Support for mothers, fathers and families after perinatal death (Review)

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[Intervention Review]

Support for mothers, fathers and families after perinatal death

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ABSTRACT

Background

Provision of an empathetic caring environment, and strategies to enable the mother, father and family to accept the reality of perinatal death, are now an accepted part of standard nursing and social support in most of the developed world. Provision of interventions such as psychological support or counselling, or both, has been suggested to improve outcomes for families after a perinatal death.

Objectives

The objective of this review was to assess the effects of the provision of any form of medical, nursing, social or psychological support or counselling, or both, to mother, father and families after perinatal death.

Search methods

We searched the Cochrane Pregnancy and Childbirth Group's Trials Register (30 October 2007) and reference lists of articles.

Selection criteria

Randomised trials of any form of general support aimed at encouraging acceptance of loss, specific bereavement counselling, or specialised psychological support/counselling including psychotherapy for mother, father and families experiencing perinatal death.

Data collection and analysis

Two review authors independently assessed eligibility of trials; a third person subsequently assessed the quality of the identified trials as a part of this review update.

Main results

No trials were included.

Authors' conclusions

There is currently insufficient information available from randomised trials to indicate whether there is or is not a benefit from interventions which aim to provide psychological support or counselling for mothers, fathers or families after perinatal death. Methodologically rigorous trials are needed.

PLAIN LANGUAGE SUMMARY

Support for mothers, fathers and families after perinatal death

Not enough information about what types of interventions and the possible benefits of interventions when providing support for mothers, fathers and their families after a baby dies at birth.

The death of a baby at, or around, the time of birth is devastating for the parents and the family. It is thought that about one in five families suffer excessively in terms of more intense and prolonged grief, and other psychological adverse outcomes, if their baby dies. The review looked for trials assessing different kinds of support and counselling in such situations for parents and families, but no trials were identified. More research is needed.

BACKGROUND

The substantial psychological impact of perinatal death on mothers and families has been extensively studied over the past 30 years, when it first became clear that the normal grief reactions to perinatal death did not differ greatly from those observed in other bereavement situations (Giles 1970; Kennell 1970). The death of an infant is now recognised as one of the most stressful life events that an adult may experience (Fish 1986; Wing 2001).

A wide range of short- and long-term negative outcomes for parents have been reported as a result of infant death (Hughes 2003). Depressed mood, anxiety, irritability, changes in eating and sleeping patterns, and preoccupation with the lost baby are normal early responses to perinatal loss, and increased levels of depression and anxiety are common among bereaved parents (Hughes 2003). In a recent review, bereaved parents were identified as a high-risk group for complicated grief (Christ 2003) and up to one-quarter of bereaved parents may display severe symptoms years after the death of their baby (Murray 2000). The recent finding that parents may also be at risk of developing post traumatic stress disorder (PTSD) as a consequence of perinatal loss has shed a new perspective on the consequences of perinatal loss. One study reported 20% of women fulfilled the criteria of PTSD in a pregnancy following a perinatal loss compared with a general population incidence of 0.4% to 4.6% (Turton 2001).

Grief may have a significant negative effect on the couple's relationship, family dynamics or parenting skills, or both. An increase in marital break and significant deterioration in the quality of the marital relationship in those bereaved parents whose relationship remained intact has been reported after the death of an infant (Najman 1993). An important finding from this research was the increased use of alcohol as a method of coping in men following a perinatal loss.

Factors which have been reported to increase the risk of adverse psychological outcomes for parents after a perinatal death include: perceived inadequate social support, traumatic circumstances surrounding the death, difficulties in coping with a crisis in the past, problematic relationships in the nuclear family and the presence of other life crises. In addition, mothers report greater distress than do fathers (Murray 2000).

