td>Descriptive study — postal questionnaire sent to families (time since the death not reported)</td>
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<tr>
<td>Dent</td>
<td>1996</td>
<td>UK — 11 health districts</td>
<td>To establish what parents thought of the care they had received after their child had died suddenly and unexpectedly from accident or illness</td>
<td>Parents’ views and satisfaction with the care they had received</td>
<td>Families&lt;sup&gt;b&lt;/sup&gt; (sudden, unexpected death of child aged between 1 week and 12 years)</td>
<td>Qualitative study — semi-structured interviews conducted 3 and 13 months after the death</td>
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<tr>
<td>McHaffie</td>
<td>2000</td>
<td>UK — three regional referral centres</td>
<td>To provide insights into the issues which might influence a chaplain’s role in supporting parents when treatment is withdrawn</td>
<td>Parents’ views about the role of the chaplain</td>
<td>Families&lt;sup&gt;a&lt;/sup&gt; (death in a NICU)</td>
<td>Qualitative study — see above (McHaffie 2000)</td>
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<tr>
<td>McHaffie</td>
<td>2001</td>
<td>UK — three regional referral centres</td>
<td>To explore parents’ experiences of bereavement care after withdrawal of intensive care</td>
<td>Parents’ perceptions and experiences of their care</td>
<td>Families&lt;sup&gt;a&lt;/sup&gt; (death in a NICU)</td>
<td>Qualitative study — see above (McHaffie 2000)</td>
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<tr>
<td>DiMarco</td>
<td>2001</td>
<td>US — perinatal loss support newsletter mailing list</td>
<td>To determine if a support group intervention makes a difference in grief reactions of parents who have experienced a prenatal loss</td>
<td>Grief reaction</td>
<td>Parents (perinatal loss)</td>
<td>Non-randomized comparison of parents who did and did not participate in a support group. Postal questionnaire sent to a convenience sample of families who received a perinatal loss support newsletter. Time lapse since death was 1 month to 13 years. Grief reaction assessed using the Hogan Grief Reaction Checklist</td>
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<tr>
<td>Lundqvist</td>
<td>2002</td>
<td>Sweden — three hospitals</td>
<td>To focus further on and illuminate mothers’ lived experiences of the professional care they received while facing the threat and reality of losing their baby</td>
<td>Mothers’ experiences of the care they received</td>
<td>Mothers (death in a NICU)</td>
<td>Qualitative study — interviews conducted 14–32 months after the death</td>
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<sup>a</sup> Families, <sup>b</sup> Families<sup>a</sup>
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<tr>
<td>Reilly-Smorawski</td>
<td>2002</td>
<td>US — single hospital</td>
<td>To gain feedback from parents who had attended a 12-week support group programme</td>
<td>Parents' views</td>
<td>Parents (death in a NICU)</td>
<td>12-week support group session</td>
<td>Descriptive study — brief informal questionnaire given to parents (time since the death not reported) at the end of the 12-week programme</td>
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<td>Pector</td>
<td>2004</td>
<td>North America — internet networks</td>
<td>To assess the experiences of bereaved parents of multiples with resuscitation and life support decisions</td>
<td>Views and experiences of parents</td>
<td>Parents (perinatal loss — multiples)</td>
<td>Not a specific intervention</td>
<td>Qualitative study — internet survey of parents who were members of internet support groups and organizations for multiple birth loss (time since the deaths not reported)</td>
</tr>
<tr>
<td>Kavanaugh</td>
<td>2005</td>
<td>US — three hospitals and through newspaper advertisement</td>
<td>To examine the experience of low-income, African American parents surrounding perinatal loss and to describe how other life stressors influenced the parents’ responses and caring needs</td>
<td>Views and experiences of parents</td>
<td>Parents (perinatal loss)</td>
<td>Not a specific intervention</td>
<td>Qualitative study — parents interviewed within 4 months of the death</td>
</tr>
<tr>
<td>Brosig</td>
<td>2007</td>
<td>US — single hospital</td>
<td>To identify factors important to parents in their baby’s end-of-life care</td>
<td>Views and experiences of parents; perceptions of grief</td>
<td>Families(^b) (death in a NICU)</td>
<td>Not a specific intervention</td>
<td>Qualitative study — semi-structured interviews with parents, mean of 1.91 years after the death. Parents completed the Revised Grief Experience Inventory</td>
</tr>
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\(^a\) Investigators did not report numbers of mothers/fathers, therefore it is not clear whether ‘family’ referred to one or both parents responding jointly.

