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EVIDENCE FOR HEALING INTERVENTIONS WITH PERINATAL BEREAVEMENT

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ABSTRACT

The purpose of this article is to explore the concept of perinatal grief and evidence-based healing interventions for it. The loss of a pregnancy or death of an infant causes profound grief, yet society has long minimized or ignored this grief, which is among the most painful of bereavement experiences. Throughout the last century, research on grief and the special needs of bereaved parents has changed the context of professional intervention from protective to supportive. The central focus of bereavement interventions is to assist families in healing by helping them make meaning of their losses. The use of symbols, spirituality, and rituals has been shown to help bring meaning. Research has shown that memories are key to healing, and that gender, age, and relationships bring different grief expressions and experiences. While children's understanding of loss and grief differs with developmental age, they should also be given the opportunity to participate in grief rituals and practices.

Professionals who care for bereaved parents have a unique opportunity to offer support by validating their grief, facilitating rituals, providing mementos, and letting the bereaved tell their stories. While no intervention can bring back their beloved children, appropriate intervention can promote healing.

Key Words: Bereavement; Perinatal; Grief.

Miscarriage, stillbirth, infant death, and child death continue to be significant topics of concern for perinatal and pediatric nurses in the 21st century. Although rates of infant mortality have decreased recently, annual reports of deaths in the United States include 54,964 perinatal deaths (Centers for Disease Control, 2004) and 28,371 infant deaths (Public Health Advisory Board, 2001). In addition, 15% to 20% of pregnancies end in miscarriage, most during the first trimester of pregnancy (Infertility Tutorials, 2005). Yet, infant deaths and pregnancy losses have often been invisible to society. This article will explore perinatal grief and describe the evidence in the literature that can assist nurses in providing healing interventions in caring for bereaved families.

Grief

Grief is now considered a normal, healthy, dynamic, universal, and individual response to loss. Grief enables the bereaved to heal and integrate the loss into their life (Andrews, 1995; Cowles, 1996; Cowles & Rodgers, 1991). Grief is a kaleidoscope through which each individual views the world; a healing process that evolves from surviving and continuing to live; and a transformational process of learning to live without the deceased, but instead with memories. Grief does not require severing of emotional bonds, is not in stages, and is not only death related (Arnold, 1995). The experience of grief, while universal, is dynamic and individual (Reed, 2003).

after miscarriage has long been underestimated. The literature has now shown us that miscarriage is a life-changing event, leading to feelings of emptiness, dread, guilt, and grief (Freda, Devine, Semelsberger, 2003). Côté-Arsenault and Morrison-Beedy (2001) have shown that women who have miscarriages have an increased need for support and experience many fears about their future childbearing. Studies have also shown that women have elevated depression and anxiety scores for up to 1 year after the miscarriage (Lee & Slade, 1996; Prettyman, Cordle, & Cook, 1993; Slade, 1994), and can also develop post-traumatic stress disorder after miscarriage (Englehard, van den Hout, & Arntz, 2001). It is essential, therefore, that nurses validate the loss that women feel after a miscarriage and encourage them to tell their stories.

In the case of stillbirth or infant death, lack of validation of that loss (by discouraging parents from seeing their deceased child or denying mourning rites) can disenfranchise grief. The lack of visible rituals following loss makes the tragedy a “nonevent” and the loss a “nondeath” (Kay, Roman, & Schulte, 1997). Disenfranchised grief can lead to exacerbated anger, psychiatric disorders, and perpetual sadness. According to Kroth et al. (2004), mothers who had not seen their deceased infants reported dreams that their babies were monsters. Others who were never told the disposition of their stillborn infants reported dreams in which they were searching for their babies. Dreams seem to enable the bereaved to express their feelings and also provide cues for professionals to facilitate therapeutic interventions; they may help in the grief recovery process (Kroth et al., 2004).

The broad spectrum of symptoms exhibited after perinatal loss include physical, psychosocial, emotional, and cognitive expressions (Table 1). As one mother said, “Grief is like a roller coaster” and comes in waves (Capitulo, 2004); it may be overlapping and interconnecting in no particular order or time frame.

