TITLE: Annotated bibliography on grief and bereavement following pregnancy loss, perinatal, and infant death, UPDATED JANUARY 2015.

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These annotated references are from 2010-1014 published literature. PubMed, CINAHL Plus, and PsycINFO were searched using the terms: grief, bereavement, perinatal loss, infant death, and culture. Articles are cited as research articles, practice recommendations, or systematic/research reviews. The previous NFIMR bereavement bibliography contains earlier publications.

Research Articles

This qualitative study's primary aim was to examine whether women experiencing grief after a miscarriage react similarly to those that accompany general grief in the Swedish population (n=25). The authors utilized the Bonanno general grief theory, which includes five aspects of the grief process: cognitive disorganization, dysphoria, health deficits, disrupted social and occupational functioning and positive aspects of bereavement.
Content analysis of transcribed conversations with women four weeks after a miscarriage showed that women with miscarriage fulfill the criteria for having normal grief as defined by Bonanno’s taxonomy. The results showed no differences in intensity of grief as it pertained to parity, age, and number of past miscarriages. Support and opportunity for expression should be provided to women following a miscarriage as their grief is as intense as general grief experienced after any type of death.

This longitudinal qualitative study examined the mother’s experience of peer support in an Internet discussion group for mothers that experienced a death of a child. The aim was to describe experiences mothers had in an online discussion group. The main themes of the analysis were emotional support, informational support, and support through communality. The discussion forum allowed mothers to share their experiences and feelings and to receive support from those experiencing similar emotions. The limitation of this qualitative study is the small number of subjects - a total of four mothers provided consent.

This cohort study aims to use the Actor-Partner Interdependence Model (APIM) of data analysis to examine shame and guilt-proneness actor (intrapersonal) and partner (interpersonal) relationships in couples 13 months after a perinatal loss (n=63). The actor-partner relationships of chronic shame (Personal Feelings Questionnaire 2), situational shame (Test for Self-Conscious Affect-2), and survivor guilt and omnipotence guilt (Interpersonal Guilt Questionnaire-67) to grief (Perinatal Grief Scale-33) were explored. The results show a correlation between self-consciousness and grief is larger in men compared to women. Chronic shame has a significant intrapersonal relationship with grief in both women and men, whereas survival guilt has an interpersonal relationship in men. The practice recommendation is for bereavement services to address shame and guilt, tending to both sexes and how they handle loss.


This qualitative study aims to explore unique experiences of same gendered couples after the loss of a child. Snowball sampling was used and six participants self-identifying as lesbians agreed to participate in in-depth interviews. The results of the study show that lesbian parents grieve similarly to heterosexual couples after a loss. One unique difference is that lesbian participants felt more disenfranchised grief due to lack of appropriate social support. The limitation of this study is that these results cannot be generalized to the entire gay and lesbian community due to lack of up to date supporting studies. Nevertheless, it provides an insight into an increasingly relevant topic.


This cross-sectional study aims to describe and compare nurses’ attitude toward perinatal bereavement care across three Asian cities and factors associated with these attitudes (n=573). It was found that nurses’ attitudes differ across the three cities: Hong Kong, Singapore, and Jinan. The attitudes towards perinatal bereavement relate to position and past experiences in handling grieving parents, irrespective of the city the nurses practiced in. Positive attitudes were associated with informed hospital policy and training in bereavement care. The limitations include limited sample size from each city and lack of information about how patients perceived nurses.

The retrospective study examined the impact of pregnancy loss on subsequent pregnancy (n=584). Having a pregnancy loss was significantly associated with higher rates of emotional issues during the most recent pregnancy. Additionally, women were also more likely to report sadness and low mood in subsequent pregnancy. Inquiring about and acknowledging prior pregnancy loss during subsequent pregnancies is crucial to planning interventions and offering services to the expectant mother.


This qualitative, descriptive study (n=19) explored the experience of healthcare professionals in situations of perinatal loss and grief. The study included nurses, nurse-midwives, nurse auxiliaries, and obstetricians. The predominant theme was that healthcare professionals viewed their primary duties in time of a loss to be medically oriented as opposed to emotionally supportive. The lack of knowledge and skills to deal with perinatal loss on the providers’ end was identified as the main reason for unsuitable attitudes and variation in response to the grieving families. The recommendation is to offer training programs to equip medical staff with the proper skills and knowledge on how to approach loss and provide care in a holistic manner.