\(^b\) Family — either mother or father or both responded. Where both responded this was treated as a joint response.
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<th>Summary of results</th>
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<tr>
<td>Rowe</td>
<td>1978</td>
<td>26 mothers</td>
<td>89.7%</td>
<td>6/26 mothers had a prolonged grief reaction (12–20 months); 13/26 obtained information during hospitalization only; 13/26 received additional information weeks or months later; 60% mothers with adequate understanding and no prolonged grief reaction felt totally dissatisfied or only partially satisfied with the information they received; follow-up contact (phone or in-person) increased understanding significantly; mothers who had in-person follow-up were more likely to be satisfied with the information they received.</td>
<td>Additional 30 families had moved and were not invited to participate.</td>
</tr>
<tr>
<td>Cohen</td>
<td>1978</td>
<td>80 mothers</td>
<td>Not reported</td>
<td>Mothers were generally in favour of being given the option to view the body of their dead baby; 18/80 refused or were not given the option.</td>
<td>Study poorly described.</td>
</tr>
<tr>
<td>Schreiner</td>
<td>1979</td>
<td>29 families¹ (number of mothers/fathers not reported)</td>
<td>Not reported</td>
<td>Follow-up telephone call (n = 18) — 3/18 had ten moderate/major grief-related problems; No follow-up telephone call (n = 11) — 11/11 had 26 moderate/major grief-related problems.</td>
<td>Same neonatologist recruited families, did follow-up call and assessed outcomes.</td>
</tr>
<tr>
<td>Mahan</td>
<td>1981</td>
<td>23 sets of parents</td>
<td>25%</td>
<td>Responses were not affected by socioeconomic status or parental age but were significantly affected by whether the mother or father answered the question; Time in NICU — topics covered were seeing/touching/holding the baby; perception of baby’s chances; maternal desire for company; level of information (incl. at time of death); helpfulness of staff; source of help at time of death; receipt of a picture of the baby Post-death — topics covered were seeing/touching/holding the baby; explaining death to siblings; funeral; contact with physician; relationship with spouse; desire for further children.</td>
<td>Questionnaire responses of mothers and fathers presented with a narrative description of the results.</td>
</tr>
<tr>
<td>Forrest</td>
<td>1982</td>
<td>50 mothers</td>
<td>Not reported</td>
<td>Planned support and counselling (n = 25) — 16/25 completed 6-month follow-up; 2/16, General Health Questionnaire score 12+ indicating psychiatric disorder and 5/16, Leeds scale score 7+ indicating pronounced symptoms of depression and anxiety Control — 19/25 completed 6-month follow-up; 10/19, General Health Questionnaire score 12+ and 12/19, Leeds scale 7+ P &lt; 0.01, Fisher’s exact test. At 14-month follow-up differences not statistically significant.</td>
<td>Recruitment of mothers, and randomization and allocation procedure not described. High rate of loss to follow-up.</td>
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<tr>
<td>Mahan</td>
<td>1983</td>
<td>40 parents (39 mothers, one father)</td>
<td>33%</td>
<td>Two mothers who responded did not read the book, and one mother read parts. In all, 36 mothers, four fathers and seven significant others read the book; 37/40 felt the book was helpful, and all but one suggested continuation of the project; 16/40 felt book was less helpful as it was about an older child; 21/40 felt that this made no difference</td>
<td></td>
</tr>
<tr>
<td>Harmon</td>
<td>1984</td>
<td>38 mothers</td>
<td>Not reported</td>
<td>Maternal grieving – no significant differences between the groups; <em>Before hospice programme</em> – 33% contacted by a member of staff to offer support; 60% contacted about post-mortem results <em>After hospice programme</em> – 75% contacted by a member of staff to offer support; 92% contacted about post-mortem results. Indication of increased husband involvement following hospice programme</td>
<td>Additional descriptive findings also reported, such as pictures of the baby</td>
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<td>White</td>
<td>1984</td>
<td>12 families (number of mothers/fathers not reported)</td>
<td>70.6%</td>
<td>6/12 families scored 8+ on the Leeds scale, of whom five also had high grief scores; no difference between maternal and paternal grief scores; grief scores did not correlate with length of mourning period; topics covered – handling of the death; mementos; funeral; communication; recurrence risk; support counselling; GPs</td>
<td>Methods of study poorly described</td>
</tr>
<tr>
<td>Dyregrov</td>
<td>1991</td>
<td>37 families (number of mothers/fathers not reported)</td>
<td>62.7%</td>
<td>n = 29 received grief counselling — experienced less anxiety at 1 and 13 months, more intrusive thoughts at 1 month, more bodily symptoms at 13 months compared to those who received no grief counselling (n = 8)</td>
<td>Examination of the impact of grief counselling not one of the original aims of the study</td>
</tr>
<tr>
<td>Calhoun</td>
<td>1994</td>
<td>23 (number of mothers/fathers not reported)</td>
<td>Not reported</td>
<td>Results of descriptive analyses presented covering the following topics: photographs and other mementoes; holding the baby; general emotional support; information about support groups; funerals, expected response of family and friends</td>
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<tr>
<td>Harper</td>
<td>1994</td>
<td>37 parents (23 mothers, 14 fathers)</td>
<td>Not reported</td>
<td>The seven categories of recommended physician actions were: method of informing parents; provide medical information; demonstrate compassion; provide support; be available; efforts to overcome denial; grief counselling. Significant correlations were found between satisfaction scores and the use of most of the recommended actions (5/7 categories). Being available, providing medical information and grief counselling were the categories with the greatest correlation</td>
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<tr>
<td>Study</td>
<td>Year</td>
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<td>Proportion (%)</td>
<td>Key Findings</td>
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<tr>
<td>Lasker</td>
<td>1994</td>
<td>194 parents (138 mothers, 56 fathers)</td>
<td>84.6%</td>
<td>Parents grouped by whether they experienced: spontaneous abortion or ectopic pregnancy; early fetal death; late fetal death; or neonatal death. 25 recommended interventions presented giving proportions of parents in each group who experienced the intervention, felt the intervention to be essential and satisfaction; in all groups for more than 70% of interventions, those who experienced the intervention were significantly more satisfied ($P &lt; 0.05$); neonatal death parents – no association between more interventions and general satisfaction; no association between satisfaction and intensity of grief; all parents – no relationship between number of interventions and the intensity of grief; satisfaction with care not associated with demographic characteristics.</td>
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<tr>
<td>Dent</td>
<td>1996</td>
<td>42 families (40 mothers, 27 fathers)</td>
<td>58%</td>
<td>Descriptive results presented on the following topics: emergency services; hospital service (including care by hospital staff, communication, mementoes etc); coroner’s office; media contact; dealing with government departments; post-mortem examinations; funeral; support (e.g. follow-up care); other children in the family.</td>
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<tr>
<td>McHaffie</td>
<td>2000</td>
<td>59 families (number of mothers/fathers not clear)</td>
<td>72.8%</td>
<td>Investigators reported families’ views on and experiences of the chaplain’s role. Five factors were identified: reassurance; comfort; sense of control; officiating at ceremonial functions; ongoing support and concern in bereavement.</td>
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<tr>
<td>McHaffie</td>
<td>2001</td>
<td>59 families (number of mothers/fathers not clear)</td>
<td>72.8%</td>
<td>Parents highlighted a number of specific needs. Follow-up appointments should be scheduled soon after the death (within 2 months), irrespective of autopsy results being available, with the named neonatologist, away from the hospital if possible. Parents indicated that they valued efforts to find out how they are coping, full and frank information given sensitively and reassurances where possible.</td>
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<tr>
<td>DiMarco</td>
<td>2001</td>
<td>121 parents (88 mothers, 33 fathers)</td>
<td>30.3%</td>
<td>No statistically significant difference in the Hogan Grief Reaction Checklist scores between parents who did and did not attend a support group.</td>
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<tr>
<td>Lundqvist</td>
<td>2002</td>
<td>16 mothers</td>
<td>76.2%</td>
<td>The primary themes identified were feeling empowered and powerless. Related issues explored included: attitude and actions of health-care staff; information and communication; touching/holding the baby; photographs of the baby; follow-up care.</td>
<td></td>
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</tbody>
</table>