A recent review of the psychological effects of perinatal death on fathers (Badenhorst 2006) identified some common themes in paternal grief, but recommend a more systematic approach to identifying affective and behavioural responses that are specific to fathers, including the prevalence of PTSD symptoms. The more active and significant role of today's fathers in child-raising and parenting is a factor likely to impact on grief intensity. Increased infant attachment associated with modern obstetric practices, such as prenatal diagnostic procedures, assisted reproduction and graphic ultrasound imaging has been reported to increase the intensity of mothers' grief (Robinson 1999); it is therefore reasonable to expect that fathers too may be at a greater risk of experiencing more intense grief with increasing attachment.

Although grief is a normal and natural response to loss, and in many instances will dissipate over time, the importance of pro-

viding quality care in the time surrounding an infant's death has been repeatedly demonstrated (Janzen 2003-2004; Kirkley-Best 1982; Mashegoane 1999; Murray 2000; Wing 2001). However, what continues to pose difficulties for those attempting to provide perinatal bereavement support is exactly what it is that comprises 'best practice', particularly in relation to psychosocial care. Early research (Kennell 1970; Peppers 1980) identified the importance of memory creation, including taking photos, seeing, holding and naming the infant, as a positive factor in recovery from grief. These practices have been introduced into maternity units and clinical practice in most countries. However, recently there has been an alert sounded that such practices have become prescriptive and 'routine' in check lists and 'do's and don'ts' and, in fact, may be failing to offer meaningful care to bereaved families (Lang 2005). A recent review showed that parents perceive many healthcare provider behaviours to be thoughtless or insensitive (Gold 2007). In addition, an association with some routine practices and adverse outcomes has been reported, specifically PTSD and viewing the deceased infant after birth (Turton 2001).

The narrative review by Forrest almost 20 years ago (Forrest 1989) on support after a perinatal death highlighted the need for further research in this area. However, there appears to be very little evidence forthcoming, other than descriptive studies based largely on the premise that all bereaved family members will have difficulty adjusting to the death and will all require specific support. More recently, a case-controlled study (Murray 2000) showed that support, including contact with a trained grief worker as well as specially designed resources, resulted in benefits in terms of psychiatric disturbance, paternal coping strategies and marital quality. In a review of randomised controlled studies related to specific grief counselling interventions in general bereavement, Neimeyer (Neimeyer 2000) cautions that these interventions are frequently ineffective, and in some instances deleterious, at least for those who are experiencing normal grief. A review of the efficacy of child or parent bereavement programmes, or both, in the paediatric area also failed to clearly identify the role of systematic approaches to support (Schneiderman 1994). However, a recent review has challenged these findings and indicates that these interventions may be beneficial (Larson 2007). This review was undertaken to assess the role of support around the time of a perinatal death from the currently available randomised controlled trials

This review was undertaken to assess the role of support around the time of a perinatal death from the currently available randomised controlled trials.

OBJECTIVES

The specific objectives of this review are to determine the effectiveness of any form of medical, nursing, psychological or social support in preventing or reducing the incidence or severity, or both, of pathological grief reaction or long-term psychopathological sequelae, or both, in mothers, fathers and families experiencing perinatal death.

METHODS

Criteria for considering studies for this review

Types of studies

Controlled trials in which social or professional support or counseling, or both, after perinatal death were compared with standard care as practiced at the time of the study; random allocation to treatment and control groups, with adequate allocation concealment; violations of allocated management and exclusions after allocation not sufficient to materially affect outcomes. 'Perinatal death' was defined as stillbirth or neonatal death according to the definitions used in the trials.

Types of participants

Mothers and/or fathers and/or their immediate families, who had experienced a perinatal death for any reason. Trials involving early spontaneous abortions or termination of pregnancy for non-medical reasons were excluded.

Types of interventions

Interventions considered include any intervention provided by professional or non-professional individuals or groups aimed at improving psychological wellbeing. These may include:

• any general supportive intervention aimed at enabling the mother, father or family to accept the reality of death, such as photographs and other memorabilia, encouraging the mother, father and family to hold and name the baby, follow-up visits and offering dignified funeral rites or disposal arrangements for stillbirths; and also support and education for professionals on perinatal bereavement;

• any form of intervention labelled as bereavement counselling;

• any other form of specialised psychological support or counselling, or both, either single or multiple episodes;

• any form of specialised psychotherapy.

