National Fetal and Infant Mortality Review Program and
Association of SIDS and Infant Mortality Programs

TITLE: Annotated bibliography on grief and bereavement following pregnancy loss, perinatal and infant death, UPDATED JANUARY 2009

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These annotated references are from 2001-2008 published literature. PubMed and CINAHL Plus were searched using the terms; grief, bereavement, perinatal loss, and infant death. Articles cited are categorized as research articles, practice recommendations, or systematic/literature reviews. The previous NFIMR bereavement bibliography contains earlier publications.

Research Articles

Aho, A.L., Tarkka, M.T., Astedt-Kurki, P., & Kaunonen, M. (2006). Fathers' grief after the death of a child. ***Issues in Mental Health Nursing*****, 27, 647-663.**

This study describes fathers' grief and life changes following the death of a child. Eight fathers completed a questionnaire with open-ended questions and an interview. Both positive and negative changes to the fathers' lives are reported. Mental health nurses should be aware that depression, other mental illness, unemployment, and financial problems were reported by some of the study participants.

Armstrong, D. (2001). Exploring fathers' experiences of pregnancy after a prior perinatal loss. ***MCN: The American Journal of Maternal Child Nursing*****, 26, 147-153.**

Phenomenological study of four men whose wives were currently pregnant subsequent to previous perinatal loss in the second or third trimester. Results of study indicate anxiety regarding outcome of current pregnancy with sense of heightened risk and need for vigilance. Themes identified and described. Study provides insight into paternal support during partner's pregnancy following loss.

Arnold, J. & Gemma, P. B. (2008) The continuing process of parental grief. ***Death Studies*****, 32(7), 658-673.**

A survey instrument that combines quantitative and qualitative measures was developed to increase understanding of parental grief. Grief themes result in a reformulation of parental grief.

Arnold, J., Gemma, P.B., & Cushman, L.F. (2005). Exploring parental grief: combining quantitative and qualitative measures. ***Archives in Psychiatric Nursing*****, 19, 245-255.**

This study explores parental grief on the death of a child for 74 respondents. Empirical support for the notion of grief as ongoing in the life of a parent whose child had died is reported in this study. The findings have significant implications for further clinical research supporting studies to explore commonalities in the experience of grieving families regardless of the cause of and time since the death of their child.

Barnes, G.L. (2008). Perspectives of African-American women on infant mortality. Social Work in Health Care, 47(3), 293-305.

The lived experience of 13 African-American women is reported. Experiences in stress and racism are constant factors and inseparable from their pregnancy experience. The women describe the importance of social support and the relationship with health care providers for positive pregnancy outcomes.

Barr, P. (2006). Relation between grief and subsequent pregnancy status 13 months after perinatal bereavement. *Journal of Perinatal Medicine*, 34, 207-211.
This longitudinal study explored the relationship between parental grief following perinatal bereavement and subsequent pregnancy. Sixty-three couples bereaved by stillbirth (n = 31) or neonatal death (n = 32) completed the Perinatal Grief Scale at one month and 13 months after the loss. Subsequent pregnancy status was also reported and examined in relation reported grief. The relation between grief and subsequent pregnancy differed with the sex of the parent and the particular facets of grief and pregnancy state being considered.

Barr, P. & Cacciatore, J. (2008). Personal fear of death and grief in bereaved mothers. *Death Studies*, 32: 445–460.
The study explored the relationship of fear of death to maternal grief following miscarriage, stillbirth, neonatal death, or infant/child death. The 400 women participants were recruited from the website, e-mail lists, and parent groups of an organization that supports bereaved parents. Fear of death had a statistically significant relationship with maternal grief.

Barr, P., & Cacciatore, J. (2008). Problematic emotions and maternal grief. *Omega (Westport)*, 56(4), 331-48.
The study was an empirical examination of the relation of personality proneness to "problematic social emotions"--envy, jealousy, shame, and guilt --to maternal grief following miscarriage, stillbirth, neonatal death, or infant/child death. The 441 women who participated in the study were enrolled from the website, e-mail contact lists, and parent support groups of an organization that offers information and support to bereaved parents. All four problematic emotions were positively correlated with maternal grief. Envy, jealousy, and guilt made significant unique contributions to the variance in maternal grief. Overall, time lapse since the loss and the four problematic emotion predispositions explained 43% of the variance in maternal grief following child bereavement

Baverstock, A., & Finlay, F. (2008). What can we learn from the experiences of consultants around the time of a child's death? *Child: Care, Health, and Development*, 34(6), 732-9.
This study describes the pediatric consultants (attending physician) approach to families during resuscitation and withdrawal of life support. Strategies to communicate with parents and individual coping is discussed.

Brosig, C.L, Pierucci, R.L., Kupst, M.J., & Leuthner, S.R. (2007). Infant end-of-life care: the parents' perspective. *Journal of Perinatology*, 27(8), 510-6.
At the end of life, parents (n=19) reported that honesty, empowered decision-making, parental care, environment, faith/trust in nursing care, physicians bearing witness and support from other hospital care providers are important to them. The study concludes that parents can cope with the end of life and health care providers can improve the process.

Buchi, S., Morgeli, H., Schnyder, U., Jenewein, J., Hepp, U., Jina, E., et al. (2007). Grief and post-traumatic growth in parents 2-6 years after the death of their extremely premature baby. *Psychotherapy and psychosomatics*, 76(2), 106-14.
Study assessed the grief and post-traumatic growth in 54 parents 2-6 years after the death of a premature baby (24-26 weeks' gestation) and to evaluate Pictorial Representation of Illness and Self-Measure (PRISM) in the assessment of bereavement. The death of an extremely premature infant is a painful long term mourning process. Mothers had more intense grief than fathers.

Capitulo, K.L. (2004). Perinatal grief online. *MCN: The American Journal of Maternal Child Nursing*, 29, 305-311.
Ethnographic methods are used to explore the culture of an online perinatal loss group. The group consisted of mothers and one grandmother who had experienced a perinatal loss through miscarriage, stillbirth, or neonatal death. 447 emails and participant feedback were analyzed. Women were from North America, Europe, Asia, and Australia particiated. Data were obtained through review of e-mails and feedback about the findings. The essence of the group's culture was 'Shared Metamorphosis.' Participants created a community and brought meaning to their losses. Joining the online perinatal loss group meant they would never be alone.

Cacciatore, J., & Bushfield, S. (2007). Stillbirth: the mother's experience and implications for improving care. *Journal of Social Work in End-of-Life Palliative Care*, 3(3), 59-79.
Results of this qualitative study suggest that stillbirth is emotionally complex with long-lasting symptoms of grief and significant struggles to find meaning. The findings also support the need for perceived psychosocial and spiritual support from professional caregivers, family, and friends. The women's own experiences argue for comprehensive approaches to support the grief and loss associated with stillbirth, and for the importance of social work involvement in both immediate and longer term interventions.

Chan, M.F., Lou, F.L., Arthur, D.G., Cao, F.L., Wu, L.H., Li, P., et al. (2008). Investigating factors associate to nurses' attitudes towards perinatal bereavement care. *Journal of Clinical Nursing,* 17(4), 509-18.
This study explored nurses' (n=169) in Hong Kong attitude towards perinatal bereavement care and to identify factors associate with such attitudes. Nurses identified their need for increased knowledge and experience, improved communication skills and greater support from team members and the hospital for perinatal bereavement care.