Gender and Grief

Men and women express feelings of grief differently (Peppers &

Knapp, 1985). Men in the American culture may quickly return to their jobs and “normalcy,” being less expressive of their feelings and declining to participate in support groups. Women are generally more expressive, cry, need to talk about their feelings, and are more likely to participate in support groups (Capitulo, 2004; Leming & Dickenson, 1998). According to Noppe (2004), women’s experiences with death are a reflection of their biologic propensity to live longer than men, and also reflect their capacities for giving life (birth) and death (miscarriage, abortion). These differences can cause incongruent grieving, resulting in



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Dreams of the deceased are common in grief. Parents may dream of their deceased babies, providing a connection between them and their babies. Dreams may include memories, symbols, and metaphors, and may reflect obstacles to grief’s expressions (Blowey, 2002). Dreams can, however, also be an expression of disenfranchised grief (a form of grief that is not publicly recognized or validated; its expressions are thwarted or prohibited). Grief following miscarriage or infant death is particularly susceptible to being disenfranchised, as only parents may have known the baby, felt it move, or seen it through ultrasound. The grief

problems in communication and relationships (Peppers & Knapp, 1985). Women may perceive their partners as uncaring and emotionally distant, and misunderstand their lack of grief expression (Capitulo, 2004). Nurses should understand that helping couples identify differences in grieving can improve the couple's communication, facilitate grief, and support the couple's relationship (DeFrain, 1991). Gender differences are found in children's grief as well. Researchers studying children found that girls expressed more emotion and guilt and an increased desire to continue a relationship with the deceased (Moss, Resch, & Moss, 1997).

Given their different needs, women and men should be allowed to grieve differently. Nurses should counsel them to express their feelings, being cognizant of gender differences in expressions. For example, a man may not support a woman's need to express sadness and cry, and may appear to be protective by blocking her efforts to grieve. This might disenfranchise her grief and actually cause her more pain and suffering. If affected couples are counseled about this, bereaved women might feel more comfortable in seeking and finding support outside of their relationship, in support groups that are face to face, or online (Capitulo, 2004; Noppe, 2004).

Grief and Children

According to Christ (2000), children experience grief in different ways, dependent on their developmental age. Younger children (ages 3 to 5) may believe death is temporary and ask if the deceased is returning for a holiday or special event. Parents, of course, have difficulty responding to such a child, and must repeat that the loved one is never returning. Young children may in turn express grief as sadness, unhappiness, anger, or withdrawal. From ages 6 to 8, children begin to understand the permanence of death. They may exhibit anxiety, sadness, and dejection. Children ages 9 to 11 are usually concrete, logical thinkers, and cope best when given concrete information. Withholding information from them can lead to mistrust. Early adolescents (ages 12 to 14) are generally optimistic and may use denial to address their feelings of grief. After an initial period of numbness, they may express sadness and cry. Older adolescents (ages 15 to 17) may express sadness, anger, depression, bitterness, and helplessness, may cry, and may have difficulty sleeping (Christ, 2000). In working with families who have living children, parents should be assisted in how to speak to siblings about the loss of a pregnancy or the death of an infant. Children should be given truthful and understandable information appropriate for their developmental stage. All children may feel guilt at the death of a sibling (Christ, 2000), which should be dispelled by giving them the option of participating in grief rituals. If they do attend funerals, a support person (separate from the griev-

TABLE 1:
SYMPTOMS AND EXPRESSIONS OF GRIEF

Physical/somatic	Head, stomach, and arm aches Changes in heart and breathing patterns Throat tightness Decreased appetite Difficulty sleeping Lack of energy Generalized malaise Tiredness Crying
Psychological/social	Isolation Withdrawal Difficulty with activities of daily living
Emotional	Anger Denial Guilt Resentment Failure Sadness Preoccupation with the deceased Shock Disbelief Bewilderment Depression Blame Envy Jealousy Suffering Self-pity Crying
Cognitive	Difficulty making decisions Dreams
From Arnold 1995; Capitulo 2004; Klass & Silverman, 1996; Kay, et al, 1997; Peppers & Knapp 1980.	

ing parent), should be with them. They should be prepared for the funeral or ritual and told, simply, what is expected to occur.

Complicated Grief

The spectrum of normal grief is very broad, but society and culture dictate expected responses and behaviors (Reed, 2003). Some grief responses are considered complicated or outside the norm of expected responses.