This qualitative descriptive study described the experiences of parents receiving and coping with a lethal fetal diagnosis in pregnancy. Five families were interviewed. The main theme was that parents demonstrated love for their baby and determination to find meaning and honor their baby's life. The interview data suggests healthcare providers should recognize the need for parents to be treated like real parents and acknowledge their baby as a person.


This study surveyed 15 women who were pregnant with a subsequent pregnancy following a perinatal loss. The authors distributed the psychometric screening tests to the subjects, including Perinatal Grief Scale (PGS), Duke Depression Inventory (DDI), Generalized Anxiety Disorder 7 (GAD), and Hoge Scale for Intrinsic Religiosity (IR). Many women in the sample scored high on the screening tests ranging from 60% on the PGS to 17% on the GAD. The results suggest that women who conceive following a loss (mean elapsed time
27 months) possess high levels of grief and anxiety during a subsequent pregnancy. The study is limited due to a low sample size.


The research study conducted analysis on questionnaire data collected as part of the Lehigh Valley Perinatal Loss Project. The responses (n=103) were evaluated for impact of initial religious practices and beliefs on the course and severity of grief after a perinatal loss. Agreement to statements of religiosity, positive religious coping, nor frequency of attendance of religious services was predictive of scores on the Perinatal Grief Scale. Religious struggle, negative religious coping, and continued attachment to the baby were associated with more severe grief. Inquiry about religious coping by medical professionals may help identify those suffering from pathological grief after a loss.


This qualitative study collected grief group participants’ recommendations for an ideal or good grief group. The sample consisted of 21 adults that lost a close person. The majority (67%) lost a child or a partner (14%). Participants attended grief groups with others that had a similar loss or heterogeneous grief groups accepting of anyone who has experienced any type of loss. The data was collected through face-to-face interviews. The results show that participants value information and explanations before and at the start of the group session. They stressed the importance of knowing the aim, structure and organization, and possible effects and limitations of group participation. Participants stated that strong leadership is necessary for a good grief group, emphasizing flexible, democratic, and facilitating leadership. Lastly, participants did not protest open group discussion but some felt comfortable being able to prepare to a certain degree prior to starting a group session.


This qualitative study aims to understand the parental response to perinatal death by describing the experiences of the families involved. The authors used a questionnaire and semi-structured interviews with 12 parents who were part of a support group. Two categories of death were explored: deaths during neonatal palliative care and deaths relating to pregnancies with multiples. These categories were used because pregnancies with multiples were among the most common reasons for specialized consultation during a follow-up after a premature birth. The results show that knowing palliative care was available helped parents feel more supported. Interestingly, parents who chose palliative care were more educated and arrived at their decision quicker. Half of the parents in the study felt that their decisions and feelings were not respected in the medical setting. The
authors recommend that healthcare professionals make an effort to understand the parents’ feelings towards neonatal death in order to provide the best care.


This study was a mail survey to 1500 US obstetricians selected through simple random sampling from the American Medical Association. The response rate was at 54% with 804 physicians completely filling out the survey. The aim was to solicit opinions of obstetricians about their recommendations for optimal timing of subsequent pregnancy after stillbirth. Two-thirds of the respondents endorsed a wait time of less than 6 months for parents who desired another pregnancy after a loss. Short interpregnancy intervals (<6 months) are associated with increased risk of poor birth outcomes. This is particularly relevant to parents that experience a prior loss because they may be considered high risk. Bereaved parents may increase their already higher risk for poor outcomes if their obstetrician is part of the majority documented in this survey.


This qualitative study (N=13) aims to identify how mothers are coping after a loss of a child in their own words. The authors used semi-structured interviews and phenomenological approach to gather themes from their interaction with the subjects. The time since death of the child ranged from 1 to 40 years with a mean of 10 years. The two most common themes expressed were the continuation of the bond between the child and mother and ambivalence to personal mortality. Some subjects expressed suicidal ideation; however, if they had children at home they felt as though they could not end their life because their other children depended on them. The ambivalence or expression of suicidal ideations calls for a need for better social services.


The aim of this experimental study was to introduce a protocol that would ensure emotional support to assist women in recovery after a loss prior to 20 weeks gestation. A total of 40 women participated in the study; 20 were randomly assigned to a group in which the protocol was used and 20 received the current standard of care. The two groups were then compared on levels of grief, coping, and despair 2 weeks after the miscarriage using the Perinatal Grief Scale. Both grief and coping ability did not differ between two groups; however, women in the experimental group scored significantly lower in levels of despair. Participants in the intervention group provided positive feedback about their care and the staff perceived the protocol as helpful. The strength of this study lies in its design with randomized assignment and the nature of the intervention. The limitation of this study is
that the authors did not account for other factors that may alleviate despair such as social support.