Types of outcome measures

The main outcome measures include:

• persisting emotional symptoms of bereavement including complicated grief;

• any psycho morbidity including anxiety and depression and post-traumatic stress disorder;

social maladjustment;

• abnormal family dynamics: marital disharmony, marital breakdown;

- physical symptoms;
- effects on next pregnancy including anxiety and depression;
- any indicators of dissatisfaction with care received.

Where appropriate, these outcomes were definable by standard clinical criteria and measurable by standard psychometric criteria using methods such as questionnaires or interviews, or both.

Search methods for identification of studies

Electronic searches

We searched the Cochrane Pregnancy and Childbirth Group's Trials Register by contacting the Trials Search Co-ordinator (30 October 2007).

The Cochrane Pregnancy and Childbirth Group's Trials Register is maintained by the Trials Search Co-ordinator and contains trials identified from:

1. quarterly searches of the Cochrane Central Register of Controlled Trials (CENTRAL);

2. monthly searches of MEDLINE;

3. handsearches of 30 journals and the proceedings of major conferences;

4. weekly current awareness search of a further 36 journals plus monthly BioMed Central email alerts.

Details of the search strategies for CENTRAL and MEDLINE, the list of handsearched journals and conference proceedings, and the list of journals reviewed via the current awareness service can be found in the 'Search strategies for identification of studies' section within the editorial information about the Cochrane Pregnancy and Childbirth Group.

Trials identified through the searching activities described above are given a code (or codes) depending on the topic. The codes are linked to review topics. The Trials Search Co-ordinator searches the register for each review using these codes rather than keywords. We did not apply any language restrictions.

Data collection and analysis

Two review authors (Helen Chambers and Fung Yee Chan) independently selected the trials to be included in this review with the reasons for exclusion of any apparently eligible trial clearly stated. Any disagreement was resolved by discussion. The same review authors assessed the methodological quality of the trials with details of randomisation, blinding and exclusions from the analyses recorded. A third author (Vicki Flenady) subsequently assessed the quality of the identified trials as a part of this update of the review.

We attempted to contact trial authors for additional information to allow both assessment of methodological quality and to permit 'intention-to-treat' analysis of data. Dr Gillian Forrest and Professor Richard Lilford provided additional information about their published trials.

For future updates of the review, we will employ the following methods where applicable:

Selection of studies

We will assess for inclusion all potential studies we identify as a result of the search strategy. We will resolve any disagreement through discussion or if required consult an outside person.

Data extraction and management

We will design a form to extract data. At least two review authors will extract the data using the agreed form. We will resolve discrepancies through discussion. We will use the Review Manager software (RevMan 2003) to double enter all the data or a subsample.

When information regarding any of the above is unclear, we will attempt to contact authors of the original reports to provide further details.

Assessment of risk of bias in included studies

We will assess the validity of each study using the criteria outlined in the Cochrane Handbook (Higgins 2005). We will describe the methods used for generation of the randomisation sequence for each trial.

(1) Selection bias (allocation concealment)

We will assign a quality score for each trial, using the following criteria:

(A) adequate concealment of allocation: such as telephone randomisation, consecutively numbered sealed opaque envelopes;

(B) unclear whether adequate concealment of allocation: such as list or table used, sealed envelopes, or study does not report any concealment approach;

(C) inadequate concealment of allocation: such as open list of random number tables, use of case record numbers, dates of birth or days of the week.

(2) Attrition bias (loss of participants, eg withdrawals, dropouts, protocol deviations)

We will assess completeness to follow up using the following criteria:

- (A) less than 5% loss of participants;
- (B) 5% to 9.9% loss of participants;
- (C) 10% to 19.9% loss of participants;
- (D) more than 20% loss of participants.

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(3) Performance bias (blinding of participants, researchers and outcome assessment)

- We will assess blinding using the following criteria:
- (A) blinding of participants (yes/no/unclear);
- (B) blinding of caregiver (yes/no/unclear);
- (C) blinding of outcome assessment (yes/no/unclear).