Lack of a grief response to the tragedy of a perinatal loss is not normal (Kay et al., 1997). The pain of the loss may be so great and require so much energy that the bereaved reverts to phases of enduring, not to be confused with ab-

TABLE 2:
HEALING PRACTICES AND RITUALS IN THE
CARE OF BEREAVED FAMILIES

- **Presence:** Facilitate the presence of loved ones, family, children, and friends. Offer your own presence.
- **Communication**
 - Inform the mother/family of what will happen (do not be silent).
 - Encourage/facilitate mother/family to “tell their stories.”
 - Give results of tests/autopsy in person.
- **Memories and Mementos**
 - Seeing baby:
 - Viewing (can be in office, chapel, house of worship, or funeral home)
 - Do not limit time
 - Photographs: instant and portrait
 - Memory boxes
 - Locks of hair
 - Name bracelets
 - Foot/hand prints and casts
 - Name certificate
 - Journals
 - Quilts of the baby’s clothing
- **Rituals**
 - Naming
 - Spiritual blessing/baptism
 - Viewing (can be in office, chapel, house of worship, or funeral home)
 - Memorial service
 - Religious rites
 - Burial
 - Balloon release
- **Support groups**
- **Holidays**
 - Encourage families to make their own decisions about how to celebrate holidays, not allowing others to tell them what to do
 - There is no right or wrong, some may follow family traditions, and some not.
 - Keep in mind the feelings of children and family; try to make it joyous for them.
 - Don’t avoid the hurt.
 - Shop in the middle of the night, there are fewer people.
 - Set limits.
 - Get enough rest.
 - Use symbols and photos of your loved one to decorate for the holiday.
 - Incorporate memories and mementos into holiday rituals.
 - Change traditions that year :
 - If you celebrate Christmas, buy a tree if you used to cut one.
 - Visit others, take a vacation.
 - Change the time/location of dinner.
 - Attend religious services at a different place.

sense of grief (Morse & Carter, 1996). Some parents may intellectualize the loss and repress feelings of grief, called a “professional” grief reaction. In cases of pregnancy loss where the mother may have considered ending the pregnancy voluntarily, she may be relieved and not express feelings of loss, or she may feel guilt, believing her desires may have precipitated the baby’s death. Complicated grief reactions also include despair and difficulty coping (Lasker & Toedter, 1991). In rare cases, individuals may experience reactions similar to post-traumatic stress disorder, including reliving the loss, inability to participate in any death-related rituals or discussions, and extreme irritability.

When is outside help warranted? Individuals with a history of previous excessive grief reactions, mental illness, anxiety, drug or chemical dependency, ambivalence, low self-esteem, and poor social support who experience a perinatal loss may be at high risk for complicated grief reactions. When a woman is unable to function or perform activities of daily living, or when signs of severe depression or suicidal ideations are present, the woman should be immediately referred to a mental health professional, preferably one with bereavement expertise. A recent study found that bereaved patients who received complicated grief treatment (a new intervention specific to complicated grief) responded quicker and had better outcomes. Key elements of this treatment are allowing the bereaved to tell and retell her stories, including having conversations with the beloved deceased; restoring their focus on positive life goals; and reengaging in meaningful relationships (Shear, Frank, Houck, & Reynolds, 2005).

How Long Does Grief Last?

One study of an online perinatal bereavement group quoted a mother this way: “*There is no time-limit for the grief we feel*” (Capitulo, 2004). According to Arnold and Gemma (1994), grieving lasts a lifetime and is a process of learning to manage and get through life knowing that a part of oneself is gone and can never be replaced. Parents will always grieve for the life that child never had. For the bereaved, grief lives on and returns with regularity, manifested as “shadow grief,” an exacerbation of feelings of grief on special occasions, such as birthdays or death anniversaries (Freud, 1917; Lupi, 1998; Peppers & Knapp, 1985). While feelings of loss may diminish over time, or after the birth of another child, mothers never resolved their feelings of grief (Peppers & Knapp, 1980, 1985). For parents, special anniversaries take on significance. Due dates are particularly significant for mothers who experienced premature birth, as are a child’s birthdays. Holidays are very difficult; according to one mother, “*Christmas is the worst time for me, when your heart is breaking it does seem worse when everyone around you is preoccupied in the joyous season*” (Capitulo, 2004). Studies of bereaved parents have led to recommendations for helping them

get through the holidays (Table 2). Parents find it helpful to plan what they are going to do on anniversary dates; some might prefer to be alone, others visit the grave, or some do special things to remember the lost child.

