The effectiveness of bereavement support interventions for parents of infants and children who die: A systematic review

Ainscough TA1,3, Fraser LK1,3, Taylor J1,3, Beresford B2,3, Booth AB1,3

1 Department of Health Sciences, University of York, UK

2 Social Policy Research Unit, University of York, UK

3Martin House Research Centre, University of York, UK

Corresponding Author:

Dr Lorna Fraser

Department of Health Sciences

Area 2 Seebohm Rowntree Building

Heslington

YORK

YO10 5DD

[lorna.fraser@york.ac.uk](mailto:lorna.fraser@york.ac.uk)

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# Abstract

## Objectives

This systematic review aims to assess the effectiveness of bereavement support interventions (BSIs) for parents of an infant or a child who has died from a medical condition or in unforeseen circumstances.

## Methods

A systematic search of MEDLINE, PsycINFO, Embase and CINAHL (1980 to January 2018) was performed to identify studies investigating BSIs for the parents of children who died between the ages of 24 weeks gestation and 30 years old. Due to significant clinical and methodological heterogeneity between studies, a narrative synthesis was performed.

## Results

The database searches returned 24,550 records, with a further six identified through other sources. Of these, eight studies, reported in nine papers, met the inclusion criteria. Most studies were conducted in the USA (n=5) and in perinatal/neonatal deaths (n=6). Five of the included studies were randomised controlled trials, three were non-randomised comparative studies. Interventions were delivered to groups, individuals or families. Outcomes of interest were grief, mental health, physical health and ‘others’.

There were major concerns over the quality of study methods and reporting. Only three of the nine studies reported a significant difference between experimental and control arm participants in any outcomes, despite a total of 23 outcomes being measured.

## Conclusions

Poor methodology and reporting of the few studies which have assessed bereavement support interventions for parents limit any conclusions on their effectiveness. Agreement on core outcomes and more robust study methodology are required in this neglected area of research.

# Introduction

The loss of a child, whether expected or not, is one of the most difficult experiences that a parent could be expected to endure. The grief experienced from the death of a child is significantly greater in intensity than that experienced from the death of a spouse or parent1 and qualitatively different to that experienced by other members of the family2 . Moreover, the death of a child can have severe adverse effects on parents’ physical and psychological wellbeing. Parental bereavement has been linked to a number of negative health outcomes, including: lower health related quality of life3, poorer mental4-7 and physical health6 7, higher rates of psychiatric admissions to hospital8, and marital breakdown5 6.

Although child mortality is reducing worldwide, 136,684 children (0 to 19 years) from developed countries died in 20139 . An average of 13 children die every day in the UK9 with a recent concerning increase in neonatal mortality10. In the US, nearly 2,000 children and adolescents die each year from cancer alone11, with a total of 45,241 deaths reported during 20139 . Moreover, the number of children living with a life-limiting condition, where premature death is expected, has been increasing for a number of years, with prevalence in the UK, for example, now at 32 children per 10,000 population12. Therefore, both in the UK and globally, a considerable number of parents will experience the death of their child each year.

Supporting parents in their bereavement to reduce the risk of adverse outcomes is therefore essential and increasingly recommended in clinical guidelines13 14. Studies exploring the experiences and perceptions of parents and healthcare staff who support families of children who have medical conditions which are potentially life-limiting also identify the valuable role of bereavement interventions, including unmet needs for support during bereavement15. However, the recommendations about what to provide are broad, and two previous systematic reviews having looked at bereavement interventions for parents provide little evidence about what interventions might work and for whom16 17. The most recent, Endo et al. (2015)16, reviewed bereavement support interventions (BSIs) for both parents *and* siblings of children who had died and provided no sub-group analysis for these groups. The only other review, which did focus on support for parents, was conducted in 2002 and identified only three studies, making it difficult to draw any meaningful conclusions17.

To ensure that policy recommendations to support parents through bereavement are implemented successfully, there is a need to re-visit the evidence on bereavement support for parents. This systematic review therefore aims to assess the effectiveness of BSIs for parents of an infant or a child who has died from a medical condition or in unforeseen circumstances.

# Methods

The protocol is registered on PROSPERO: [CRD42018081945](http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018081945), and the review is reported in accordance with the PRISMA guidelines18. This paper answers the following review question: What is the current evidence base for effectiveness of bereavement support interventions (BSIs) for the parents of children who have died?

## Search Strategy

Studies were identified using MeSH and keyword searches of Medline, Embase, PsychINFO, and CINAHL. Searches were limited to studies published in the English language from 1980 to January 2018. The search strategies are available as supplementary material.