Chan, M.F., Wu, L.H., Day, M.C., & Chan, S.H. (2005). Attitudes of nurses toward perinatal bereavement: findings from a study in Hong Kong. *Journal of Perinatal & Neonatal Nursing*, 19, 240-252.
This study explored nurses' attitudes towards perinatal bereavement care, support, and training. A descriptive, correlational survey design was used and 169 nurses recruited from two local public hospitals. The majority of nurses held a positive attitude towards bereavement care, but attitudes towards bereavement support varied by demographics, practical experience, and training factors. Only about 29.6% had bereavement related education. The findings suggest that nurses' attitudes towards bereavement care are positively correlated with their bereavement care training needs and hospital policy support.

Côté-Arsenault, D., & Donato, K.L. (2007). Restrained expectations in late pregnancy following loss. *Journal of Obstetric, Gynecologic, and Neonatal Nursing,* 36(6), 550-7.
Pregnant women with a history of perinatal loss completed a pregnancy calendar of experiences. A thematic analysis indicated increased anxiety as due date approached. Clinicians can have a positive impact on women by discussing their feelings during pregnancy.

Cote-Arsenault, D., Bidlack, D., & Humm, A. (2001). Women's emotions and concerns during pregnancy following perinatal loss. *MCN: The American Journal of Maternal Child Nursing*, 26, 128-134.
Women in two hospital based support groups were interviewed. Seventy-three women provided demographic information, described their feelings after pregnancy loss, and identified concerns during the subsequent pregnancy. Content analysis of the responses revealed that the most frequently used descriptor was 'anxious,' followed by 'scared' and 'nervous.' During post-loss pregnancy, the top five concerns were losing another baby, overall health of baby, emotional stability of self, impact of another loss on the future, and lack of support by others.

DiMarco, M.A., Menke, E.M., & McNamara, T. (2001). Evaluating a support group for perinatal loss. *MCN: The American Journal of Maternal Child Nursing*, 26, 135-140.
A convenience sample of 121 parents completed a mail survey about the impact of a support group for parents grieving a perinatal loss. Sixty-seven of the parents had attended at least one support group meeting and 54 had not attended any meetings. There was no significant difference between the two groups on a quantitative measure of grief. However, qualitative responses indicated that the support group was helpful to those who had attended. Helpful supports are identified.

Dyregrov, K. (2004). Bereaved parents' experience of research participation. *Social Science & Medicine*, 58, 391-400.
This study evaluated the perceived stress experienced by bereaved participating in research (n=232). These data are from a nationwide, three-phase study in Norway among parents who had lost their child by suicide, SIDS, and accidents. All parents reported a positive experience with participation and none regretted participating. The positive experience was linked to being allowed to tell their complete story. Many interviewees reported that it was painful to talk about the loss. Regression analysis showed that being a woman and high levels of psychic distress were most important predictors of a painful interview experience.

Dyregrov, K., Nordanger, D., & Dyregrov, A. (2003). Predictors of psychosocial distress after suicide, SIDS and accidents. *Death Studies*, 27, 143-165.
This study compared the outcome and predictors of psychosocial distress in 232 parents bereaved by sudden unexpected death of their child (suicide, sudden infant death syndrome and child accident). The similarities between the samples on outcome and predictors was striking. One and a half years after the loss, 57-78% of the survivors scored above the cut-off levels for traumatic grief reactions. Survivors of suicide and accidents had significantly greater subjective distress than the survivors of SIDS. Self-isolation was the best predictor of psychosocial distress in all three samples. Sudden and traumatic death in general appears to be a factor associated with post-traumatic reactions and complicated mourning.

Engler, A.J., Cusson, R.M., Brockett, R.T., Cannon-Heinrich, C., Goldberg, M.A., West, M.G., & Petow, W. (2004). Neonatal staff and advanced practice nurses' perceptions of bereavement/end-of-life care of families of critically ill and/or dying infants. *American Journal of Critical Care*, 13, 489-498.
This study explored neonatal nurses' perceptions of bereavement/end-of-life care of families of critically ill or dying infants. A total of 190 nurses from 125 hospitals completed a mail survey. The respondents were comfortable with many aspects of bereavement/end-of-life care. Comfort and roles scores correlated significantly with number of years as a neonatal intensive care nurse. The nurses agreed about many important aspects of their roles with patients' families, especially the importance of providing daily support to the families. Most respondents identified caring for a dying infant, the actual death of an infant, and language or cultural differences as influential factors in the level of their involvement with families. The implications for nurse education and training are discussed.

Flenady, V., & Wilson, T. (2008). Support for mothers, fathers, and families after perinatal death. *Cochrane Database of Systematic Reviews*, 23(1), CD000452.
Authors independently searched for controlled trials and none were found. Authors conclude that currently insufficient information is 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.

Glaser, A., Bucher, H.U., Moergeli, H., Fauchere, J.C., & Buechi, S. (2007). Loss of a preterm infant: psychological aspects in parents. *Swiss Medical Weekly*, 137(27-28), 392-401.
This qualitative study interviewed 10 mothers and 9 fathers at three points after the loss (hospitalization, 6 months, 3.5 to 6.5 years). Parents were interviewed regarding their emotional, cognitive, physical and social experience following the death. These parents had the psychological strength to live normally again and professionals can play an important role in supporting them. Some parents require additional help to overcome the loss.

Gold, K.J., Dalton, V.K., & Schwenk, T.L. (2007). Hospital care for parents after perinatal death. *Obstetrics and Gynecology*, 109(5), 1156-66.
This study reviewed parent experiences with hospital care following a perinatal death. Results were compiled on five aspects of recommended care: 1) obtaining photographs and memorabilia of the deceased infant, 2) seeing and holding the infant, 3) labor and delivery of the child, 4) autopsies, and 5) options for funerals or memorial services. Sixty eligible studies with over 6,200 patients were reviewed. In general, parents reported appreciating time and contact with their deceased infant, being given options about labor, delivery, and burial, receiving photographs and memorabilia, and having appropriate hospital follow-up after autopsy. Some parents report limited choices and inadequate communication. Authors suggest increasing parental choice in areas specified.

Gold, K.J., Kuznia, A.L., & Hayward, R.A. (2008). How physicians cope with stillbirth or neonatal death: a national survey of obstetricians. *Obstet Gynecol*, 112(1), 29-34.
A total of 1,500 randomly selected U.S. obstetricians were mailed a self-administered survey about their experiences and attitudes in dealing with perinatal death. Eight hundred four physicians completed the entire survey. Perinatal death has a profound effect on the

delivering obstetrician. Improved bereavement training may help obstetricians care for grieving families but also cope with their own emotions after this devastating event.

Hasui, C., & Kitamura, T. (2004). Aggression and guilt during mourning by parents who lost an infant. *Bulletin of the Menninger Clinic*, 68, 245-259.
This study examined aggression and guilt in parents mourning the loss of an infant. The authors conducted in-depth interviews with 38 mothers and fathers. These parents reported feelings of strong irrational guilt, aggression, and hesitation toward others. Mourners did not lose their sense of reality, continued to do daily chores, and kept taking care of others.

Hsu, M.T., Tseng, Y.F., Banks, J.M., & Kuo, L.L. (2004). Interpretations of stillbirth. *Journal of Advanced Nursing*, 47, 408-416.
This ethnographic study explored the interpretation of twenty Taiwanese mothers' to their pregnancy loss. The women had a stillbirth at 20 weeks or greater. The major themes that emerged included a loss of control, broken dreams, shattered self, and the feeling that 'something is wrong with me.' The Taiwanese women also reported a sense of personal failure in maternal identity and the female cultural role. Talking about the death and expressing grief are some of the culturally-bound taboos in this population. The authors recommend that nurses talk with the mothers to help them deal with the death. However, knowledge of their cultural beliefs is necessary to effectively support these mothers.