Of the 194 parents, 27 had experienced neonatal death. Results are presented by type of loss.
<table>
<thead>
<tr>
<th>Lead author</th>
<th>Year</th>
<th>Number of participants</th>
<th>Response/participation rate</th>
<th>Summary of results</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reilly-Smoranowski</td>
<td>2002</td>
<td>Not reported</td>
<td>Not reported</td>
<td>54% of parents attended the 12-week support groups. Parents who did not attend were usually single mothers. Couples reported that the support groups were helpful overall and specifically aided learning to tolerate the grief and pain of having lost a baby. Parents also reported that they were able to get through particularly difficult moments by telling themselves to 'save it for the group'. Some parents reported no longer feeling afraid to talk to each other about the baby. Methods of evaluation poorly reported. No comparison between parents who did and did not attend the support group sessions.</td>
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<tr>
<td>Pector</td>
<td>2004</td>
<td>71 parents (67 mothers, four fathers)</td>
<td>Not reported</td>
<td>Topics covered were: resuscitation decisions; influence of multiple-birth status on decision-making, style of decision-making (e.g. collaborative, parent-initiated; support and criticisms of parental choices); the death process (e.g. importance and meaning of time with deceased baby, desired experiences, multiple memories, such as photographs); parent preferences for being informed about the death; and discussing death (e.g. follow-up)</td>
<td></td>
</tr>
<tr>
<td>Kavanaugh</td>
<td>2005</td>
<td>23 parents (17 mothers, six fathers)</td>
<td>Not reported</td>
<td>Main themes which emerged were: recognizing problems and responding to the loss (e.g. misreading symptoms of pregnancy complications, maintaining hope during medical treatment, feeling intense emotions after the death); dealing with stressful life events (e.g. feeling abandoned or unsupported, suffering economic hardship, experiencing other’s serious illness or untimely deaths, receiving unfair treatment); creating and cherishing memories of their baby (e.g. being with their baby, noticing family resemblances, gathering keepsakes of and remembering their baby, deciding on burial); living with the loss (e.g. encountering difficult situations, relying on their spirituality, seeking diversions and support, making sense of the loss, contemplating future pregnancies)</td>
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Neonatal hospice programme