Healing Interventions

Over the past several decades, professional intervention with bereaved families has changed significantly from a protective model, in which grief was denied and thwarted, to open support of families, validating the death (Rand, Kellner, Revak-Lutz, & Massey, 1998). Interventions should focus on making meaning of the loss for the bereaved (Swanson, Pearsall-Jones, & Hay, 2002; Uren, 2002), facilitating the expression of grief, and providing a supportive environment for the family. This is particularly challenging with perinatal deaths. Some professionals may be uncomfortable with their own feelings surrounding the death of infants and may prefer to avoid the bereaved, or may act impersonally. Others, including family, may assume a paternalistic role, making decisions for the bereaved, under the guise of protecting them from the feelings of loss (Rand et al., 1998). Neither approach is effective or healing. The primary focus of healing communication with

“passed,” “lost,” and “expired” do not connote the appropriate meaning, and should be avoided as well. It is important to validate the death by using the words “death” or “died.”

Support Groups

Hospital-based bereavement teams facilitate grief and mourning rituals and funerals for babies (Capitulo & Maffia, 1985). The Cochrane Database (Chambers & Chan, 2000) examined the literature for the effects of any form of psychological support to families after a perinatal death, and found that no recommendations could be made because no randomized trials had been published; therefore, research is clearly needed in this area. While few studies of any kind have been conducted on the outcomes of perinatal bereavement teams, some research on bereavement support groups in general has shown positive outcomes for families and for staff. Burke and Gerraughty (1994) described a multidisciplinary bereavement support program for oncology patients, which was highly rated by the participants and staff. An article from Duke University Medical Center described a neonatal intensive care bereavement team that follows families for up to 1 year after the death

(Jansen, 2003); unfortunately, no outcome data were provided. Di Marco, Menke, and McNamara (2001) described a support group intervention for perinatal grief and found that support groups helped some women, but were not the best type of support for all women, because some women preferred support from their extended families instead of professionals. Calhoun, Napolitano, Terry, Bussey, and Hoeldtke (2003) have described a perinatal hospice for the supportive care of families with prenatal diagnoses of lethal congenital anomalies, including ongoing supportive care until delivery; this program was effective in supporting families during their prolonged grief. Côté-Arsenault and Freije (2004) have described pregnancy-after-loss support groups, showing that women in these groups developed caring relationships, learned new coping skills, and reconciled the paradox of pregnancy after a loss. Bereaved parents who find support groups particularly helpful include those experiencing perinatal losses who saw their babies, parents who had memorial services, or those who requested bereavement counseling (Heiman & Yankowitz, 1997). A new venue for bereavement support is found in online bereavement support groups. One study described bereaved mothers who found support online as members of a listserv with a unique culture. Through a shared metamorphosis, they created a bereave-



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bereaved parents is letting them tell their stories repeatedly: the stories of their pregnancy, their child's life, and their child's death (Capitulo, 2004).

What do you say to a parent whose baby has just died or been stillborn? As in other death experiences, it is appropriate to express sorrow and validate the loss, for example, “I’m sorry, I understand your baby/child has died.” Euphemisms sometimes heard in clinical practice settings such as “You’re young, you can have another one,” “It’s better the baby/child died, she/he may have been sick for a lifetime,” or “The baby must have died for a reason,” are not helpful, and should clearly be avoided. The words

nancy-after-loss support groups, showing that women in these groups developed caring relationships, learned new coping skills, and reconciled the paradox of pregnancy after a loss. Bereaved parents who find support groups particularly helpful include those experiencing perinatal losses who saw their babies, parents who had memorial services, or those who requested bereavement counseling (Heiman & Yankowitz, 1997). A new venue for bereavement support is found in online bereavement support groups. One study described bereaved mothers who found support online as members of a listserv with a unique culture. Through a shared metamorphosis, they created a bereave-

ment community, expressed their feelings about their losses, and gained new identities as “mommies of angels” (Capitulo, 2004).

Promotion and Creation of Memories

Bereaved mothers have expressed that their greatest fear was that their children would be forgotten (Capitulo, 2004). Therefore, nurses should promote and support the creation of memories of these children. Seeing and holding the baby is important to families. In a study of mothers experiencing stillbirth (Trulsson & Rådestad, 2004), it was found that after the sudden diagnosis of a loss (such as an

deceased infants/children. One key to providing a quality memory is education of the staff in the use of the camera and posing, and clothing the baby to provide a positive memory. Some families may have real portraits done of their children, using the photographs as models. Photo journaling and videos enable families to chronicle the life, particularly useful in a neonatal intensive care unit, and create lasting memories (Cincotta, 2004).