Hughes, P., Turton, P., Hopper, E., & Evans, C.D.H. (2002). Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: a cohort study. *The Lancet*, 360, 114-118.
Sixty five women pregnant after a stillbirth and 60 matched controls completed outcome measures for depression, anxiety, and post-traumatic stress disorder in pregnancy and one year after the next birth. Authors report that for some parents, contact with the stillborn infant was associated with worse outcomes. The authors state that failure to see and hold the dead infant does not have an adverse effect on parent mourning.

> This article generated very critical letters to the editor. The study is limited by sample size and generalizability. The findings have NOT been validated by any other studies. Two additional articles (Haas F. Bereavement care: seeing the body. Nurs Stand. 2003. 17(28):33-7 and Hughes P, Riches S. Psychological aspects of perinatal loss. Curr Opin Obstet Gynecol. 2003. 15(2):107-11) make practice recommendations based on data from this flawed article. JS

Jind, L. (2003). Parents' adjustment to late abortion, stillbirth or infant death: the role of causal attributions. *Scandinavian Journal of Psychology*, 44, 383-394.
This study explored the attributional processes and the effects of various causal attributions on post-traumatic symptomatology among 110 parents who had lost an infant. Longitudinal data were collected over 12 months. One to four weeks post-loss, approximately half of the parents did not report blaming anyone for the death. Attributions (blame) to oneself, others, or God were positively and significantly associated with numerous post-traumatic symptoms. The results are discussed with reference to other studies dealing with the effect of attributions on subsequent adjustment among victims of trauma.

Kavanaugh, K., & Hershberger, P. (2005). Perinatal loss in low-income African American parents. ***Journal of Obstetric, Gynecologic, and Neonatal Nursing*****, 34, 595-605.**
These authors examined the lived experience of low-income African American parents following a perinatal or neonatal loss. Based on interviews with 23 parents, four major themes emerged: recognizing problems and responding to the loss, dealing with stressful life events, creating and cherishing memories, and living with the loss. Parents reported that stressors such as the death of a close family member and undesirable employment occur before, during, and/or after the pregnancy loss. The stressors contributed to women's reported difficulty identifying or responding to symptoms of pregnancy complications. Some mothers and fathers described feelings of racism from the medical system. They also reported not understanding all the burial options offered.

Keesee, N.J., Currier, J.M., & Neimeyer, R.A. (2008). Predictors of grief following the death of one's child: the contribution of finding meaning. ***J Clin Psychol,*** **64(10), 1145-63.**
Parents (157) whose child had died completed bereavement questionnaire. Results showed that the violence of the death, age of the child at death, and length of bereavement accounted for significant differences in normative grief symptoms. Other results indicated that the cause of death was the only objective risk factor that significantly predicted the intensity of complicated grief. Sense-making emerged as the most salient predictor of grief severity, with parents who reported having made little to no sense of their child's death being more likely to report greater intensity of grief.

Kersting, A., Kroker, K., Steinhard, J., Ludorff, K., Wesselmann, U., Ohrmann, P., et al. (2007). Complicated grief after traumatic loss: a 14-month follow up study. ***European Archives of Psychiatry and Clinical Neuroscience*****, 257(8), 437-43.**
The traumatic loss of an unborn child after termination of pregnancy due to fetal malformation and/or severe chromosomal disorders in late pregnancy is a major life-event and a potential source of serious psychological problems for those women. Sixty-two women who terminated their pregnancy between 15-32 weeks gestation were compared to women with a healthy full term baby. Grief, posttraumatic stress, depression, anxiety and psychiatric disorders were evaluated 14 days, 6 months and 14 months after the event. Twenty-five percent of mothers had complicated grief following this major life event.

Kroth, J., Garcia, M., Hallgren, M., LeGrue, E., Ross, M., & Scalise, J. (2004). Perinatal loss, trauma, and dream reports. ***Psychological Reports*****, 94, 877-882.**
This study investigated correlations among dream characteristics and measures of trauma and perinatal bereavement as reported by women who experienced perinatal loss. Thirty-seven women were randomly selected from a perinatal support group and administered the Impact of Event Scale (IES), the Perinatal Grief Scale, and the KJP Dream Inventory. Results are discussed in terms of the role dreams may play in the grief-recovery process.

Lang, A., Goulet, C., & Amsel, R. (2004). Explanatory model of health in bereaved parents post-fetal/infant death. ***International Journal of Nursing Studies*****, 41, 869-880**.
This longitudinal study explored factors related to health in 110 bereaved couples. The study tested an explanatory model of health to identify the factors that contribute to attenuating or intensifying the deleterious consequences of the loss. Elements of the model included internal resources (hardiness), external resources (marital and social supports), and appraisal of the situation.

Lang, A., Goulet, C., & Amsel, R. (2003). Lang and Goulet Hardiness Scale: development and testing on bereaved parents following the death of their fetus/infant. ***Death Studies*****, 27, 851-880.**
This article describes the development and testing of the Lang and Goulet Hardiness Scale (LGHS). LGHS is a self-report instrument designed to measure hardiness in bereaved parents following the death of their fetus/infant. A validation study was conducted with 220 bereaved parents who had experienced the death of their fetus/infant 2 months earlier. Analyses indicate that the LGHS is a valid and reliable instrument for measuring hardiness and that it is sensitive enough to detect changes in the construct over time.

Lundqvist, A., Nilstun, T., & Dykes, A.K. (2003). Neonatal end-of-life care in Sweden: the views of Muslim women. ***Journal of Perinatal & Neonatal Nursing*****, 17, 77-86.**
This study explored Muslim women's views of neonatal end-of-life-care in Sweden. The authors conducted standardized interviews with 11 immigrant women of Muslim background. The interview included open-ended questions about care before birth, directly after birth and after the death of the infant. The women provided suggestions for improving care, such as being given sufficient information and receiving culturally sensitive care.

Lundqvist, A., Nilstun, T., & Dykes, A.K. (2002). Both empowered and powerless: mothers' experiences of professional care when their newborn dies. ***Birth,*** **29, 192-199.**
The purpose of this study was to examine mothers' experiences and perceptions of the care given to them at neonatal clinics. Sixteen mothers were interviewed two years after the death. The primary themes identified were feeling empowered and feeling powerless. All mothers felt both empowered and powerless. Feelings of empowerment emerged when the health care professionals not only saw the mother as an individual but also "saw through the mothers' eyes" and "felt with the mother's feelings". Feelings of powerlessness emerged when the mothers and the health care professionals perspective did not correspond.

McCoyd, J.L. (2007). Pregnancy interrupted: loss of a desired pregnancy after diagnosis of fetal anomaly. ***Journal of Psychosomatic Obstetrics and Gynaecology*****, 28(1), 37-48.**
This qualitative study reports on 30 intensive interviews with women during the process of prenatal diagnosis and decision to terminate the pregnancy. Contradictory societal norms further complicate the dilemma a woman faces. Recommendations for providers are included.

McCreight, B.S. (2008). Perinatal loss: a qualitative study in Northern Ireland. ***Omega*** **(Westport), 57(1), 1-19.**
This qualitative study uses a narrative approach based on in-depth interviews with 23 women attending pregnancy loss self-help groups in Northern Ireland. Women placed emotion in the center of their narrative. Support from professionals is important to mothers as they determine the meaning of their loss experience.