A cohort study using historical controls investigated the impact of a neonatal hospice programme by comparing two groups of parents before and after its implementation. Staff were given training to implement the programme which included the use of a 'family room', frequent family conferences, and the provision of ongoing support. Staff were encouraged to take pictures to offer to the family, discuss the results of post-mortem examinations, and provide information about funeral arrangements. A telephone interview conducted 3 to 6 months post-bereavement revealed that after the programme, there was a substantial increase in the proportion of bereaved parents (from 33% to 75%) who were contacted by a member of the hospital staff, as well as an increase in the numbers contacted about post-mortem results. Most mothers reported that post-mortem information helped them understand why their baby had died and expressed gratitude that someone cared enough to talk to them directly about their baby's care and death. Increased involvement from their partners appeared to be another benefit of the programme.

Evaluation of broader aspects of bereavement care (n = 14 studies)

Fourteen studies examined the impact of bereavement care more broadly by seeking the views of parents about the care they had received. Data were collected either through face-to-face interviews, postal questionnaires, or an internet survey. Several themes emerged from these studies.

Communication strategies

Poor communication was frequently mentioned by parents, particularly around the time of and following the death. Parents were said to want frank, honest information about their child's condition even if this meant receiving bad news. An appointment to discuss the death with a neonatologist or paediatrician was judged to be very important. The provision of medical information was found to greatly influence parental satisfaction. Information which answers parents' questions, clarifies exactly what happened, and provides reassurances about their baby's care was reported as being important in helping parents to cope with their grief. Explanations, including written information, about the grieving process and how families might be affected were also considered very helpful by parents and were associated with greater levels of satisfaction and less understanding of the cause of death if there was no follow-up contact with a physician.