This qualitative, longitudinal analysis of 13 bereaved couples focused on identifying categories of ambiguity and disenfranchised grief. Parents expressed concerns about the viability of pregnancy and worry about ominous signs such as lack of movement. Both mothers and fathers felt that healthcare professionals did not adequately explain the physiological changes the body will go through during a loss and what to do with the baby’s remains. Parents felt that no one discussed their wishes regarding their customary mourning rituals and the remains were treated more like “biomedical waste.” Lastly, the participants had a difficult time sharing the news of a loss with family, friends, and acquaintances. It was difficult to share the news because the parents were not exactly sure how to define their loss, was it a baby? Was is ‘a specimen’? Were they parents?


This qualitative study used the life story interview approach with 19 mothers of Maori SIDS infants to illustrate the social and personal environments in which SIDS most often occurs. The authors extracted two main themes: childhood recollection and experiences and adult life experiences. The themes suggested that women bore large responsibility for family functions early in life (e.g., child care), personal history of abuse, and lack of support for educational goals. Additionally, women brought up struggle with economic resources. Some subjects mentioned that experiencing the death of their child reminded them of and exacerbated past life traumas. The current approach to improve SIDS death rates is to address modifiable risk factors such as behavior and health practices. The authors argue that addressing nonmodifiable risk factors such as socioeconomic status would aid in decreasing SIDS deaths because the modifiable risk factors such as smoking are closely related to nonmodifiable ones such as socioeconomic status.


This qualitative study analyzed responses of an online survey administered to participants via SurveyMonkey (N=60). The participants were recruited through various LGBT email lists and newsletters in the UK, USA, Canada and Australia. Majority of respondents conceived using donor sperm and experienced at least one loss. The study aim is to explore the experience of LGBT women following miscarriage, stillbirth or neonatal death. The study highlighted three themes: processes and practices for conception; amplification of losses; and healthcare and heterosexism. Conception was difficult because subjects
needed donor sperm and assistive methods. The loss was amplified due to undergoing extra measures to conceive. Most respondents reported that healthcare received during their loss was appropriate and helpful. The practice recommendations include asking about sexual orientation, preparation for possible pregnancy outcomes, and increased representation of the LGBT community in academic and lay literature. The strength of this study is that it used a sample of women from different continents, which aids in generalization; however, the countries are all developed nations with similar medical resources.


The purpose of this retrospective study was to describe the conditions of decision making for dying infants and the effects of culture on the process of infant death in the NICU in Taiwan. Fifty charts were reviewed for causes of death, do not resuscitate orders, family decision making (ex. family-provider conferences), interventions during terminal stage of life, cultural practices, and customs related to death. Past studies showed that parents in Taiwan tend to propose that physicians should make decisions regarding resuscitation without parental input. In this paternalistic culture, the parents hope for survival and agree with physician’s authority. This study, however, showed that in 30 documented cases (60%) family conferences were held to obtain opinions and consent of the parents and other healthcare team members. In 30 cases, families were offered a quiet place to grieve, and in 10 cases, nurses stayed with the family and allowed them to express emotions. The recommendation is for a family-provider conferences and offer support regardless of religious or ethnic background.


The authors evaluated a bereavement program that spanned generations in families affected by perinatal loss. The bereavement program was offered to the parents, grandparents, and siblings on an outpatient basis. Survey analysis showed that parent (N=107), grandparent (N=8), and sibling (N=132) participants deemed the program useful or very useful for themselves and the entire family. The limitations include small sample size and lack of ethnic diversity (the sample size was predominately Caucasian). The recommendations are to train and educate staff in intergenerational bereavement services, offer bereavement to extended families, and provide an opportunity for all members to give back to the bereavement program in different ways.

The objective of this article was to determine research trial activity in UK neonatal and pediatric intensive care units, number of deaths prior to discharge, and to determine whether bereavement support policies were available within research trials. The study shows that during a five-year period (2002-2006), over 3000 babies and children were enrolled into 50 trials (36 neonatal and 14 pediatric) and 16% died, predominantly in the neonatal population. Only three research trials had a formal policy for responding to bereavement. The study benefitted from a high survey response rate from the neonatal units (87%) and pediatric units (88%). The limitations include lack of a needs assessment from the parents and exclusion of post discharge deaths in the analysis. The authors recommend that studies include a bereavement protocol for subjects who die.