McCreight, B.S. (2004). A grief ignored: narratives of pregnancy loss from a male perspective. ***Sociology of Health & Illness*****, 26, 326-350**.
This study examined the experiences of men whose partner had experienced a pregnancy loss. Data were collected through observation and interviews with 14 men who attended pregnancy-loss self-help groups in Northern Ireland. Thirty-two midwives and nurses also

were interviewed to examine providers' attitudes toward bereaved fathers. The study uncovered several recurring themes among the bereaved men, including self-blame, loss of identity, and the need to appear strong and hide feelings of grief and anger. The findings underscore the need for hospital staff and the community at large to acknowledge male partner grief as being a valid response to the loss suffered.

Meert, K.L, Eggly, S., Pollack, M, Anand, K.J., Zimmerman, J., Carcillo, J., et al. (2007). Parents' perspectives regarding a physician-parent conference after their child's death in the pediatric intensive care unit. *Journal of Pediatrics*, 151(1), 50-5.
Audio taped interviews were conducted with 56 parents 3-12 months after the death of their child in a PICU. Only 13% scheduled a meeting and 59% wanted to talk to the intensive care physician. Topics that parents wanted to discuss included the chronology of events leading to PICU admission and death, cause of death, treatment, autopsy, genetic risk, medical documents, withdrawal of life support, ways to help others, bereavement support, and what to tell family. Parents sought reassurance and the opportunity to voice complaints and express gratitude. Parents seek to gain information and emotional support, and to give feedback about their PICU experience.

Moules, N.J., Simonson, K., Prins, M., Angus, P., & Bell, J.M. (2004). Making room for grief: walking backwards and living forward. *Nursing Inquiry*, 11, 99-107.
This study involves the examination of grief experiences with attention to troublesome or problematic beliefs that affect the extent of suffering in the bereaved. Data were obtained from a review of videotaped clinical interviews with families seen in the Family Nursing Unit at the University of Calgary, and were analyzed. Findings suggest that grief is an experience that is ongoing and changes in nature over time, but involves a continuing relationship with the deceased.

Nations, M.K. (2008). Infant death and interpretive violence in Northeast Brazil: taking bereaved Cearense mothers' narratives to heart. *Cad. Saúde Pública*, 24(10), 2239-2248.
This study critically examines the anthropological debate concerning "selective maternal negligence" as a relevant explanation for high infant mortality, based on an analysis of preexisting data in Northeastern Brazil. There was no evidence of maternal carelessness, detachment or negligence.

Neugebauer, R., & Ritsher, J. (2005). Depression and grief following early pregnancy loss. *International Journal of Childbirth Education*, 20, 21-24.
Perinatal Bereavement Scale and Center for Epidemiological Studies Depression Scale were administered to 304 women at 2 weeks, 6-8 weeks and 6 months following a spontaneous abortion (involuntary pregnancy loss). Results indicate that depression and grief constitute related but distinct reactions to loss. Women who were grief stricken were more likely to report depressive symptoms. Approximately 20% of women were grief-stricken at six to eight weeks and again at six months after loss. Depression was more common among nulliparous women and among women who did not want the pregnancy. Women who experienced quickening were more likely to be grief stricken.

Nikcevic, A.V., Kuczmierczykb, A.R., & Nicolaidesa, K.H. (2007). The influence of medical and psychological interventions on women's distress after miscarriage. *Journal of Psychosomatic Research*. 63, 283-290.

This prospective study examined the impact of medical and psychological interventions on women's distress after early miscarriage (10-14 weeks gestation). Women attended a routine scan and found to have a missed miscarriage. An intervention group of 66 women had medical investigations to ascertain the cause of miscarriage, and at 5 weeks after the scan, they all had a medical consultation to discuss the results of the investigations. Of this group, 33 received further psychological counseling. The women were compared to a control group of 61 women who received no specific post-miscarriage counseling. All participants completed pre/post-intervention measures and 4-month follow-up questionnaires. The scores on the outcome variables decreased significantly with time for all three groups. The intervention groups had a significantly greater decrease over time for levels of grief, self-blame, and worry. The authors conclude psychological counseling, in addition to medical investigation and consultation is beneficial in reducing a women's distress after a miscarriage.

Nuru-Jeer, A., Sominguez, T.P., Hammond, W. P. et al. (2009). "Its the skin you're in: African-American women talk about their experiences of racism. An exploratory study to develop measures of racism for birth outcome studies. ***Matern Child Health*** **J, 13, 29-39.**
Six focus groups with a total of 40 African American women described experiences during childbearing. Women reported experiencing racism throughout the lifecourse. This study recommends measurement of discrete, interpersonal experiences, including active/passive responses as they relate to birth outcome.

O'Leary, J. & Thorwick, C. (2006). Fathers' perspectives during pregnancy, postperinatal loss. ***Journal of Obstetric, Gynecological, and Neonatal Nursing*****, 35, 78-86.**
This phenomenological study explored the father's perspective during the experience of a pregnancy following perinatal loss. Ten fathers who had experienced a loss within the previous year and were currently with that partner in a subsequent pregnancy participated. Four main themes emerged: (1) the need to be recognized by others, (2) the disruption of daily lives by preoccupation with the pregnancy, (3) the inability to share their own anxiety and fear because they want to protect the mother, and (4) failure to seek support because of societal pressure to 'be strong' and the belief that 'men don't share.' Strategies are needed to assess and support fathers emotionally at the time of loss and in the subsequent pregnancy.

Pector, E.A. (2004). Views of bereaved multiple-birth parents on life support decisions, the dying process, and discussions surrounding death. ***Journal of Perinatology*****, 24, 4-10**.
This study assessed the experiences of bereaved multiple-birth parents regarding resuscitation and life-support decisions, the death process, and notification of death by health care professionals. Data were obtained from 71 parents via narrative e-mail survey. Results indicate that most life support decisions were collaborative. Most parents found meaning in holding their dying children. Many desired privacy, availability of symptom management, and family or clergy involvement. Photographs of multiples together were valued. Parents offered suggestions for compassionate death notification, which most felt should occur in person if parents are not present for the death. Respondents also valued clear, prompt discussion of the cause of death, and wanted the clinician available for later review of clinical events or decisions. Comment in: J Perinatol. 2004 Jan;24(1):2-3.

Price, S.K. (2008). Stepping back to gain perspective: pregnancy loss history, depression, and parenting capacity in the Early Childhood Longitudinal Study, Birth Cohort (ECLS-B). ***Death Studies*****, 32(2), 97-122.**
This article examined the relationships among pregnancy loss history, current maternal depressive symptoms, and mother-infant interaction in secondary data analysis of the ECLS-B (N=10,688). Depressive symptoms were consistent across racial groups. Multiple loss history was associated with slight increase in overall depressive symptoms. African-American women have more pregnancy losses. An important limitation is that the data do not allow for inferences specific to the type of loss, gestational age of fetus, time since loss, or whether the loss was spontaneous or induced. Findings from this population-based research contribute to a wider perspective regarding maternal response to reproductive loss that can inform future research and targeted bereavement support.

Säflund, K., Sjögren, B., & Wredling, R. (2004). The Role of Caregivers after a Stillbirth: Views and Experiences of Parents. ***Birth*****, 31, 132-137.**
The clinical role of the caregiver to parents in the event of a stillbirth is described by parents as important. One or both parents of 31 stillborn infants (28 weeks) were interviewed twice. Six major "qualities" were identified: support in chaos, support in meeting with and separating from the baby, support in bereavement, explanation of the stillbirth, organization of the care, and understanding the nature of grief. The authors recommend that the "qualities" identified here should be implemented in clinical care for bereaved parents who have experienced a stillbirth.