Touching and holding the baby

Parents seem to have mixed views about touching or holding their baby. Many were positive about viewing or touching their baby, particularly while still alive; this was viewed as essential by almost all parents in one study. However, there seemed to be some reluctance to have physical contact with their baby during the dying process or after death. There was no significant difference in scores between parents who had hospice/palliative care involvement with those who had not.

Mean Post-Death Adaptation Scores indicated that the investigators viewed parents as adapting positively. Topics covered were: honesty; empowered decision-making; parental care; environment; faith/trust in nursing care; physicians bearing witness; support from other hospital care providers; things that helped coping, family support, keeping the memory alive; spirituality/faith; altruism; refocusing on life; validation of decision; bereavement support groups; parental recommendations.
death. White and colleagues, for example, reported that seven of the ten parents invited to touch or hold their live baby did so, whereas after death only four out of the ten parents did so. For some, being repeatedly urged to touch their baby created unpleasant feelings. In the most recent of the studies, however, it was reported that ‘mothers readily embraced their infants’ and all but one of the 17 study mothers held their baby at the time of death; for most, this was the only opportunity they had to hold their baby.

**Mementoes**

It was important to parents to receive mementoes such as photographs, handprints, footprints, casts, or clothes that the baby had worn in hospital. Investigators report that, in general, the response to such gestures was positive, and that parents who were not offered or who declined mementoes often regretted this subsequently. Parents wanted photographs to be taken before their baby’s death without any equipment, particularly on the face. Parents of multiples felt that it was important to have an image of their babies together, even if it was taken shortly after one baby had died.

**Parental care**

Parents need staff to take care of them, as well as their baby, both physically and emotionally. Parents reported finding it very helpful when nurses made themselves available to listen, allowing them to express their feelings. They also appreciated nurses talking openly and honestly with them about their loss. Compassion from staff was important, and parents described feeling upset when they felt staff members were insensitive to their feelings. Non-clinical hospital staff, particularly chaplains, were found to be very important sources of parental support.

**Methodological issues in the identified studies**

Different methodological approaches were adopted to investigate the effectiveness of bereavement interventions in the 21 studies. Only one was an RCT, and four studies included a non-randomized control group. Even in the RCT there were threats to internal validity, including the possibility of contamination in the control group, and a differential and low rate of follow-up of patients (36% of mothers in the intervention group and 24% in the control group). Research may be limited by a number of factors, such as:

- NICU-led bereavement care is changing;
- effectiveness of bereavement interventions is difficult to measure, and concepts of effectiveness are not static;
- effectiveness is often assumed; and
- ethical concerns complicate experimental research.

**NICU-led bereavement care is changing**

Research in this area is undoubtedly complicated, especially as the field itself is changing in a variety of ways, with modifications to existing approaches and the introduction of novel interventions. These changes may be subject to a high degree of local variability, making research difficult to conduct and the results difficult to apply. This raises new research questions and new methodological challenges, as highlighted by two examples of evolving practice: developments in the use of bereavement photography, and the wider introduction of ritual into bereavement care.

**Bereavement photography**

Commentators suggest that parents value bereavement photographs, but with the caveat that for some they have been ‘too clinical’. Images of babies on ventilators can be difficult for parents, and many only have instantly developed photographs which can be stark and fade with time. Digital cameras are, however, increasingly available, and it has been suggested that nurses should develop skills in bereavement photography.

This aspect of bereavement care is changing. Some NICUs now utilize the specialist skills of medical photographers.
Professionals can produce long-lasting sensitive images, and some can offer creative services, manipulating details or combining images of siblings who were not photographed together. Websites offer the services of independent photographers, some for free (www.news.therecord.com/Life/article/279525; www.toddhochberg.com/see.cfm; www.nowilaymedowntosleep.org/pageDisplay.php?page = 3). Some produce DVDs of images and music for parents to share with friends and relatives and to use on websites and at funerals (http://bereavementservices.org/newsletters/summer2007.pdf). When death is imminent, photographers may take pictures with parents before their baby dies. These can be deliberately posed to leave parents with positive images, or they can be a broad record of events around death, including images of parents in their grief.

