Grief and Bereavement After Infant Death: A Selected Annotated Bibliography


Care of relatives following sudden infant death.

This paper deals with 301 families who have been offered a consultation for managing bereavement following sudden infant death. Eighty-eight percent of the parents (269 families) accepted and 36 more families out with Lower Saxony wished to be cared for. Without a previous autopsy 1,172 contacts happened from 1989 to 2003 comprising primary crisis intervention and long-term care, the latter including saying farewell before and after autopsy. One main aim was a close linking with the international self-help organization of parents (GEPS). Single cases conferences were carried out for more than five years according to the Sheffield model. There is given the methodical basis and many details of the care project.


Scheidt CE, Waller N, Wangler J, Hasenburg A, Kersting A.
Mourning after perinatal death--prevalence symptoms and treatment--a review of the literature.

Miscarriage and perinatal loss are associated with considerable psychosocial distress. A substantial proportion of women who suffered the loss of a child develop a psychological disorder. Depression, anxiety disorder, post-traumatic stress disorder and somatoform disorder all have been linked in various studies to grief reactions in response to perinatal loss. A number of studies based on clinical and empirical evidence suggest various therapeutic procedures. However, a current Cochrane review fails to provide empirical evidence favouring a specific treatment strategy. In Germany in routine care in gynaecology no psychological support is offered to women suffering from grief reactions due to perinatal loss. Further research is needed to develop evidence based treatment strategies for secondary prevention in this field.


Vennemann MM, Rentsch C, Bajanowski T, Zimmer G.
Are autopsies of help to the parents of SIDS victims? A follow-up on SIDS families.

9/12/2007
Little is known about what bereaved parents feel about the autopsy performed on their child. A multi-centre case control study of sudden infant death syndrome (SIDS) victims was carried out in Germany between 1998 and 2001, in which all infants had been autopsied. We performed a follow-up study 4-7 years after the parents had lost their child. A total of 141 parents filled in the questionnaire, which were sent to them by the study centre. Of these, 71% had had another child after the SIDS/sudden unexpected death in infancy. The majority (83%) of the participating parents found the autopsy helped them to cope better with the death. A large proportion (46%) did not want any professional help after the death, and 55% did not wish to have any contact with a self-help group. We conclude that the autopsy is helpful to the majority of bereaved parents. Professional help and self-help groups should be offered to the parents even if the majority in our study did not want to use either.

Full-text available at: http://www.springerlink.com/ (not a U.S. Government site)

Krueger G. 
Meaning-making in the aftermath of sudden infant death syndrome. 

The reconstruction of meaning in the aftermath of sudden infant death syndrome (SIDS) is part of the grieving process but has to date been poorly understood. Earlier theorists including Freud, Bowlby and Kübler-Ross provided a foundation for what occurs during this time using stage theories. More recent researchers, often using qualitative techniques, have provided a more complex and expanded view that enhances our knowledge of meaning reconstruction following infant loss. This overview of representative contemporary authors compares and contrasts them with the longstanding models that are being supplanted within the emerging field of thanatology. Understanding parental reactions within this new framework can help healthcare professionals in dealing with those affected by SIDS and provide a more empathic and sensitive approach to individual differences. Parents' own accounts of their post-SIDS experience are consistent with these newer theories. Comprehending how parents cope and reconstruct their lives is an important element in providing appropriate psychological support services.


Raz YH, Peled M, Perry S, Raz R, Hod M. 
Parents coping with stillbirth: detachment or attachment? 

Stillbirth, a major crisis for parents, is marked by strong emotional, mental and behavioral reactions. Coping with and adjusting to the loss is instantaneous at the moment when parents are told that there is no heartbeat. At once they are forced to make three difficult decisions: Should they look at or hold their dead baby? Give consent to an autopsy? Bury the baby on their own? These most crucial decisions will have an impact.
on the recuperation process, both in the short and long term. This article presents findings of a pilot study conducted in a hospital center for women's medicine, which focused on these issues. The findings show that most parents prefer not to see the baby, tend to refuse autopsy and want the hospital to make the burial arrangements. The significance of the findings is discussed in reference to the three content areas of stillbirth that interact with one another: death and grief, the trauma, and the medical problem. These content areas emphasize the complexity of the event, and bring to the fore the dilemmas which must be faced in each decision, signaling a need for multidisciplinary support. The conclusions indicate a need for differing support approaches for each couple, rather than one overall policy. It is important to identify the particular needs of each couple as well as provide the proper responses for each couple, even for each spouse, and to assign a multidisciplinary team to support the parents' lengthy adjustment process.