Grey literature was identified using the advanced Google search facility (pdfs only, first 50 records) and by hand searching the websites of Cruse and Child Bereavement UK. All studies meeting inclusion criteria were backwards and forwards reference searched. Review articles were not included in the synthesis, but the reference lists were checked for potentially relevant studies.

## Inclusion and Exclusion Criteria

Studies were eligible for inclusion if they reported i) primary research, ii) were published in a peer-reviewed journal, and iii) evaluated the effectiveness of a BSI(s) for the parents of a child who died between 24 weeks gestation and 30 years of age.

For the purposes of this review, ‘bereavement support intervention’ was defined as any intentional activity undertaken to support adjustment to and recovery from the death of a child. This included interventions ranging from specific psychological or psychosocial interventions such as grief counselling or multi-component bereavement support programmes, to aspects of clinical practice and service delivery, such as facilitating spending time with their child’s body; or de-briefing appointments with the medical team.

Studies were excluded if they: *i)* focussed on supporting pregnancy loss before viability (24 weeks gestation); *ii)* evaluated a BSI for parents and other family members (e.g. siblings, grandparents) but did not report effects for each separately; *iii)* were a case report, case series, case study, discussion article or review article; *iv)* conducted in a non-OECD country; *v)* offered a BSI for the parents of children who were dying but still alive; *vi)* tested a BSI for the parents of (adult) children who died whilst serving in the military.

## Study Selection and Risk of Bias

Titles and abstracts of studies were independently reviewed by two reviewers (LF,TA), with conflicts resolved by a third (AB). Full-text screening was conducted by two reviewers independently (TA,LF), with disagreements settled by consultation with the wider team.

The quality of the included studies was assessed using the Downs and Black tool for assessing methodological quality of both randomised and non-randomised study designs19. All studies were assessed by one reviewer (LF) and independently checked by another (JT). Disagreements were discussed between the two reviewers. We used <15 as low quality, 15-20 moderate quality and > 20 high quality.

## Data Extraction and Synthesis

Data were extracted by a single reviewer (TA) and checked by a second member of the team (AB).

Due to heterogeneity in methodology, outcomes assessed and presentation of the results in studies that met inclusion criteria, meta-analysis was not possible and so a narrative synthesis was instead performed.

# Results

## Study characteristics

The database searches returned 24,550 records, with a further six identified through other sources. Of these, eight studies, reported in nine papers, investigating eight different interventions met the inclusion criteria20-28. Figure 1 demonstrates the study selection process and Table 1 summarises the included study characteristics.

Figure 1 Study flow chart

Four of the included studies were conducted in the USA20 21 24-26; two in Finland22 27 and one study each in the UK23 and Australia28.

Five were randomised controlled trials20-23 26 27and three were non-randomised comparative studies24 25 28.

A total of 1,433 parents were initially recruited to these studies; final follow-up data from 1,331 participants were included in the analyses. The included studies were published between 1985 and 2015. Only four studies reported the time period for data collection20 22 24 27 and those studies were published between 2 and 6 years after data were collected.

## Population

Children of the parents included in the studies had died between 22 weeks gestation and 28 years old. Six of the studies concerned perinatal/neonatal deaths, with cause of death, where reported, similar across the studies20 22 23 25 27 28. In one study bereavement was from the sudden, violent death of a 12 to 28 year old child21 26. The final study did not report the age range, however the background and causes of death suggest that parents of a child of any age at death were included24.

## Interventions

Three of the included studies tested interventions delivered to groups of parents21 24-26, three were delivered one-to-one22 23 27, (one to fathers only22, one to mothers only27), and two delivered to individual families20 28. Interventions for parents bereaved by a perinatal death included a range of activities while still in hospital such as: holding the baby; having photographs and other memorabilia; discussion with various health professionals; and being given packs of tailored information to take away (including one in DVD format)20 22 23 25 27 28. Follow-up after leaving hospital included either individual personal or group support sessions focussing on various aspects such as grief, mental and physical issues and practicalities such as financial and legal matters and delivered by a practitioners/clinicians and/or peers (i.e. bereaved parents). The two studies including parents of older children who had died both looked at group support covering a range of emotional and practical issues24 26. However, one was clearly described as a manualised BSI26 but the other gave little information but appeared to be parent led24.

Details of the interventions and controls are presented in Table 2, though these were generally poorly reported. Where reported, the duration of the interventions ranged between a single 90-minute encounter and 12 weeks; the number of sessions offered to parents also varied within these delivery times (range 1-12 sessions).