Measures of treatment effect

We will carry out statistical analysis using the Review Manager software (RevMan 2003). We will use fixed-effect meta-analysis for combining data in the absence of significant heterogeneity if trials are sufficiently similar.

Dichotomous data

For dichotomous data, we will present results as summary relative risk with 95% confidence intervals.

Continuous data

For continuous data, we will use the weighted mean difference if outcomes are measured in the same way between trials. We will use the standardised mean difference to combine trials that measure the same outcome, but use different methods. If there is evidence of skewness, we will report this.

Unit of analysis issues

Cluster-randomised trials

We will include cluster-randomised trials in the analyses along with individually randomised trials. We will adjust their sample sizes using the methods described in Gates 2005 using an estimate of the intracluster correlation co-efficient (ICC) derived from the trial (if possible), or from another source. If ICCs from other sources are used, we will report this and conduct sensitivity analyses to investigate the effect of variation in the ICC. If we identify both cluster randomised trials and individually randomised trials, we plan to synthesise the relevant information. We will consider it reasonable to combine the results from both if there is little heterogeneity between the study designs and the interaction between the effect of intervention and the choice of randomisation unit is considered to be unlikely.

We will also acknowledge heterogeneity in the randomisation unit and perform a separate meta-analysis. Therefore we will perform the meta-analysis in two parts as well.

Dealing with missing data

Available case analysis

We will analyse data on all participants with available data in the group to which they are allocated, regardless of whether or not they received the allocated intervention. If in the original reports participants are not analysed in the group to which they were randomised, and there is sufficient information in the trial report, we will attempt to restore them to the correct group.

Assessment of heterogeneity

We will apply tests of heterogeneity between trials, if appropriate, using the I² statistic. If we identify high levels of heterogeneity among the trials, (exceeding 50%), we will explore it by prespecified subgroup analysis and perform sensitivity analysis. We will use a random-effects meta-analysis as an overall summary if this is considered appropriate.

Subgroup analysis and investigation of heterogeneity

We will conduct planned subgroup analyses classifying whole trials by interaction tests as described by Deeks 2001.

We plan to carry out the following subgroup analyses.

(1) Intervention: person delivering the intervention: clinician (midwife, obstetrician); professionals specifically trained in bereavement counseling; trained psychologist.

intensity of the intervention: e.g. according to duration of time and number of times specific support was provided (number of consultations).

(2) Population: interventions provided for fathers or families, or both; mothers and fathers considered to be at increased risk.

Sensitivity analysis

We will carry out sensitivity analysis to explore the effect of trial quality. This will involve analysis based on an A, B, C, or D rating of selection bias and attrition bias. We will exclude studies of poor quality in the analysis (those rating B, C, or D) in order to assess for any substantive difference to the overall result.

Where applicable, we will also undertake sensitivity analysis for cluster trials where an estimate of the intracluster correlation coefficient (ICC) borrowed from a different trial to explore the effect of different values of the ICC on the results of the analysis.

RESULTS

Description of studies

See: Characteristics of excluded studies.

We identified three trials as potentially eligible for inclusion in the review and we excluded all of them (Forrest 1982; Lake 1987; Lilford 1994) (*see* table 'Characteristics of excluded studies'). The large loss to follow-up rate was the major reason for exclusion.

Risk of bias in included studies

Not applicable.

Effects of interventions

Not applicable.

DISCUSSION

This review has highlighted the difficulty and inadequacy of research in the area of grief support surrounding perinatal death. From being largely neglected in the past, it has been encouraging to see that a few attempts have now been made to address the question by randomised controlled trials. The available data are sparse and variable, and the trials are of insufficient quality, size and comparability to enable any valid conclusions. The trials are not comparable: that of Lake 1987 was set in a population of predominantly indigent single or poorly socially-supported mothers, or both, in west central Florida, while the other two (Forrest 1982; Lilford 1994) were in large British teaching hospitals and included partners in the intervention. The most recent trial (Lilford 1994) was the only one which included couples who had experienced termination of pregnancy for fetal anomaly as well as stillbirths and neonatal deaths.