Full-text available at: http://www.ima.org.il/ (not a U.S. Government site)

Lundqvist A, Nilstun T, Dykes AK.  
**Neonatal end-of-life care in Sweden: the views of Muslim women.**  

OBJECTIVE: To explore Muslim women's views of neonatal end-of-life-care in Sweden.  
METHODS: Interviews using a standardized questionnaire with open-ended questions about care before birth, directly after birth, and during and after the death of the infant. Content analysis was performed on the data. PARTICIPANTS: Eleven immigrant women of Muslim background living in Sweden. RESULTS: The categories identified were information both useful and threatening, priority of medical facts, maternal feelings, roles of significant others, predetermined lifetime, protection of the dying infant, staff's role, memories aggravate the grief, special tradition, life after death and belief in the future. CONCLUSIONS: The women provided suggestions for improvement of care including being given sufficient information of and the need for culturally sensitive care. In providing care for Muslim women it is imperative that care take into account the woman's religion and ethnicity as well as individual preferences.

Full-text available at: http://meta.wkhealth.com/ (not a U.S. Government site)

Vance JC, Boyle FM, Najman JM, Thearle MJ.  
**Couple distress after sudden infant or perinatal death: a 30-month follow up.**  

OBJECTIVE: To examine, using a 30-month prospective study, patterns of anxiety, depression and alcohol use in couples following stillbirth, neonatal death or sudden infant death syndrome. METHODOLOGY: One hundred and thirty-eight bereaved and 156 non-bereaved couples completed standardized interviews at 2, 8, 15 and 30 months post-loss. RESULTS: At all interviews, bereaved couples were significantly more likely than non-bereaved couples to have at least one distressed partner. Rarely were both partners distressed in either group. For bereaved couples, 'mother only' distress declined from 21% to 10% during the study. 'Father only' distress ranged from 7% to 15%, peaking at
30 months. Bereaved mothers who were distressed at 2 months reported significantly lower marital satisfaction at 30 months. CONCLUSIONS: At the couple level, the experience of a baby's death is multifaceted. Gender differences are common and partners' needs may change over time. Early recognition of these differences may facilitate longer-term adjustment for both partners.


Sansoni J, Giaquinto A.
**Parent's grief for the loss of a preterm child.**

The study takes into consideration the loss of a preborn child and the consequent grief of parents. The Italian nursing literature is quite poor on the subject while international literature show a variability of some phenomena particularly in the first three-five years from the loss. The present research, by a quantitative design and the Hogan bereavement conceptual framework, has considered parents since three years loss. A general socio demographic questionnaire, the Hogan Grief Reactions Checklist (HGRC), and the Beck Depression Inventory (BDI-II) have been utilized to collect data. The first instrument has been ad hoc formulated to enrich data, the second explores, by 61 items, 6 factors of reaction to the loss and the third, that consists of 21 groups of statements, measures the presence and the range of the depression. The HGRC has been validated for the Italian utilisation while the BDI-II has been validated in previous studies. Results, in accordance with the international literature, show a variability of different behaviours of explored phenomena for both questionnaires (Hogan's factors and depression). in the first three years of the grief. Parents suffer for the loss of a preborn child and their feelings of despair, disorganization, guilt, detachment, panic and personal growth change by the time from the loss.

Full-text available at: http://profinf.net/pro/ (not a U.S. Government site)

Toedter LJ, Lasker JN, Janssen HJ.
**International comparison of studies using the perinatal grief scale: a decade of research on pregnancy loss.**

The Perinatal Grief Scale (PGS) has been used in many studies of loss in pregnancy, including miscarriage, stillbirth, induced abortion, neonatal death, and relinquishment for adoption. This article describes 22 studies from 4 countries that used the PGS with a total of 2485 participants. Studies that report Cronbach's alpha for their own samples give evidence of very high internal consistency reliability. Evidence for the validity of the PGS is also reviewed, such as convergent validity seen in its association with measures of mental health, social support, and marital satisfaction. The standard errors of the means for the total scale and for the subscales reveal fairly consistent scores, in spite of very different samples and types of loss; computation of means and standard deviations for the studies as a whole permits us to establish normal score ranges. Significantly higher scores
were found in studies that recruited participants from support groups and self-selected populations rather than from medical sources, and from U.S. studies compared with those in Europe.

Full-text available at: http://www.informaworld.com/ (not a U.S. Government site)

Murray JA, Terry DJ, Vance JC, Battistutta D, Connolly Y.  
**Effects of a program of intervention on parental distress following infant death.**  

A longitudinal study of 144 parents (65 fathers, 79 mothers) was conducted to evaluate the effectiveness of a program of intervention in relieving the psychological distress of parents affected by infant death. Participants were assessed in terms of their psychiatric disturbance, depression, anxiety, physical symptoms, dyadic adjustment, and coping strategies. The experimental group (n = 84) was offered an intervention program comprising the use of specially designed resources and contact with a trained grief worker. A control group (n = 60) was given routine community care. Parental reactions were assessed at four to six weeks postloss (prior to the implementation of the intervention program), at six months postloss, and at 15 months postloss. A series of multivariate analyses of variance revealed that the intervention was effective in reducing the distress of parents, particularly those assessed prior to the intervention as being at high-risk of developing mourning difficulties. Effects of the intervention were noted in terms of parents' overall psychiatric disturbance, marital quality, and paternal coping strategies.

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