## Outcomes and measures

Outcomes measured across the studies were grief, mental health, physical health, social support/functioning, and religious/spiritual beliefs. The measures used included both validated instruments such as the Hogan Grief Reactions Checklist29 and questionnaires purposively devised by the study authors. The timings of outcome measurement of these outcomes varied from one single baseline measurement to follow-up of maximum of 15 months. Results from all time points were included in this review.

## Quality assessment

Overall 3 studies were low and 6 moderate on the quality assessment tool (Table 3 and Supplementary material). There were concerns over external validity, bias and confounding in most of the studies. Less than half of the studies provided any sample size calculation and the statistical analyses were not appropriate in many studies.

Reporting of details of both the interventions and the controls was generally incomplete in all the studies, in particular details of informational materials provided to participants as part of the intervention, and the frequency and duration of delivery were missing or unclear. Five of the included studies report that fidelity was measured, but fail to report the results and describe whether fidelity was achieved20-23 26 28. Where relevant, none of the studies reported whether or not interventions were modified during the delivery.

## Analysis

The high risk of bias and major differences on a range of aspects of the included studies made it inappropriate to undertake a meta-analysis. Instead we present a narrative synthesis of outcomes grouped as relating to grief, mental health, physical health and ‘other’ outcomes.

Grief: Four RCTs and one comparative study examined grief outcomes in parents of peri/neonates or babies to age 3 who had died20-22 25-27. The only significant difference between the group who received the intervention and those in the control group in any of these studies was reported by Aho22. Here, at six months post bereavement, fathers who had received the multi-component BSI intervention (comprising an information resource, telephone call and home visit from a bereaved father peer contact, and a session with a member of the health care team ~ 6 weeks post-bereavement) showed stronger personal growth, an item in the Hogan Grief Reactions Checklist, compared to fathers who received standard care. No other significant differences were observed.

Mental Health: Of the five studies that measured mental health outcomes20 21 23 24 26 28, two reported significant intervention effects23 28.

Murray et al.28 observed a significant improvement in mental distress and depression for mothers and fathers (following infant death) receiving the intervention (information and resource pack, grief counselling for family members) compared to control group participants30. Fathers in the intervention group were also more likely to be using adaptive coping strategies, but this was not observed for mothers. There were no differences between groups for anxiety.

An RCT of 50 mothers of deceased neonates, found that at six months post-loss, significantly fewer mothers receiving the support and bereavement counselling intervention met clinical cut-offs for psychiatric disorder than those in the control group 23. The same trend was observed for anxiety and depression, with fewer mothers in the intervention arm meeting clinical cut-offs but this did not reach significance. At 14 months post-loss, however, there were no statistically significant differences between the groups for either outcome. All fathers were offered counselling alongside mothers: only six attended the initial assessment interview, and 26 returned self-report data. No significant differences were observed between fathers in either group for psychiatric disorder or depression and anxiety.

One RCT evaluated an intervention that provided parents with an audio-visual compilation of stories from bereaved parents, grandparents and siblings (contained on a DVD and organised into topic sections). No significant differences were found in mental health outcomes between intervention and control groups. However, there was an issue with treatment fidelity, with only 18 of the 39 parents in the intervention group having actually watched the DVD by the 12-month assessment20.

A further study (an uncontrolled pre- and post-experimental design) tested an intervention on a cohort of bereaved parents, comparing the outcomes of bereaved parents who had either 1) attended a self-help group (hosted and facilitated by a national parent bereavement charity), 2) had sought out and received professional counselling, or 3) done neither 1) or 2). Parents were surveyed at two time points, one year apart, although the timing varied in relation to their child’s death and in 25% of the parents > 3 years24. The mental health outcomes of parents who had attended a self-help group or sought professional counselling, were not significantly different to those who had done neither of these.

Murphy et al. assessed the effectiveness of a 12 week, 12 session, group-delivered, manualised bereavement support programme for parents whose child died as a result of accident, homicide or suicide between the ages of 12 and 28 years old21 26. At 12 weeks and 6 months post intervention (5-10 months and 8-13 months post bereavement) no significant differences were observed between the intervention and non-intervention group in terms of mental distress and post-traumatic stress disorder symptoms.

Physical Health: Two studies included physical health as an outcome. Murphy et al. found no differences in self-reported physical health status between those receiving the group intervention that included targeting physical health and parents in the control group (who received information which encouraged self-care of physical health)21 26.