Certificates of birth and religious rituals are important memories. In some localities, no certificate is issued to parents of stillborns. In these cases, special certificates may be made by the institution for the parents. Such certificates

can also be purchased from bereavement organizations. Most parents do choose a name for their baby, even if stillborn, unless it is a cultural tradition not to do so. Today, many parents know the sex of their baby from ultrasounds and have already established the baby's identity with a name. Use of the name on certificates, on documents, and in discussions is a positive way to remember the baby and is healing to the family.

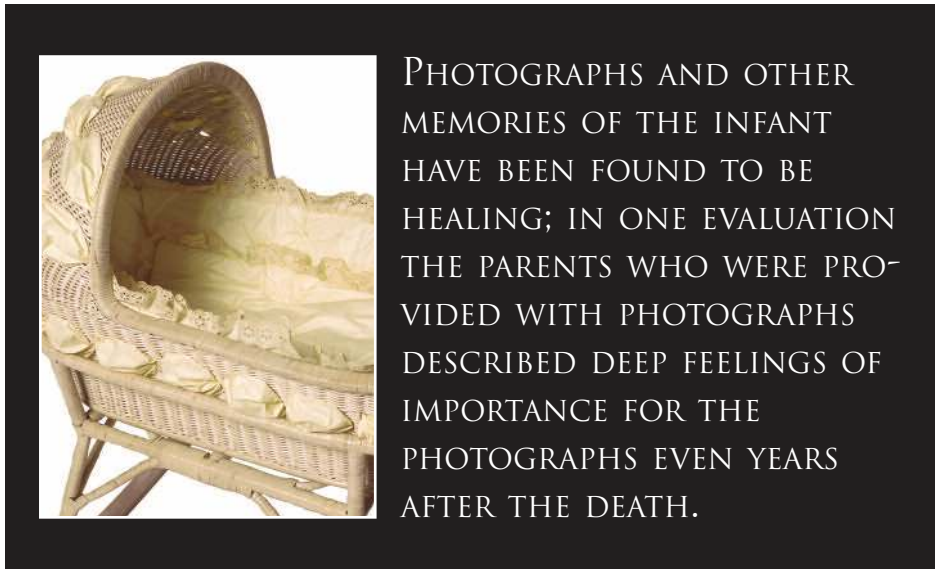
Mementos can be preserved in special memory boxes, available for purchase from bereavement companies. Some foundations and individuals will give hospitals

intrauterine death), parents need time to make decisions and prepare for the birth and should not be rushed to deliver. In that study, some mothers expressed hesitation in seeing their babies, but ultimately did so after encouragement of the staff; most parents wanted time with their infants and did not want the time to be limited. No parent regretted seeing their baby, and those who did not see their baby regretted that staff did not further encourage them to do so. It seems clear that this special time with their infant is critical to bereaved families.

Photographs and other memories of the infant have also been found to be healing (Lundqvist, Nilstrum, & Dykes, 2002). Mementos such as locks of hair, handprints, footprints, foot casts, name cards, sonogram negatives, and photographs are cherished. In one evaluation the parents who were provided with photographs of their child described deep feelings of importance for the photographs, even years after the death (Alexander, 2001). Instant photos can be taken before and after death and given to parents immediately, but more permanent, portrait photos provide lasting memories. Many hospital baby photo companies will provide a separate camera, free of charge, to enable staff to take portrait-quality photos of sick or

hand-painted memory boxes to use for bereaved parents. Should parents not want to keep the mementos or box at the time of death, the hospital should keep it, for parents may return in years to come to take home the memories and photographs. Memories can be made from clothing bought for or belonging to the deceased child. Bereavement counselors have facilitated creating quilts out of the child's clothing. Both the process of quilting and the permanent memory have been healing to families. Ellard (1997) has described a memory box program, in which the hospital provides a special box in which to place all the memories of the infant.

Symbols have been found to provide parents with a positive memory of the infant. The most common symbol in perinatal bereavement is angels. In one study, bereaved mothers called themselves “mommies of angels” (Capitulo, 2004). Parents may have angel jewelry, photos, statues, and other items. In a service commemorating the anniversary of a deceased child's death, one mother served angel food cake. Other symbols used in bereavement include candles, dragon flies and butterflies, hearts, stars, and flowers. Some bereaved memorize their loved ones by naming a star for them, connecting them forever to eternity.