Whilst studies suggest support for the use of bereavement photographs,11,23,25 they largely report on issues of satisfaction in small research populations. It is important that the short- and long-term effects of such a potentially powerful tool should be properly assessed to provide a sound basis for NICU policies on a practice which is pushing new boundaries in care. Experimental research may well be difficult, but not beyond the realms of possibility. A cluster trial involving randomization at the NICU level could be coupled with a qualitative study. A mixed-methods approach such as this would provide data on effectiveness as well as preferences, and could be used to explore wider practical and ethical questions, such as who should take the photographs, how, when and where? When should they be given to parents: at an early stage, on leaving the hospital, or at a follow-up visit? Who should have responsibility for this: photographers, nurses, bereavement counsellors or consultants? Style and content of photographs can differ, and reactions to these should be explored. It would be appropriate to consider not only whether parents want to have these images, but also whether partners, siblings or wider family members need and respond to them in the same way.

The introduction of ritual into NICU bereavement care

The use of ritual around death in the NICU is not new. Many parents have participated in religious rites if death is likely, and most NICUs have tiny robes for such ceremonies. Some NICUs are giving greater prominence to rituals as an element of bereavement care. It has been suggested that bathing or holding a baby can become an important ritual, with the introduction of music or scents to trigger later bathing or holding a baby can become an important ritual, element of bereavement care. It has been suggested that NICUs are giving greater prominence to rituals as an

...
box to store mementoes; another gives two inscribed ceramic hearts, one for burial or cremation with a child, the other for parents to keep.

Bereavement care is clearly driven by compassion. It is therefore not surprising that practices such as listening to parents, avoiding minimizing their loss, and attending funerals, can seem obviously and intuitively beneficial. They reflect the type of non-professional support that decent and caring individuals might offer. Other practices, such as facilitating time with a baby after death, initiating rituals or photographs, or providing information on sources of support, arise from professional roles and are also widely endorsed. Professional responsibilities and gestures of humanity and empathy combine with other structured aspects of care such as follow-up visits and the availability of bereavement counsellors to become formalized bereavement programmes with mission statements and protocols. The use of experimental research to assess interventions within such complex situations can be challenging, both for researchers and for those whose practice or caring environment comes under scrutiny. Certainly the failure of potentially informative trials has been directly attributed to professional discomfort with research and convictions about best practice. Cautionary tales warn against assumptions of benefits for interventions which later prove to be ineffective or harmful. It may be that the chances of this occurring seems unlikely for compassion-led non-pharmacological interventions, but they are interventions nonetheless and so require rigorous evaluation.

Ethical concerns complicate experimental research
Research involving bereaved parents is difficult and requires careful ethical consideration. It is perhaps significant that much of the research considered here is qualitative or broadly descriptive rather than directly intervening in care. Qualitative research is particularly suited to sensitive situations, emphasizing the value and variety of individual experiences and perspectives, and can provide an excellent springboard for experimental work. The insights gained have not, however, fuelled further evaluation; only five of the reviewed studies are experimental, and one was conducted this century. The RCT, so widely used to generate evidence to guide care in even the most difficult of clinical situations, is a rarity in this field.

Equipoise is fundamental to the successful conduct of RCTs but care-givers and parents are likely to have preferences and beliefs about the value of many bereavement interventions. Certain interventions, such as seeing and holding a baby around the time of death, involve deeply personal experiences; they cannot be undone, and if the moment is lost, it cannot be repeated. They might therefore be viewed as especially difficult to randomize. Statham cites Zeanah’s discussion of the likely difficulties for trials of such interventions with parents of stillborn babies: ‘Giving parents the opportunity to see and to touch stillborn infants has become so widely accepted that random assignment in order to test this theoretically appealing and anecdotally supported hypothesis is probably no longer possible’. Zeanah’s also argues that a trial allocating parents to no contact with a baby would ‘probably be as rare and problematic now as including them in the process might have been 25 years ago’.

Certainly considerations fundamental to the conduct of all RCTs may raise greater concerns in this particular field. For any RCT which randomizes potentially desirable but unevaluated interventions, informing possible participants about the research can be a demanding if not daunting task. There might also be concerns over a ‘deprivation effect’ as observed by Oakley amongst women who were informed, but not allocated to, additional social support during high-risk pregnancy. An RCT of a communication strategy and brochure for relatives of dying patients has been successfully completed in adult intensive care. In the NICU setting, however, the vulnerability of recently delivered, recently bereaved parents, coupled with the compassionate drive of those who care for them, may render experimental research particularly difficult.