Murray et al.28 found no differences in the number of reported physical health symptoms (e.g. insomnia, headaches) between the intervention and control group at each follow-up time point, with a reduction in both groups observed31. The same was true for within group results for those thought to be at low or high risk of developing mourning difficulties.

### ‘Other’ outcomes: Three studies measured other outcomes related to social aspects of life and attitudes21 24 26 28. These were; social support, marital role strain, relationship quality, strength of religious views and parental functioning.

Videka-Sherman and Lieberman (1985) measured six elements of marital strain/distress (strain in reciprocity, strain in acceptance by spouse, strain in role expectation of spouse, marital distress, marital satisfaction and comfort in communication) and two elements of parental strain/distress (parental distress and preoccupation with parental problems).24 They also collected data on parental attitudes to different grief responses (e.g. internalisation vs externalisation of anger, optimism vs pessimism about grief), and their level of agreement with statements such as “discomfort in relating to bereaved parents is others’ problem”, “bereaved parents sometimes show too much emotion”, and “there is no good way to respond to a grieving person”. The authors used a combination of standardised scales and scales designed specifically for this study. No significant differences in scores were observed between the intervention and control group for any of these outcomes.

Marital strain was also measured In Murphy et al.’s evaluation of a BSI for parents losing a child through violent death; no significant difference in marital strain between the intervention and control group was observed at 12 weeks or 6 months follow-up21 26. Relationship quality, divided into the subscales of dyadic consensus, satisfaction, affectional expression and cohesion, was assessed by Murray et al28. The results were presented separately for mothers and fathers and in sub-groups of those assessed as being at low or at high risk of developing mourning difficulties. Overall, high risk mothers and fathers receiving the intervention showed significantly greater improvement over time in relationship quality than parents in the control arm.

# Discussion

In nearly 40 years, only eight published studies have assessed the effectiveness of bereavement support interventions for parents of infants and children who die. Only three of these eight studies reported a significant difference in outcomes between experimental and control arms, despite a total of 23 outcomes being measured across these studies22 23 28. All three studies reporting a significant effect were bereavement support interventions for parents bereaved during the perinatal or neonatal period and all interventions commenced delivery very close to the time of death (1 day- 6 weeks). However, there were differences between these three studies in the outcomes assessed and where significant effects were observed, and whether or not study participants were mothers and/or fathers. For example, the multi-component BSI which reported a significant impact on personal growth was for fathers only22, the bereavement counselling service which reported significantly fewer psychiatric disorders was in mothers23, and the multi-component family-directed intervention, which was for both parents, observed significant differences for mental distress, depression and perceived relationship quality for mothers and fathers28. Given the scope and quality of evidence currently available, it is therefore not possible to conclude what types of bereavement support interventions for the parents of children who have died are effective, and whether parent-centred or other factors affect intervention effectiveness.

None of the interventions represented in the review were subject to more than one evaluation. However, aside from the intervention which concerned changes to usual practice23, interventions did include one or both of two core components. First, all the interventions included information provision about grief and grief responses, although the extent to which this information provision was systematic and the mode by which it was provided (printed, DVD, verbally) differed. In addition, some but not all included the use of personal stories. The second core component was psychotherapeutic support. The interventions including this component varied in the approach taken to providing it (individual vs group delivery), and whether the intervention worked with family/couple units or, if available to both, with mothers and fathers separately. In addition, different types of professionals were involved and some also used peers. That almost all interventions represented in the review comprised one or both components aligns with wider evidence on bereavement support 32.

Unfortunately, the poor reporting of the intervention and control conditions limits the findings of this review and prevents replication studies. While there appeared to be a trend towards more detailed reporting in the more recent publications, it is unlikely that any of the interventions or controls could be replicated based on the information provided in the study reports. Future studies should, where relevant, make publicly available all intervention materials required for replication (e.g. information resources, intervention protocols or manuals, staff training protocols/manuals). Interventions should also be clearly reported in line with the Tidier checklist 33. There was also no reporting of potential harm in any of these studies which would be an important consideration for future research seeking to evaluate these interventions.

There are some methodological challenges with undertaking research with bereaved parents that also need to be addressed in future research, although it is worth noting here the several studies which have shown that the parents value participating34-36. Most importantly, robust study designs are needed which consistently evaluate the most important outcomes to allow for future aggregation of evidence, including those that are meaningful and important to parents. The eight studies included in the current review measured 23 different outcomes variables using 17 different scales some of which were not validated. There is no current consensus on the core outcomes that should be used to evaluate the effectiveness of bereavement support interventions but there are two ongoing studies registered on the COMET database which begin to address this. One is developing a core outcome set for bereavement support after stillbirth, perinatal and neonatal loss and one for any bereaved relative after advanced illness37. These studies are due to report soon but further work to refine a core outcome set specifically for parents may still be required; for example measurement development and defining ‘clinically meaningful’ change in these outcomes for this population.