The three excluded studies (*see* table 'Characteristics of excluded studies') do however provide some insight into the areas of difficulties in these studies, and may guide the design of future trials. Only one trial (Lilford 1994) provided power calculations of the numbers needed to be randomised, and the results of this trial could be utilised towards better estimation of the numbers required in future studies to retest the hypothesis. The large loss to follow-up rate was the major reason for exclusion of all three trials, and should alert future researchers to specifically target this problem and to seek sufficient resources to enable better follow up.

All three trials identified certain high-risk groups that may warrant further study. Two (Forrest 1982; Lake 1987) noted that socially isolated women or women with low levels of social support tended to have a higher incidence of psychiatric symptoms. One trial (Lilford 1994) suggested that women who underwent termination of pregnancy for fetal anomalies had slightly worse outcomes than those who had experienced stillbirth or neonatal death. This is likely to be related to the specific grief issues related to termination of pregnancy, including active decision making, guilt and shame. Given the difficulty of research in this area, it may be that specific emphasis and attention to these high-risk groups, with adequate levels of follow up, may be warranted.

Although two trials (Forrest 1982; Lilford 1994) included partners in the interventions, they were not able to draw any specific conclusions and further attention to the effects of such interventions for fathers is needed. The influence of cultural and racial differences on the incidence of psychiatric symptoms remains a potentially interesting but unexplored aspect of adjustment to perinatal death and as yet no randomised controlled trials have specifically addressed this issue.

The current discussion and planning towards the inclusion of complicated or pathological grief as a distinct category of mental disorder in the upcoming Diagnostic and Statistical Manual of Mental Disorders (DSM-V) will have implications on both the identification and potential interventions for bereaved parents (Zhang 2006). Clarity of the definition and classification of pathological grief is likely to increase the identification of a population for whom intervention is likely to be helpful, and this in turn is likely to lead to the development of interventions that can be empirically tested. Another emerging area of research which will contribute to our scientific knowledge and grief interventions is that of the neurobiology of grief and trauma indicating that grief is mediated through a neural network across regions of the brain (Gundle 2003). Also growing research into resilience (Zhang 2006) and post-traumatic growth (Buchi 2007) will add further to the development of effective post-loss interventions.

AUTHORS' CONCLUSIONS

Implications for practice

Due to insufficient evidence from randomised controlled trials, this review is not able to provide reliable information on which to base practice. While providing support for parents and families after a perinatal death is justified based on other types of research, there is insufficient evidence to confirm or refute the benefit of the different types of interventions aiming to provide such support.

Implications for research

Methodologically rigorous trials are needed in order to assess the effects of interventions aimed at providing appropriate support for parents and families after a perinatal death. Certain high-risk groups (*see* 'Discussion') may need to be specifically targeted, as will the effect of interventions for fathers. It is likely that multicentre studies will be necessary, with adequate funding to ensure proper follow up in order to definitively address these questions. Further trials should ensure that the range of outcome measures is

clearly defined and is assessed by standard psychometric tools, as far as possible validated for the purpose, that data are numerically complete and appropriately presented and that adequate follow up is possible.

ACKNOWLEDGEMENTS

We acknowledge Helen Chambers for undertaking the initial ver-

sion of this review in collaboration with Fung Yee Chan. We thank Caroline Crowther (The University of Adelaide) and Sonja Henderson (Review Group Co-ordinator for the Pregnancy and Childbirth Group, Liverpool) for their advice, encouragement and support during the preparation of this systematic review. We also thank Dr Gillian Forrest and Professor Richard Lilford for providing additional information about their published trials.

The authors would like to dedicate this review to Professor Fung Yee Chan, who passed away in May 2007.