Incorporating Cultural and Spiritual Views of Grief Into Interventions

While the experience of grief may be universal, grief expression is framed in the culture and beliefs of the individual. Knowledge of an individual's cultural beliefs and practices is essential to plan appropriate care and interventions. Such rituals include death rituals, spiritual rituals, funerals, burial, and mourning. Since the meaning of any loss can be determined only by the person experiencing the loss, it is essential to follow rituals requested by families, not necessarily prescribed religious or cultural practices (Arnold, 1995).

It is common for parents who have a spiritual belief to want to connect their baby with God, often through religious rituals (Case, 1978). Some formal religions have rules about when, how, and by whom rituals are done. When conflicts with religion arise, professionals should do what is possible to provide and facilitate the ritual that brings positive meaning to the experience for the family. This can be done by asking families what rituals or practices they wish to have for the deceased. It is never appropriate to prevent families from participating in religious and cultural rituals, for this can disenfranchise grief.

Funeral Rituals

Funeral rituals are influenced by cultural backgrounds. Viewing of the deceased may be appropriate in some cultures, but not in others. If viewing is desired, it can be done in a funeral home or in a hospital chapel or another location in an institution. Use of a hospital chapel enables families who might be unable to afford a funeral home to have a memorial service for their child. If a hospital memorial service is planned, the family should be asked if they want the deceased infant to be viewed at the ceremony. If so, the child should be prepared by washing and clothing the body, using baby lotion for its fragrance. In cases where postmortem examination has already taken place, the body can be sutured to enable it to be clothed and present at a service. Even small babies can be prepared for viewing. The dressed baby should be taken to the chapel or other location for the service, using a basket with baby blankets for this transportation. Infants should not be shown to the parents in morgue attire nor transported in a bag; this is not healing for families or staff. Should families wish to participate in preparation of the body following religious or cultural customs, this should be facilitated, as it enables families to do something for their child (Capitulo & Maffia, 1985).

If a family desires a memorial service, care should be taken to create a service that is positive and healing and brings special meaning to them. Several publications have poetry, readings, and prayers that can be used in such services (Harris, 1999; York, 2000). Programs can be distributed during memorial services, easily created on a word processing computer program. Outside clergy who officiate at the service should be informed if the deceased infant will be present, for some may need guidance from hospital bereavement/pastoral staff.

Burial

Burial is required depending on local laws and regulations. Some funeral directors will do at-cost or low-cost burials for infants, particularly if they have previously cared for a member of the family. Some religious groups, such as the St. Vincent de Paul Society and Hebrew Free Burial Society, may provide free or low-cost burial in a religious cemetery for needy families. Spiritual and cultural rituals at the burial have been shown to bring comfort, peace, and healing to families (Jacobs, 2004).

Implications for Research

While much has been learned about grief and healing interventions over the past several decades, many unanswered questions remain:

1. What are the long-term effects of the death of a child on the parents' and family's lives?
2. What interventions bring meaning and healing to bereaved families?
3. What interventions are not effective?
4. What death and grief education, particularly surrounding perinatal losses, are included in multidisciplinary professional education?

In our specialty of maternal-child health, bereaved families are among the most vulnerable and needy in our care. Pregnancy loss or death of an infant or child brings special challenges to the bereaved and to the staff. Validation of the loss, support of the families, and facilitation of grief rituals are key components of professional healing interventions. For bereaved families life will never be the same. They will forever remember the grief experience. For those who care for these bereaved families, know that they will forever remember what you said and did. Using evidence in practice, professionals can make their interventions provide meaning to the tragedy of the death, create a positive memory, and facilitate healing. ❖

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ONLINE



Ceremonies for Jewish Living: Pregnancy Loss

www.ritualwell.org/Rituals/overview.html?catId=145

Compassionate Friends

www.compassionatefriends.org/Brochures/stillbirth.htm

March of Dimes: Bereavement Kit

www.marchofdimes.com/professionals/2222_2303.asp

Memories Unlimited Memory Boxes

www.memoriesunlimited.com

Rituals/Memorializing "Our Precious Babies"

www.storknet.com/cubbies/pil/mem.htm

Share: Pregnancy & Infant Loss Support

www.nationalshareoffice.com/