The overall findings of the current review are similar to the most recent systematic review of RCTs on this topic16, though this also included BSIs aimed at siblings. They too highlighted the methodological issues with the published evidence in this area, an issue that has been raised in the reviews of bereavement interventions more generally30 31 38 and highlighted in the James Lind Alliance Palliative and End of Life care priority setting Partnership39. There are instances, though, where the findings of our review disagree with those of previous reviews. For example, the last systematic review of BSIs specifically for parents17, published in 2002, concluded that BSIs for parents can be effective in reducing psychological symptoms and marital dysfunction in highly distressed parents17. However, this conclusion was based on findings from post hoc analyses reported by three studies which explored whether specific types of parent benefitted more from the BSI under investigation. In our review, the multiple posthoc analyses undertaken by many studies were of particular cause for concern, due to the substantial risk of type one error inflation. Consequently, we have chosen not to report such findings. However, we would advocate that future evaluations are designed so they can identify if certain factors (e.g. parents’ gender, age of child, nature of death etc.) affect whether and how much benefit is experienced. Furthermore, to understand longer-term impacts, including preventing the development of ‘complicated grief’, outcomes should be assessed at least up to 6 months post-intervention40.

The review found relatively few studies focused on BSIs for parents whose child, rather than baby, dies. This is likely to reflect differences in provision and practice. Mortality is highest in the new-born age group who are generally seen by two distinct services, therefore obstetric or neonatal teams may be more likely to include bereavement support within their provision. In contrast, causes of death among older children are wide-ranging. Among those with LLC, the death of their child will be the point at which parents’ contact with their child’s healthcare team is likely to cease. In terms of informing the agenda for future research, it is important that attention and investment is given to this group of parents as well as furthering the evidence base on BSIs for parents who have experienced baby loss.

As with many other countries, bereavement support for parents is mainly provided by third sector organisations (children’s hospices, bereavement support charities). Such organisations provide a range of BSIs (e.g. information, be-friending, individual counselling, group-delivered interventions, support groups, family days, physical and virtual memorials). However, historically, they have not had the expertise or capacity to engage in robust evaluations of their work and this (at least) partly accounts for the paucity of evidence. Going forward, researchers have a choice: to evaluate existing interventions or design and implement new ones. Either way, these are complex interventions and we would recommend any evaluative research needs to take place within the framework set out by the Medical Research Council’s guidance on evaluating such interventions41.

## Strengths and Limitations

The current review has a number of strengths, including a very specific research question, and its adherence to a published study protocol and a robust search strategy.

Despite these strengths, this review is not without its limitations. For example, restricting the search to studies published only in the English language, may have missed relevant studies.

Key limitations of the primary studies included in this review are the poor quality methodology and reporting which meant it was inappropriate to undertake a meta-analyses.

## Conclusions

In conclusion, poor methodology and reporting of the few studies which have assessed bereavement support interventions for parents limit any conclusions on their effectiveness. Reporting of intervention details appears to have improved marginally overtime, but the majority of interventions reported here could not be replicated based solely on the information provided in the published articles. Agreement on core outcomes for assessing effectiveness of bereavement support interventions for parents is required and future research should adhere to guidance on the evaluation of complex interventions.

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Table 1 Study Characteristics