Future research
There is a need not only to improve understanding of the impact of practice as it currently stands, but also to guide its evolution before unevaluated changes become firmly entrenched as new standard practice. Possibly the greatest challenge will be to find the means to conduct studies which are methodologically and ethically sound, and acceptable both to care-givers and to bereaved parents.

A first step towards meeting such a challenge is gaining an understanding of the views of those most closely involved in research in this area. Forte and colleagues suggest a consensus-building conference involving stakeholders and investigators to define a research agenda, to identify which outcomes are valued by bereaved individuals, and to consider which interventions might achieve those outcomes. Such a consultation may also be conducted through qualitative research processes. Attitudinal research uncovering the barriers and facilitators to good-quality bereavement-related studies in the NICU might also be informative. It is important to ensure that the design of research assessing bereavement interventions is not only grounded in existing high-quality theoretical and empirical research, but also reflects stakeholder priorities and addresses their methodological and logistical concerns.

Qualitative research might be used to further explore the perspectives of parents and care-givers with the aim of improving the management of bereavement interventions. Qualitative approaches may also be incorporated into the design of RCTs. Here parental responses to allocated interventions might be sensitively explored, taking into account contextual elements of individual experiences.

It is likely that the design of future trials necessarily will be non-standard and will require some creativity. Patient preference trials, for instance, might allow parents to follow a course which they feel will suit them; however, such trials can be difficult to interpret because of unknown and uncontrolled confounders. Cluster RCTs would work well for interventions not in current practice as they would allow an intervention to be introduced into some NICUs but not others, and they have the advantage of reducing contamination between experimental and control groups. Where there is reluctance to withhold an intervention, an
individually or cluster-randomized stepped-wedge trial design might be used.\textsuperscript{56} This involves the sequential random-ized roll-out of an intervention to participants over time until all participants have received the intervention. This design, like other non-standard designs, is a compromise; contamination may still be an issue, analysis is complex, and it is likely take longer than a conventional design.\textsuperscript{56} Such methodological compromises may, however, be the means by which the evidence base is improved and NICU-led bereavement interventions are given a firmer empirical footing than they currently have.

Conclusions

A range of bereavement interventions has been adopted as part of neonatal intensive care. Although there is evidence that these are largely appreciated and valued by parents who have participated in research, there has been little rigorous evaluation of their effectiveness. The authors of several of the papers discussed here acknowledge the need for research, but often do so from the perspective of recommending interventions or packages of care as evidently beneficial. We suggest that it is important to question a wide range of NICU-led bereavement practices, not with the aim of disproving their value, but with a neutral line of inquiry and the intention to refine and improve their use if beneficial. Conducting bereavement-related RCTs in such a difficult setting is challenging but not impossible. Neonatal intensive care has a good record of collaborative research evaluating new and existing technologies. Bereavement care is, however, a sensitive subject, and the vulnerability of potential research participants is an important consideration which must be taken into account. This creates ethical dilemmas for the conduct of RCTs. Even though it is widely recognized that interventions have not been adequately evaluated, and the possibility of delivering potentially ineffective or even deleterious interventions raises ethical issues in its own right, the lack of RCTs suggests an understandable reluctance to discuss research and randomize bereavement interventions for parents at an extremely stressful time in their lives.

In this review we have suggested ways in which research might move forward, using less traditional RCT designs. Whilst these have their limitations, they do offer alternative approaches to evaluating bereavement interventions that may be more acceptable to parents and clinicians. Before designing new studies, however, there needs to be consensus amongst the relevant stakeholders as to the appropriate outcomes and time points at which these should be measured. To rise to the challenges inherent in this field, researchers should seek out the questions of importance, and design high-quality studies — whether quantitative or qualitative — which are capable of addressing those questions appropriately and with sensitivity.

Acknowledgement

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Disclaimer: the views and opinions expressed in this article do not necessarily reflect those of the NHS or the Department of Health.

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