Seecharan, G.A., Andresen, E.M., Norris, K., & Toce, S.S. (2004). Parents' assessment of quality of care and grief following a child's death. ***Archives of Pediatric & Adolescent Medicine*****, 158, 515-520.**
This study examined aspects of bereavement for parents who experienced the death of a child, and compared these aspects by parent sex, type of death, and overall experience. A sample of 79 parents or guardians (59 child deaths) were interviewed a mean of 21.8 months after the child's death. Participants also completed standardized measures of grief and satisfaction with care. Scores for parent grief were high, as were scores for satisfaction with care. Levels of grief were similar for fathers and mothers, although mothers who experienced the sudden death of a child had somewhat more intense grief reactions than those whose child died of a chronic condition. Grief scores did not vary according to satisfaction with treatment. Comment in: Arch Pediatr Adolesc Med. 2004 Jun;158(6):590-1.Moules NJ, Simonson

Serrano, F., & Lima, M.L. (2006). Recurrent miscarriage: Psychological and relational consequences for couples. ***Psychology and Psychotherapy: Theory, Research and Practice*****, 79(4), 585 – 594.**
The objectives of this study are to describe the consequences of recurrent pregnancy loss for the couple's relationship, and explore gender differences in attitudes and grief intensity toward this kind of reproductive failure. Each member of 30 couples with at least 3 recurrent miscarriages answered a set of questionnaires. Results showed that men do grieve, but less intensely than their partners. Although the couple's relationship seemed to not be adversely affected by recurrent miscarriage, couples described sexual changes after those events. Grief was related to the quality of communication in the couple for women, and to the quality of sex life for men.

Smart, L.S. (2003). Old losses: a retrospective study of miscarriage and infant death 1926-1955. *Journal of Women & Aging,* 15, 71-91.
This qualitative study examined the childbearing-related losses of 16 elderly Caucasians (13 women and 3 men, aged 69-90). The inquiry focused on recollections of social support, grief at the time of loss, and current meaning attributed to the loss. Most respondents recalled feeling grief at the time of miscarriage, fetal death, or infant death, and most did not have lingering feelings of grief. Women who did not have grandchildren and who recalled insufficient social support appeared to be more vulnerable to feelings of lasting grief. A life course approach, which examines personal narrative in relation to ontological, generational, and historical time, fits with the interpretation given by elderly respondents to their childbearing losses.

St John, A., Cooke, M., & Goopy, S. (2006). Shrouds of silence: three women's stories of prenatal loss. *Australian Journal of Advanced Nursing*, 23, 8-12.
An exploratory qualitative study using mini-biographies (three women) was used to record the experiences and stories of three women. The stories revealed the tragedy, pain, and silence endured by these women, as they live with loss and grief. Common themes emerged including grief, isolation, anger, and self-blame in the face of their loss and subsequent full term pregnancy. The women give voice to current health care practices that may be modified to better support the needs of women who have suffered a prenatal loss.

Swanson, K.M., Conner, S., Jolley, S.N., Pettinato, M., & Wang, T. (2007). Contexts and evolution of women's responses to miscarriage during the first year after loss. *Research in Nursing and Health*, 30(1), 2-16.
Descriptions of 85 women's feelings about miscarriage at 1, 6, 16, and 52 weeks post-loss were inductively coded, rank-ordered, and clustered into 3 responses: healing, actively grieving, and overwhelmed. Women who were actively grieving or overwhelmed at 1 week experienced significantly less distress from 6 weeks on. Responses at 1 week differed with regards to those who had a history of perinatal loss or went on to experience negative life events or sexual distance after loss. One year responses differed based on post-loss pregnancy status, post-loss negative life events, or relationship difficulties their mate. Responses were not influenced by gestational age at loss or having other children.

Swanson, P.B., Pearsall-Jones, J.G., & Hay, D.A. (2002). How mothers cope with the death of a twin or higher multiple. *Twin Research*, 5, 156-164.
This study examined 66 bereaved mothers with at least one surviving multiple. For many, this contact was the first acknowledgement of their status as multiple birth mothers since their loss. The Beck Depression Inventory 2nd Edition (BDI) showed significant reduction in depression between the time of loss and interview. For mothers as a group there was a high correlation between current and retrospective BDI. Spiritual beliefs and finding meaning in loss were positively related to scores for adjustment and acceptance. Although traumatized, most mothers accommodated their losses meaningfully in their lives. Recommendations for supporting mothers are included.

Trulsson, O., & Rådestad, I. (2004). The silent child mothers' experiences before, during, and after stillbirth. *Birth*, 31, 189-195.
This study explored mothers' experiences from diagnosis of uterine death to stillbirth. Twelve women were interviewed about their experience. Interviews took place 6 to 18

months after the delivery and were analyzed using phenomenological methodology. The women reported experiences such as premonition, difficulty communicating their worry, cessation of verbal communication with staff, feelings of unreality and numbing, and a desire to get rid of the dead child immediately. Many women felt they were not respected as a human being during the process of diagnosing the intrauterine death. The findings suggest that caregivers should not induce delivery immediately after the diagnosis of intrauterine death. Time may be needed to obtain medical information about the delivery and to prepare the mother for meeting with and saying goodbye to her baby.

Tuffrey, C., Finlay, F., & Lewis, M. (2007). The needs of children and their families at end of life: an analysis of community nursing practice. ***International Journal of Palliative Nursing*¸ 13(2), 64-71.**
There are few studies in the literature describing or evaluating the workload of pediatric community nurses prior to and following the death of a child with a non-oncological life-limiting disorder is assessed. Pediatric community nurses coordinate with a wide range of professionals and organizations and the nature of their workload at the end of life is often hidden.

Van, P. (2001). Breaking the silence of African American women: Healing after pregnancy loss. ***Health Care for Women International*, 22, 229-243.**
African American women face rates of pregnancy and infant loss twice those of European American women and members of other ethnic and racial groups. The grief following such losses may be unrecognized. This article explores the experiences of 10 African American women grieving the loss of a pregnancy or infant. It focuses on the strategies these women used to heal after the loss. Data were collected through interviews and analyzed using grounded theory methodology. The healing strategies used by the participants reflect predominately inner and instinctive processes, resources, and remedies. Culturally appropriate strategies for health care interventions and research activities are offered.

Van, P., & Meleis, A.I. (2003). Coping with grief after involuntary pregnancy loss: Perspectives of African American women. ***Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 32, 28-39.**
This study explored the coping strategies used by African American women following miscarriage, ectopic pregnancy, fetal death, or stillbirth. The sample consisted of 20 women with a history of involuntary pregnancy loss (IPL) during the previous 3 years. Data were collected through semi-structured interviews and analyzed using grounded theory methods. The women's responses to their IPL were grouped into four areas. They coped with personal reactions to the loss, the reactions of others, memories of the baby, and subsequent pregnancies. These women used inner resources to develop self-help strategies for coping with reactions following IPL. Educating women to recognize grief responses after IPL and to manage these responses effectively may prevent adverse outcomes to their physical and mental health. A culturally sensitive framework of clinical assessment and intervention for African American women experiencing IPL is presented.

Vance, J.C., Boyle, F.M., Najman, J.M., & Thearle, M.J. (2002). Couple distress after sudden infant or perinatal death: a 30-month follow up. ***Journal of Paediatric Child Health*, 38, 368-372.**
Patterns of anxiety, depression, and alcohol use in couples following stillbirth, neonatal death or sudden infant death syndrome were examined in a 30-month prospective study.