This qualitative descriptive study (n=21) focused on themes associated with the recovery process after a stillbirth in Taiwanese women. The women were interviewed about their experience of stillbirth. Due to culture and tradition, Taiwanese women are encouraged to not interact with the child after it is born, make any mementos, or talk about the loss. The cultural constraints proved to be difficult for all participants, as they wanted to search for meaning in this experience. The desire for postpartum bonding and need for social support in time of grieving provides a unique opportunity for healthcare workers to offer opportunities to bond and talk about the loss with the grieving Taiwanese mother.


This descriptive, cross sectional study explored the grief experiences in African-American mothers following a pregnancy loss (n=86). The women participated by completing the Perinatal Grief Scale-Short Form, Women’s Role Integration Protocol, and a personal profile tool. The findings suggest that grief intensity is affected by factors associated with reproductive history, gestation at time of loss, and time since loss. Women experiencing more severe type of grief were affected by level of role integration. Level of role integration is defined as social support from friends, family, and healthcare personnel. The authors recommend that women who experienced pregnancy loss be screened for residual grieving across the lifespan. Additionally, they call for more inquiry into interpersonal relations that facilitate grief management and the partner’s experience following a loss in the African-American population.

This qualitative study aimed at describing the perceived strategies African American women used to cope with their pregnancy loss (n=10). The early grief responses of African American participants were similar to those of European American women. Each study participant described a variety of practices to deal with loss and the author used the Grounded Theory to group them into four groups: “Putting it Aside,” “There Was a Purpose,” “Heal Yourself,” and “He’s In a Good Place.” All of the strategies fall under the self-help category and involve inner and instinctive processes, which may be indicative of limited outside resources. The author cautions to not generalize these findings to all African American women, but rather inquire about a woman’s loss experience even if she does not offer it.


This qualitative study aimed at exploring the subsequent children’s experiences of being born into and raised in a family following an infant death. The study used a sample of 10 children who were all at least 13 years of age and collected data through conversational style interviews. Subsequent children were aware of the deceased sibling but did not feel as though he or she had an impact on their attachment and bonding with their mother. Additionally, there were no statements suggesting parents were overprotective in their parenting of the subsequent child. The limitation of this study lies in its sampling. The children were recruited because their parents had used bereavement services in the past. Utilization of bereavement services may have had an impact on how parents processed grief and coped with their loss, which in turn could alter their parenting style of subsequent children. The recommendation is for parents to part-take in bereavement services, share their grief, and talk openly about their experience with family members.


This qualitative study (n= 13) explored families’ experience in raising their subsequent child following a loss. The study included mothers and fathers in conversational style interviews. The participants were bereaved through stillbirth, neonatal death, and SIDS and recruited through bereavement agencies. The main theme, which the authors named “paradoxical,” centered on a parenting style that included both emotional closeness and restraint from “investing everything” in the subsequent child. The mixed feelings towards subsequent children experienced by parents carry through into their parenting style long after a loss. The authors call for more research into how a loss can affect subsequent children and mental status of the bereaved parents.
Practice Recommendations

This publication advocates for the use of ATTEND intervention model as a means to improve the acute and chronic states of bereavement. The acronym stands for attunement, trust, therapeutic touch, egalitarianism, nuance, and death education. The mindfulness-based techniques outlined by ATTEND promote self-awareness and provide a framework through which healthcare personnel may be able to approach painful experiences with the traumatic deaths rather than avoid them.

This article provides an overview and a history of support groups for parents who have experienced a death of a baby. The publication outlines the history and the positive and negative aspects of face-to-face support groups as well as online support chat rooms. The summary includes helpful resources on sustaining a face-to-face support groups such as a sample of ground rules to be used in a support group settings and desirable facilitator personality traits. Lastly, the article offers implications and interventions for healthcare providers, which include: being present, encouraging the bereaved person to tell his or her story, and being knowledgeable about concrete therapeutic procedures that help make sense of the loss.

This publication describes the development of the Alliance for Perinatal Bereavement Support Facilitators in Chicago over 25 years ago. The alliance activities include education, networking/support, policy, and recognizing outstanding service to families. The publication outlines the history, components, and the change experienced by the alliance overtime. The alliance employs success indicators to formulate activities and measure its success. These indicators include: collaboration between members, member involvement, environment of trust and supporting relationships among members, impact on the community focus, sustainability, and collaborative leadership. This alliance has shown to be successful and a long-lasting model of collaboration that can be considered in other regions.