| **Study ID and country** | **Stated aim** | **Study design and setting** | **Intervention vs control** | **Age at and cause of death** | **Number of participants** | **Outcomes and measures** | **Data collection method and timing** | **Key findings** |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Aho et al. 2011  Finland | To evaluate a bereavement follow-up intervention for grieving fathers | Randomised controlled trial: pilot study  All university hospitals in Finland (n=5) | Three-part behavioural support package for bereaved fathers. 1. A tailored support package; 2. Peer contact; 3. Health care personnel’s contact  vs  Standard hospital care | 22 weeks gestation - 3 years  SIDS; accidental, neonatal/perinatal; crisis care | Number of fathers invited to participate not reported.  Data collection: 103 fathers were randomised by Hospital attended (62 intervention: 41 control) | Grief measured using: the Hogan Grief Reactions Checklist; a scale for measuring received social support; and a scale to measure fathers’ experiences of the intervention (developed by authors) | Postal questionnaire  6 months after the child's death | Intervention group reported statistically significant stronger personal growth |
| DiMarco et al. 2001  USA | To determine if a support group intervention makes a difference in grief reactions of parents who have experienced a perinatal loss | Cross-sectional, retrospective, two-group design  Parents receiving a perinatal death newsletter from single hospital | A support group of 8 to 12. Topics discussed matched needs of the parents e.g. how to cope with feelings of grief, family, friends, work, and holidays. 30 minutes for socialising. Books on perinatal loss available  vs  No support group | Perinatal death (age not reported)  Miscarriage, ectopic pregnancy, stillbirth, early infant loss | Invited: 200  Responses: 128  Included in analysis: 121 (67 intervention (49 mothers): 54 control (39 mothers)) | Grief measured using: the Hogan Grief Reaction Checklist | Postal questionnaire  Single retrospective data collection point (range of times after child’s death: 1 month to 13 years) | No statistically significant differences between groups found |
| Forrest et al. 1982  UK | To test the hypothesis that psychological recovery from stillbirth/neonatal death is enhanced by support and counselling | Randomised Controlled Trial  Maternity Hospital, Oxford | Proposed "ideal" care: being encouraged to see, hold, photograph and name their baby; choice of returning to own or an isolation ward; unhurried discharge with access to medical staff, social worker, midwife, GP. Follow-up planned for counselling; discussion of post-mortem results  vs  Usual Hospital care | >28 weeks - newborn period (not specified)  Stillbirth; congenital malformation; immaturity; “asphyxia” during birth; rhesus incompatibility | Recruited: 50 mothers  Responses at 6 month follow-up: 35 (16 intervention: 19 control)  Limited results also collected for fathers | Psychiatric disorder, depression and anxiety measured using: General Health Questionnaire and the Leeds Scales | Semi-structured interviews and completion of self-rating scales in parent’s home.  Six and 14 months after the death of the baby | Significantly fewer mothers in the intervention group met clinical cut-offs for psychiatric disorder, but only at 6 months |
| Murphy et al. 1997/1998  USA | To evaluate the effectiveness of a parent bereavement program | Multi-site randomised controlled cohort study  Participants identified from death certificates in two States | Group intervention to provide information and skills on the topics: emotional, cognitive and health responses, parental role loss, legal concerns, marital, significant other and family relationships. Written information provided and participants made notes.  vs  No treatment | 12 - 28 years  Accidental, homicidal or suicidal death | Approached: 329 families  Agreed: 204 families  Randomised: 261 parents (153 intervention (101 mothers: 52 fathers) 108 control (70 mothers: 38 fathers)  6 month follow-up:216 remained in the study | Mental distress; posttraumatic stress; loss accommodation; physical health; marital role strain  Brief Symptom Inventory, Traumatic Experiences Scale\* Grief Experiences Scale\*, Health Status / Health Behaviours Scale\*, Dyadic Adjustment Scale  *\* developed by PI for the study* | Participant attendance at data collection sessions or postal questionnaire  Baseline, end of treatment (12 weeks) and 6 months later | No statistically significant differences between the groups found |
| Murray et al. 2000  Australia | To develop and evaluate the effectiveness of an integrated program to relieve the distress of parents bereaved through infant death | Repeated measures pre-test–post-test control group design  Three major maternity hospitals in Brisbane | Standard hospital care, plus: written information on medical aspects of infant death, mourning and effects of infant death on family members, family systems and decision making. Pack included information tailored for different family members for parents to share. At least one session with a grief worker.  vs  Standard hospital care | >20 weeks gestation, neonatal or infant  Stillbirth, cause of neonatal death not specified, SID  4-6 weeks after child's death | Baseline: 172 parents  Final follow-up: 144 (65 fathers: 79 mothers) (84 intervention: 60 control) completed all three interviews | Anxiety, depression, physical symptoms, coping responses, and relationship quality  Subscale of the Delusions–Symptoms–States Inventory; a scale and a subscale from the Health and Daily Living Form Manual; the Dyadic Adjustment Scale | Semi-structured interviews  4-6 weeks, 6 months and 15 months post-loss | Both mothers and fathers in the intervention group showed significant improvement compared to the control group in mental distress, depression and relationship quality |
| Raitio et al. 2015  Finland | To produce information about a parental grief intervention and its impacts on maternal grief. | Randomised controlled trial  All university hospitals in Finland (n=5) | Three-part behavioural support package for bereaved fathers. 1. A tailored support package; 2. Peer contact; 3. Health care personnel’s contact.  vs  Standard hospital care | 22 weeks gestation - 3 years  Causes of death not reported | Number of mothers invited to participate not reported.  Data collection: 139 mothers were randomised by Hospital attended (86 intervention: 53 control) | Grief measured using: the Hogan Grief Reactions Checklist | Postal questionnaire  6 months after the child's death | No statistically significant differences between groups found |
| Rosenbaum et al. 2015  USA | To test the effect of a neonatal bereavement support DVD on parental grief | Randomised Controlled Trial  Single neonatal intensive care unit (NICU) | Standard bereavement care and a 90-minute DVD (Grieving in the NICU: Mending Broken Hearts When a Baby Dies)  vs  Standard bereavement care | Average 23.8 days old  Died in NICU, cause of death not reported | Randomisation:160 families (85 control: 75 intervention)  3 months contact: 132 parents consented: 99 completed the interview  12-month follow-up: 82 (74 completed both interviews, but data analysed for all respondents) | Parental grief; depression; strength of parents’ religious views; social support  Perinatal Grief Scale; Centre for Epidemiologic Studies-Depression questionnaire; the Royal Free Interview for Spiritual and Religious Beliefs; Social Provisions Scale | Telephone interviews  3 and 12 months after baby’s death | No significant differences between groups found for grief or depression |
| Videka-Sherman & Lieberman 1985  USA | To examine psychosocial adjustment of parents and the effects of two forms of psychological help on parents’ mental health and social functioning following the death of a child | Longitudinal cohort study | Compassionate Friends (CF), a national self-help organisation for bereaved parents and psychotherapy (no specific programme). CF offer monthly face-to-face meetings for bereaved parents.  Vs  Survey respondents who said they had not received the intervention | Age of child at death not reported.  Death due to accidental  causes, sudden illness, illness of some duration, murder, or suicide | Baseline: 2422 questionnaires sent to bereaved parents: 667 returned (28%)  One year follow up: 667 questionnaires sent: 391 returned (59%) | Mental Health: depression, anxiety, somatization, self-esteem, happiness with life, masterful orientation toward life's problems, use of psychotropic medication. Social functioning: self-assessment in the marital role. Parental functioning: distress in the parental role, frequency of preoccupation with parental problems, attitudes. Attitudes: degree of anger, optimism versus pessimism  Measures used not reported but included validated and study specific measures | Postal questionnaires and interviews with a sub-sample of parents  Baseline and 12 months | No treatment effect found for any outcome measured |