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* Indicates the major publication for the study

CHARACTERISTICS OF STUDIES

Characteristics of excluded studies [ordered by study ID]

Study	Reason for exclusion
Forrest 1982	High loss to follow up, particularly in treatment group. 25 women were randomised to the treatment group and 25 to the control group. At 6 months, the loss to follow up in the treatment group was 36% and in the control group, 24%
Lake 1987	High loss to follow up overall. Of 78 women recruited, 44 (56.4%) were lost to follow up. Randomisation method not stated. Data available are in an unsuitable form for analysis
Lilford 1994	Randomisation method not stated; strong possibility of selection bias (22 randomised to control group, 35 to treatment group). High loss to follow up. Of 57 women who were enrolled, 8 (36.3%) of control group and 18 (51.4%) of treatment group were lost to follow up. Data available are in an unsuitable form for analysis

DATA AND ANALYSES

This review has no analyses.

FEEDBACK

Lang, September 2005

Summary

The authors are to be commended for taking on the important, and often neglected, issue of providing support to bereaved families following perinatal loss.

None of the published studies met the quality criteria for inclusion in the review, and data on this topic are described as 'sparse' and 'variable'. In their discussion, the authors appropriately identify the limitations of their study, but then go on to state that the lack of trials was further complicated by "the evolution over 15 years of so called 'standard care' after perinatal death: the provision of an empathic caring environment, which was regarded in the earlier trials as part of the intervention, is now standard care in most centres". The basis for this conclusion is, however, questionable, and there is evidence to the contrary. Indeed, among health professionals there continues to be a sense of discomfort with the subject matter that frequently spills over into the care provided, which is often inadequate and can actually be detrimental.

Conclusions emanating from reviews where no quality studies are included must be carefully considered, and should be well-substantiated by other evidence. Ill-informed conclusions cited in The Cochrane Library can have an important impact on practitioners, researchers and funders.

(Summary of comments from Ariella Lang, September 2005)

Reply

We thank Ariella Lang for her comments and hope that our reply adequately addresses the concerns raised regarding our comments in the discussion of the review on the quality of current practice for parents after a perinatal death.

We agree that care for parents around the time of a perinatal death often falls short. We also agree that a sense of discomfort by healthcare professionals when dealing with a perinatal death may have negative effects on the quality of care and outcomes for parents. To better reflect this, the issue of care around the time of death is now discussed with appropriate references in the background, and the sentences about evolution of care have been removed from the background and discussion. Also, the list of interventions included in the review has been expanded to include support and education for professionals on perinatal bereavement. However, for this update we were not able to identify any randomised trials addressing this intervention.

The conclusions of the review clearly highlight the current lack of evidence to guide care and the need for well-designed trials to determine the appropriate support interventions for parents following a perinatal death. As is discussed in the conclusion, this lack of clearly defined and tested interventions may affect the confidence of practitioners, as well as funding opportunities, which may further contribute to the inadequate care currently provided to families who experience perinatal loss. (Summary of reply by Vicki Flenady and Trish Wilson, May 2007)

Contributors

Feedback: Ariella Lang Response: Vicki Flenady, Trish Wilson

WHAT'S NEW

Last assessed as up-to-date: 5 November 2007.

Date	Event	Description
18 January 2011	Amended	Contact details edited.

HISTORY

Protocol first published: Issue 3, 1997

Review first published: Issue 2, 1998

Date	Event	Description
29 January 2009	Amended	Author's contact details edited.
11 February 2008	Amended	Converted to new review format.
6 November 2007	New citation required and conclusions have changed	Substantive amendment

CONTRIBUTIONS OF AUTHORS

For this update, Vicki Flenady revised the background and discussion of the original version of the review in collaboration with Trish Wilson.

DECLARATIONS OF INTEREST

None known.

SOURCES OF SUPPORT

Internal sources

• Centre for Clinical Studies, Mater Hospital, Brisbane, Australia.

External sources

• No sources of support supplied

INDEX TERMS

Medical Subject Headings (MeSH)

*Bereavement; *Counseling; *Death; *Nuclear Family; *Social Support; Infant, Newborn; Life Change Events

MeSH check words

Humans