This article outlines the components of forming a successful perinatal palliative care team (PPCT). It underscores the importance of proper referrals from physicians and midwives in the community, a clearly defined role of every PPCT participant (neonatologist, chaplain, L&D nurse, NICU nurse, social worker, and other supporting departments), PPCT and staff
debriefing, and community contributions (ex. photographers). The publication provides great resources such as perinatal palliative care intake worksheet and a family birthing plan handout. The most common challenges are continuity of care and role of an L&D nurse as a staff nurse and a PPCT member. The recommendation is for more institutions to partake in this endeavor because families provide positive feedback and the staff are more comfortable confronting loss.

This article discusses guidelines for bereavement support to parents in the emergency department (ED). In Britain, bereavement education recommendations by the British royal family were made in 2001 and this publication provides further supporting research that nurses and providers in the ED need to learn, practice, and utilize bereavement skills. Additionally the author suggests that at least one member of the staff should be assigned to stay with the family at all times, learn the family members’ names, and refer to the deceased infant by name. The ED staff needs not to restrain their emotion; however, they must remain professional. Siblings should be included in the family centered approach. Lastly, privacy, momentos, and after-care should be offered and conducted. Bereaved parents can access resources after discharge; however, staff in the ED should be prepared to provide first line bereavement services following fetal and infant death.

The article describes the modified guidelines set forth by the National Institute for Health and Clinical Excellence (NICE) in the United Kingdom on whether or not mothers should be actively persuaded to hold their stillborn infants following birth. The final recommendation by NICE is “If your baby is stillborn or dies soon after birth, it is your choice whether or not you wish to see or hold your baby, and your health professional should support you in making this decision.” The Stillborn and Neonatal Death Society in the United Kingdom also supports this recommendation.

The article describes the few research studies that explore Latino grief related to perinatal loss. Traditionally, Latina clients tend to be religious, therefore offering measures such as holding the baby, making mementos, and especially baptism may be important rituals. Hispanic clients rely heavily on family support and family should be included in bereavement. Due to the scarcity of research related to grief expression in Latino clients, staff should always ask parents which rituals would comfort them at time of loss.
Systematic Research/Reviews

This article reviews literature on complicated grief reactions following perinatal loss. Mothers with previous psychological disorders such as depression and anxiety are at an increased risk for developing complicated grief. Other predictors cited in literature include lack of social support, pre-existing relationship difficulties, absence of other children at home, and ambivalent attitude towards pregnancy. The risk for complicated grief was especially high for those that terminated a pregnancy due to an abnormality. It is important for providers to identify risk factors for developing complicated grief in order to connect the mother with appropriate services. The review calls for more randomized control studies in this field.

This publication explores bereavement research and clinically based writings about relationship in the care of bereaved families and offers practical applications for nursing practice. The clinical nursing implications and recommendation include; facilitating a relationship with the bereaved family, avoiding coercive statements such as “you need to see your baby,” and understanding the life-limiting conditions such as Trisomy 18. It is important to assess and support families’ changing hopes, individualize the approach by learning what loss means to the particular family, and provide photographs and capture moments if desired.

This systematic review provides a description and summary of important post discharge nursing interventions following perinatal loss. Nurses play a role in helping families distinguish between grief and depression and mobilizing necessary support for the mother or the couple. Specifically, nurses can evaluate support systems in place and recommend group therapy or connect families with appropriate providers. Lastly, nurses can help families acknowledge fears and worry that comes with planning a subsequent pregnancy.

This is a literature review focusing on how culture has been defined and what recommendations have been made to promote more culturally sensitive care by nurse-midwives. The authors searched related terms on the following databases: Medline, Sociofile, and Expanded Academic Access. This review took two approaches in defining culture in nursing and midwifery literature: cognitive aspects and structural framework that focuses on the person’s social position. The first approach tends to provide generic information.
about different groups of ethnically diverse people, which is used to develop a “cookbook” of recipes for care. This approach does not take into account socioeconomic status or education level of an individual. The second approach is broader and includes the person’s social status (socioeconomic and educational level) and how it impacts their health and well-being. Although the latter approach is more comprehensive, very little research is available on how it is or can be incorporated into practice.