**Table 2 Details of interventions and controls**

| **Study** | **Intervention** | **Duration** | **Delivered by/ setting** | **Timing of intervention** | **Control details** |
| --- | --- | --- | --- | --- | --- |
| Aho et al. 2011 | Standard care plus: a three part behavioural support for bereaved fathers. 1. A tailored support package; 2. Peer contact; 3. Health care personnel’s contact. | Offered from leaving hospital; healthcare personnel contact as requested | Delivered face to face to individuals by peer supporters and nurses/doctors, | 1. support package on leaving hospital; 2. Peer contact about a week later; 3. Health care personnel’s contact offered 2-6 weeks post child’s death. | Standard hospital care (not described) |
| DiMarco et al. 2001 | A support group of 8 to 12. Topics discussed matched needs of the parents but usually included how to cope with feelings of grief, family, friends, work, and holidays. 30 minutes for socialising. Books on perinatal loss available to borrow. | Met for two hours once each month | Facilitated by the primary author or nurse/patient and a chaplain.  Setting not reported. | 1 month to 13 years after child's death (average 2.3 years) | Control group constituted bereaved parents who had not taken part in a support group. |
| Forrest et al. 1982 | Proposed "ideal" care: being encouraged to see, hold, and name their baby; photograph of the baby taken and kept; choice of returning to own or an isolation ward; unhurried discharge with access to medical staff, social worker, midwife, GP. Follow-up planned for obstetric and/or genetic counselling; discussion of post-mortem results with paediatrician. | Support while in hospital  Number of follow-up sessions was dependant on needs of participants | Counselling was delivered face to face to mothers/ couples by either social worker or family psychiatrist in the mother’s own home. | In hospital options offered before discharge including arranging counselling. First session usually 24-48 hours after the baby's death. Sessions continued until parents were well established in their mourning and had home support network (max was 8 sessions over 4 months) | Usual care varied greatly depending on both parent and staff attitudes. Minimum care (applied in a few cases) consisted of no opportunity to see the baby; automatic placement in a single room on the isolation floor; discharge home within 24 hours; and no hospital follow-up. |
| Murphy et al. 1997/1998 | Group intervention to provide information and skills on the topics: emotional, cognitive and health responses, parental role loss, legal concerns, marital, significant other and family relationships. Written information provided and participants made notes. | Weekly 2 hour sessions for 12 weeks | Delivered by men-women pairs of group leaders (psychologists, nurses or family therapists).  Neutral site e.g. office, community centre | Time since child’s death ranged from 2 - 7 months | No treatment. (Control group were offered reduced version of intervention after trial participation) |