Standardized interviews at 2, 8, 15 and 30 months post-loss were completed for 138 bereaved and 156 non-bereaved couples. At all interviews, one partner of a bereaved couples was significantly more likely than non-bereaved couples to be distressed. 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. At the couple level, the experience of a baby's death is multifaceted. Gender differences are common and partners' needs may change over time.

Wells, N., Sbrocco, T., Chiao-Wen, H., et al. (2008). The impact of nurse case management home visitation on birth outcomes in African-American women. Journal of the National Medical Association, 100(5), 547-552.
A retrospective cohort study was conduction using existing data from 109 mothers enrolled in a home visiting program. Antepartum home visits appeared to be protective against preterm delivery and could contribute to reducing racial disparities in infant mortality.

Wheeler, S.R., & Austin, J.K. (2001). The impact of early pregnancy loss on adolescents. *MCN: The American Journal of Maternal Child Nursing*, 26, 154-159.
This cross-sectional study examined the impact of pregnancy loss in teenage girls. The sample consisted of 164 adolescents, aged 13-19 years, divided into four groups: never pregnant (n=62), pregnant (n=50), early pregnancy loss (n-31) and early pregnancy loss and subsequent pregnancy (n=21). The groups were compared on measures of self esteem, depression, satisfaction with family, grief responses, and perception of life changes. Adolescents with very early pregnancy loss (abortion or miscarriage) were more likely to be depressed. Grief responses (physical, emotional, social, cognitive) also were significant for the pregnancy loss group.

Widger, K., & Picot, C. (2008). Parents' perceptions of the quality of pediatric and perinatal end-of-life care. *Pediatric Nursing*, 34(1), 53-8.
The purpose of this study was to describe the quality of care provided before, at the time of, and following the death of an infant, child, or adolescent from the perspective of the parent, using a newly developed survey. Thirty-eight families were contacted 12-24 months after the death. Survey questions asked parents to report on the care received rather than rate how satisfied they were with care. Every parent could relate a particular event or person who had a negative impact on their experience. Parents identified communication between health professionals, relationships with health professionals, care at the time of death, and bereavement follow-up as problematic areas. There is room for improvement in the end-of-life care provided to infants, children and youth, and their families.

Wijngaards-de Meij, L., Stroebe, M., Schut H., Stroebe W., van den Bout, J., van der Heijden, P.G., et al. (2007). Patterns of attachment and parents' adjustment to the death of their child. *Personality and Social Psychology Bulletin*, 33(4), 537-48.
The impact of adult attachment on psychological adjustment among bereaved parents and the mediating effect of relationship satisfaction were examined among a sample of 219 couples of parents. Data were collected from parents at 6, 13, and 20 months after loss. Multilevel regression analysis enabled exploration of both individual as well as partner attachment as predictors of grief and depression. Results indicated that the more insecurely attached parents were (on both avoidance and anxiety attachment), the higher the symptoms of grief and depression. Marital satisfaction partially mediated the association of anxious attachment with symptomatology. Contrary to previous research findings, avoidant attachment was associated

with high grief intensity. These findings challenge the notion that the avoidantly attached are resilient.

Wijngaards-de, M., Stroebe, M., Stroebe, W., Schut, H., Van den Bout, J., Van Der Heijden, P.G, et al. (2008). The impact of circumstances surrounding the death of a child on parents' grief. *Death Studies*, 32(3), 237-52.
A longitudinal study was conducted among bereaved parents to examine the relationship between the circumstances surrounding the death of their child and psychological adjustment. Two hundred nineteen couples participated at 6, 13, and 20 months post-loss. Examination was made of two categories of factors: those that were determined by the particular death circumstances (e.g., whether the parent was present at the death) versus those over which parents themselves could have influence (e.g., choice of cremation or burial). Results indicated that some but not all factors were related to adjustment over time. Importantly, the feeling of having said goodbye to the child and presenting the body for viewing at home were associated with lower levels of the parents' grief. Implications for supporting bereaved parents are discussed.

Wilson, R.E. (2001). Parents' support of their other children after a miscarriage or perinatal death. *Early Human Development*, 61, 55-65.
This study explores the way parents who have recently lost a baby support other children in the family. Data were collected through semi-structured interviews with eight families. Support parents provided to their children fell under three main headings: recognizing and acknowledging the child's grief, including the child in family rituals and keeping the baby alive in the family memory. There was some recognition by parents, in their longer-term support and the range of family activities, of continuing and changing bonds with the deceased baby rather than the severing of bonds

Practice recommendation articles

Badenhorst, W., & Hughes, P. (2007). Psychological aspects of perinatal loss. *Best Practice and Research Clinical Obstetrics and Gynaecology*, 21(2), 249-59.
Perinatal loss is a painful experience for mothers and fathers with the same pattern of symptoms. Article provides guidelines for follow up of parents and acknowledgement that subsequent pregnancy will be stressful.

Boyce, P.M., Condon, J.T., & Ellwood, D.A. (2002). Pregnancy loss: A major life event affecting emotional health and well-being. *Medical Journal of Australia*, 176, 250-251.
This article recommends that health practitioners provide comprehensive management following a pregnancy loss. Psychosocial support and follow-up counseling should be included. Practitioners are also encouraged to foster open discussion of the loss, including patients feelings of guilt and self-blame. Follow-up through six months is suggested with special attention to normal grief versus depression. Depressive illness will require specific treatment. Peer support is also suggested.

Callister, L.C. (2006). Perinatal loss: a family perspective. *Journal of Perinatal and Neonatal Nursing*, 20(3), 227-34.

Perinatal loss is a profound experience for childbearing families. Nursing interventions have been refined as research studies contribute information about the experience for families. Aspects of bereavement programs include helping to create meaning through the sharing of the story of parental loss, the facilitation of rituals associated with loss, the provision of mementos, sensitive presence, and the validation of the loss. Outcome evaluations of such interventions are recommended.

Carter, B.S. (2004). Providing palliative care for newborns. *Pediatric Annals*, 33, 770-777.
Community pediatricians and other clinicians can cooperate to provide an environment in the delivery room or NICU where palliative care can be integrated into patient and family care plans. The treatment goal may be obtaining a cure, prolonging life, or exclusively palliation and comfort until an expected death. Care should be consistent with the goals and preferences of the family, and respectful of their culture and faith traditions. Bereavement support recommended following an infant's death.

Capitulo, K.L. (2005). Evidence for healing interventions with perinatal bereavement. *MCN: The American Journal of Maternal Child Nursing*, 30, 389-396.
This article discusses the concept of perinatal grief and interventions. It provides a historical perspective on grief and support of bereaved parents. It concludes with recommendations for professionals caring for bereaved parents. Support should include validating parental grief, facilitating rituals, providing mementos, and letting the bereaved tell their stories. Author concludes that appropriate intervention can promote healing.

Chichester, M. (2005). Multicultural Issues in Perinatal Loss. *AWHONN Lifelines*, 9, 312-320.
Article discusses cultural sensitivity during perinatal loss and nursing implications. American Christian, African American, Amish, Judaism. Hispanic/Latino American, and Muslim traditions are included.

Clements, P.T., Vigil, G.J., Manno, M.S. et al. (2003). Cultural perspectives of death, grief, and bereavement. *Journal of Psychosocial Nursing*, 41, 18-26.
This article presents cultural considerations of grief in Latino, African American, Navajo, Jewish and Hindu groups derived from the NFIMR bulletin entitled *When an Infant Dies: Cross-cultural Expressions of Grief and Loss* (Shaefer, 1999).