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| --- | --- | --- | --- | --- | --- |
| Murray et al. 2000 | Standard hospital care, plus: Written information on medical aspects of infant death, mourning and effects of infant death on family members, family systems and decision making. Pack included information tailored for different family members for parents to share. At least one session with a grief worker. | Support while in hospital.  Grief worker sessions offered over a 15 month period | Grief workers (registered social workers and psychologists) given 40 hours training, training manual and materials. Regular case meetings.  Parents chose where sessions were held | 4-6 weeks after infant/child's death | Standard hospital care that involved practical assistance, comfort and reassurance, and the provision of information and memorabilia. No formal follow-up was provided by the hospital. For SIDs, a single or limited contact with verbal or written information about community support. |
| Raitio et al. 2015 | Standard care plus: a three part behavioural support for bereaved fathers. 1. A tailored support package; 2. Peer contact; 3. Health care personnel’s contact. | Offered from leaving hospital; healthcare personnel contact as requested | Delivered face to face to individuals by peer supporters and nurses/doctors, | 1. support package on leaving hospital; 2. Peer contact about a week later; 3. Health care personnel’s contact offered 2-6 weeks post child’s death. | Standard hospital care (not described) |
| Rosenbaum et al. 2015 | Standard care plus a 90 minute DVD: Grieving in the NICU: Mending Broken Hearts When a Baby Dies. Contains five chapters to permit parent choice; | From immediate post death of baby while still in hospital, up to 12 weeks after the death. | Interdisciplinary team includes nurses, neonatologists, social workers, chaplain, patient-care associates. Parents chose time of viewing DVD.  In hospital: setting for follow up not reported. | 8-12 weeks after child's death | Standard care included: care by an interdisciplinary NICU team; a memory packet; photos; hand/foot prints; lock of hair; baby gown; engraved ring and necklace for parents; follow-up care meetings 8-12 weeks after death of baby; NICU team answers questions, reviews autopsy results and assesses family for symptoms of pathological grief. |
| Videka-Sherman & Lieberman 1985 | Compassionate Friends (CF), a national self-help organisation for bereaved parents and psychotherapy. CF offer monthly face-to-face meetings for bereaved parents.  Psychotherapy was defined as seeking help from a professional counsellor for problems experienced as a result of the child’s death: no specific program was studied | CF meetings held monthly. Parents can attend for as long as desired.  Duration of psychotherapy not reported | CF or a professional psychotherapist  Setting for delivery not reported | 8 months to 3 or more years after child's death | Survey respondents who said they received either of the interventions were compared with those who reported they had not. |

Table 3 Summary of Quality Assessment using Downs and Black Tool

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| --- | --- | --- | --- | --- | --- | --- | --- |
| Paper | Reporting (max 11) | External Validity (max 3) | Internal Validity  Bias (max 7) | Internal Validity  Confounding (max 6) | Power (max 5) | Total  (max 32) | Rating# |
| Forest 1982 | 5 | 2 | 2 | 2 | 1 | 12 | Low |
| Videka-Sherman 1985 | 4 | 2 | 3 | 2 | 0 | 11 | Low |
| Aho 2011 | 8 | 2 | 4 | 2 | 0 | 16 | Moderate |
| Di marco | 8 | 0 | 1 | 1 | 1 | 11 | Low |
| Rosenbaum 2015 | 6 | 1 | 4 | 4 | 2 | 17 | Moderate |
| Murray 2010 | 8 | 3 | 5 | 1 | 0 | 17 | Moderate |
| Murphy 1998 | 8 | 1 | 4 | 4 | 0 | 17 | Moderate |
| Navidian 2017 | 7 | 1 | 3 | 3 | 2 | 16 | Moderate |
| Ratio 2015 | 8 | 2 | 4 | 2 | 0 | 16 | Moderate |

# Low <15, Moderate 15-20, High >20