Dyer, K.A. (2005). Identifying, understanding, and working with grieving parents in the NICU: Identifying and understanding loss and the grief response. *Neonatal Network*, 24, 35-46.
The admission of an infant to an NICU is highly stressful and overwhelming for parents of newborns. This article provides NICU professionals with general information about loss and the subsequent grief response, focusing on losses from sources other than death. It includes descriptions of common emotional and physical responses to help professionals recognize them in affected parents.

Geller, P.A., Psaros, C., & Kerns, D. (2006). Web-based resources for health care providers and women following pregnancy loss. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 35(4), 523-32.

This article highlights the use of Internet resources for specific content about pregnancy loss. A summary table is included for distribution to women and providers.

Gemma, P.B., & Arnold, J. (2002). Loss and grieving in pregnancy and the first year of life: A caring resource for nurses. White Plaines, NY: March of Dimes, 2002.
This nursing education module discusses grief associated with death during the perinatal through postnatal periods; heightens nursing awareness and understanding of parental and family grief; provides guidelines for nursing interventions and support mechanisms (#33-1547-01)

Jansen, J.L. (2003). A bereavement model for the intensive care nursery. *Neonatal Network*, 22, 17-23.
This article describes the model of care developed at the Duke University Medical Center Intensive Care Nursery. This bereavement program provides education and assistance to the intensive care nursery staff caring for the family at the time of death and for up to one year after the death.

Jonas-Simpson, C. & McMahon, E. (2005). The language of loss when a baby dies prior to birth: cocreating human experience. *Nursing Science Quarterly*, 18, 124-130.
Language families use during the loss of a baby prior to birth can intensify or enhance the grief experience. Authors offer comments on the meaning of words used at a time of grief and loss. The role of art as expressing loss is also explored by the authors.

Kavanaugh, K., & Moro,T. (2006). Supporting parents after stillbirth or newborn death: There is much that nurses can do. *American Journal of Nursing*, 106, 74-97.
Article describes strategies for nurses to support families during the tragedy of an infant death.

Kobler, K., Limbo, R., & Kavanaugh, K. (2007). Meaningful moments. *American Journal of Maternal Child Nursing*, 32(5), 288-95.
Rituals provide meaning and order to transitions, and symbolically connect people and events. The purpose of this article is to define the dimensions of a ritual as each pertains to perinatal and pediatric death, and provide concrete applications for use in clinical practice. The article recommends studies designed to explore the outcomes of using ritual.

Laing, I.A. (2004). Clinical aspects of neonatal death and autopsy. *Seminars in Neonatology*, 9, 247-254.
Requesting an autopsy of parents following the death of their child is stressful to parents. Neonatal autopsy rates have declined since 1990. These authors suggest that trust between parents and professionals is needed to reverse this trend. Empathetic support by health professionals following the death will lead to parents perception of committed health care providers. They may then be more likely to understand the importance of autopsy and to provide authorization.

Lamb, E.H. (2002). The impact of previous pernatal loss on subsequent pregnancy and parenting. *The Journal of Perinatal Education*, 11, 33-40.
This review of the literature identifies four recurring themes related to pregnancy following the death of a child: the effects of grief on the subsequent pregnancy, the notion of a

replacement child, parenting issues with the subsequent child, and coping mechanisms during the subsequent pregnancy.

Layne, L.L. (2006). Pregnancy and infant loss support: a new, feminist, American, patient movement. *Social Science & Medicine*, 62, 602-613.
Author argues that pregnancy loss groups are a unique patient movement. Initial efforts were to change ideas and feelings. Since the turn of the century, efforts have expanded to collaborate with physicians to work toward prevention. During the first phase (mid-1970s to mid-1990s), it was a women's movement, though it did not present itself as such. During the second phase, as physicians and researchers have become more involved, leadership has become somewhat less female-centric while at the same time, more initiatives are explicitly feminist.

Lightbody, T.K. (2005). Neonatal death: a grief intervention framework. *Illness, Crisis & Loss*, 13, 191-200.
Article reviews five intervention models of grief, starting with Lindemann (1944) through Worden (2001). Author recommends that care for each family should be individualized.

Mander, R., & Marshall, R.K. (2003). An historical analysis of the role of paintings and photographs in comforting bereaved parents. *Midwifery*, 19, 230-242.
This article reviews the historical role of paintings and photographs in comforting bereaved parents. While in the late 20th century the practice of taking photographs of the baby who had died became widely accepted, it has a long history. There are similarities between photographs currently being produced and the paintings produced in the 16th and 17th centuries. The paintings gave parents an opportunity for parents to include the child as part of the family.

Milstein, J.M., & Raingruber, B. (2007). Choreographing the end of life in a neonate. *American Journal of Hospice and Palliative Care*, 24(5), 343-9.
This article describes a theoretical approach to end of life care for a neonate. The approach is applicable to patients of all ages.

Romesberg, T.L. (2007). Building a case for neonatal palliative care. *Neonatal Network*, 26(2), 111-5.
This article describes the components of neonatal palliative care, identifies the challenges associated with the implementation of such programs, and proposes strategies for addressing these challenges.

Shaefer, J. (2003, 2007). *When an Infant Dies: Cross-Cultural Expressions of Grief and Loss II*. Washington, DC: American College of Obstetricians and Gynecologists.
These NFIMR educational bulletins describes a variety of cultures and a family's response to infant death. Publication is available online,
http://acog.org/departments/dept_notice.cfm?recno=10&bulletin=2866

Shaefer, J., Noell, D., & McClain M. (2002). *Fetal and Infant Mortality Review: A Guide for Home Interviewers*. National Fetal and Infant Mortality Review Program. Washington, DC: American College of Obstetricians and Gynecologists.

This publication provides FIMR home interviewers with technical skills and best practices necessary to conduct maternal interviews. Publication is available online, http://acog.org/departments/dept_notice.cfm?recno=10&bulletin=2431

Shear, K., & Shair, H. (2005). Attachment, loss, and complicated grief. *Developmental Psychobiology*, 47, 253-267.
A provisional model of bereavement, guided by Myron Hofer's question "What exactly is lost when a loved one dies?" is described. Insights about biobehavioral regulation from Hofer's animal studies of infant separation, research on adult human attachment, and new ideas from bereavement research are integrated.

Silver, R.M., Varner, M.W., Reddy, U, et al. (2007). Work-up of stillbirth: a review of the evidence. *American Journal of Obstetrics & Gynecology*, 433-444.
This paper reviews known and suspected causes of stillbirth including genetic abnormalities, infection, fetal-maternal hemorrhage, and a variety of medical conditions in the mother. Recommended diagnostic tests for stillbirth are discussed. The work of NICHD Stillbirth Collaborative Research Network is presented.

Wallerstedt, C., Lilley, M., & Baldwin, K. (2003). Interconceptional counseling after perinatal and infant loss. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 32, 533-542.
Historically, preconceptional health promotion has been recommended for all prospective parents to improve perinatal outcomes. Preconceptional health promotion and interconceptional counseling may be even more beneficial for parents who have had previous perinatal losses. Perinatal loss can be devastating, with long-term effects on subsequent pregnancies and children. A theoretical framework for interconceptional counseling after perinatal loss needs to be developed. Interconceptional counseling can give couples important information to improve outcomes, acknowledge fears and anxieties, evaluate genetic risks, facilitate grieving, and explore attachment and parenting issues.

Wing, A.E., & Carter, B.S. (2004). Once again, Vanderbilt NICU in Nashville leads the way in nurses' emotional support. *Pediatric Nursing*, 30, 471-472.
The ongoing program at Vanderbilt NICU provide ethical and emotional support to those working in the NICU. This article describes their pioneering program.

Woodroffe, I. (2006). Multiple losses in neonatal intensive care units. *Journal of Neonatal Nursing*, 12, 144-147.
The parental grief experience in the neonatal intensive care unit can be overwhelming. Staff's understanding of the parental grief process can facilitate better support of families.

Worden, J.W. (2001). *Grief counseling & grief therapy: A handbook for the mental health practitioner* (3rd ed). New York: Springer Publishing Company.
Worden presents his current thinking on bereavement drawn from extensive research, clinical work, and the best of the new literature. Four tasks of mourning and seven mediators of mourning are described. In this third edition, new information on special types of losses is included on children's violent deaths, grief and the elderly, and anticipatory grief as well as refinements to his basic model for mourning.

Workman, E. (2001). Guiding parents through the death of their infant. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 30, 569-573.
Supporting a family through the impending death of their infant challenges the health care team to create opportunities for the parents to complete the attachment process and begin to grieve. Even in the neonatal intensive-care unit, the family can be brought together with their child in activities that comfort and console, lay the foundation for positive memories, and initiate healing after the death of the infant. Interventions for grieving parents are described in this article.

Systematic/Literature Reviews

Badenhorst, W., Riches, S., Turton, P., & Hughes, P. (2006). The psychological effects of stillbirth and neonatal death on fathers: systematic review. *Journal of Psychosomatic Obstetrics and Gynaecology*, 27(4), 245-256.
This systematic review searched electronic databases from 1966-2005. Quality of methodology varied and generally described classic grief responses of fathers with less guilt than mothers. Fathers described experiences related to their social role and the potential conflict between grieving couples. Quantitative research reported symptoms of anxiety and depression, but at a lower level than mothers. Fathers may develop post-traumatic stress disorder following stillbirth.

Bartellas, E., & Van Aerde, J. (2003). Bereavement support for women and their families after stillbirth. *Journal of Obstetric and Gynaecolology Canada*, 25, 131-138.
Literature search of English-language articles about grief and bereavement following infant/perinatal death. Suggested interventions provided and success reported in preventing, recognizing, and treating psychological problems in family. Health care providers can help these families to build meaningful experiences and positive memories from their loss.

Brier, N. (2008). Grief following miscarriage: A comprehensive review of the literature. *Journal of Women's Health*, 17(3), 451-464.
Paper reports the need for more research but also identifies the importance of encouraging parents to discuss the loss and its meaning.

Brier, N. (2004). Anxiety after miscarriage: A review of the empirical literature and implications for clinical practice. *Birth*, 31, 138-142
This article reviews the literature on the risk of anxiety after miscarriage and effective interventions. The search revealed seven studies that examined level of anxiety after miscarriage (loss before 20 weeks gestation) and three that examined risk for particular anxiety syndromes. Results suggest that a significant percentage of women experience elevated levels of anxiety after a miscarriage up until about 6 months postmiscarriage, and they are at increased risk for obsessive compulsive and posttraumatic stress disorder. The author concludes that practitioners should screen for signs of anxiety as well as depression as part of routine care after a miscarriage. Interventions suggested.

Davies, R. (2004). New understandings of parental grief: literature review. *Journal of Advanced Nursing*, 46, 506-513.
This review uses an Anglo-American cultural perspective to trace changes in theoretical perspectives of parental grief in the last century. It starts with Freud’s analytic tradition of

breaking bonds with the deceased that is the basis of traditional models of the grief process and the tasks of grieving. Qualitative studies identify enduring bonds as a common phenomenon among parents learning to live with the death of their child. Newer models of parental grief include continued attachment as an integral part of process of honoring and remembering a dead child.

DeBackere, K.J., Hill P.D., Kavanaugh, K.L. (2008). The parental experience of pregnancy after perinatal loss. *JOGNN*, 37, 525-537.
Review of research literature on parental experience of pregnancy after a perinatal loss. Research based articles from 1997-2007 are included. Only 17 studies were identified. The majority of subjects are white, middle class. Depression and anxiety frequently observed in women during pregnancy following a loss. It is recommended that practitioners discussing pregnancy history with clients.

Gold, K.J. (2007). Navigating care after a baby dies: a systematic review of parent experiences with health providers. *Journal of Perinatology*, 27(4), 230-7.
This systematic review of more than 1100 English-language articles from 1966 to 2006 addressed fetal and early infant loss and extracted information about interactions with health providers. Interactions with health providers has profound effects on parents with perinatal losses. Grieving parents perceive many behaviors to be thoughtless or insensitive. Physicians and nurses may benefit from increased training in bereavement support.

Harvey, S., Snowdon, C., & Elbourne, D. (2008). Effectiveness of bereavement interventions in neonatal intensive care: a review of the evidence. *Seminars in Fetal and Neonatal Medicine*, 13(5), 341-56.
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.

Hutti, M.H. (2005). Social and professional support needs of families after perinatal loss. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 34, 630-638.
This author reviews the literature on perinatal loss. Specific recommendations are made for nursing care of these families.

Kain, V.J. (2007). Moral distress and providing care to dying babies in neonatal nursing. *International Journal of Palliative Nursing*, 13(5), 243-8.
Moral distress in nursing is a prevalent theme in the literature. This issue has not been investigated by empirical research in the emotionally and ethically sensitive area of providing care to dying babies. Moral distress occurs when nurses are prevented from translating moral choices into moral action. The response to moral distress is anger, resentment, guilt,

frustration, sorrow and powerlessness. If not addressed, self-worth may be jeopardized, affecting personal and professional relationships. A review of the literature was conducted to explore moral distress in neonatal nursing when providing care to dying babies. This literature review provides a basis for the direction of further research and hypothesis testing. Further focused research is necessary to clarify the significance of moral distress for neonatal nurses caring for dying babies.

Lok, I.H., & Neugebauer, R. (2007). Psychological morbidity following miscarriage. *Best Practice and Research Clinical Obstetrics and Gynaecology*, 21(2), 229-47.
Emerging evidence has suggested that miscarriage could be associated with significant and possibly enduring psychological consequences. As many as half of women suffer some form of psychological morbidity up to one year after the loss. Elevated anxiety and depressive symptoms are common, and major depressive disorder has been reported in 10-50% after miscarriage. Risk factors are identified. While studies have highlighted that psychological follow-up was highly desired by miscarrying women, and that psychological intervention was potentially beneficial, there is a substantial lack of randomized controlled intervention studies in this area.

Stratton, K. & Lloyd, L. (2008). Hospital-based interventions at and following miscarriage: Literature to inform a research-practice initiative. *Australian and New Zealand Journal of Obstetrics and Gynecology*, 48: 5–11.
Literature review used to determine evidenced-based guidelines for hospital based services following a miscarriage. Services at time of delivery is well documented in the literature. Post discharge efficacy has not been studied in detail. Further research is needed to establish the impact of follow-up care after miscarriage.

Terhaar, M. & Shaha, M. (2006) Palliative approach to perinatal and neonatal care. *eNeonatal Review*, 3(11).
http://www.hopkinscme.edu/ofp/eneonatalreview/Newsletters/0706.pdf
ePublication provides a review of articles related to palliative care perinatal and neonatal patients.