REDUCING Risk

A periodic column from the Center for Reducing Risks in Vulnerable Populations, College of Nursing, University of Illinois at Chicago

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Supporting Parents After Stillbirth or Newborn Death

There is much that nurses can do.

Despite advances in obstetric and neonatal care, many parents will experience the birth of a stillborn infant or the death of a newborn. In 2002 there were 18,747 neonatal deaths,[1] and each year there are over 26,000 stillbirths.[2] Most parents who experience the death of an infant have never encountered a loss of such magnitude. Studies on perinatal loss by one of us (KK) found that even mothers who had complications during pregnancy were unprepared for the infant's death and their own intense grief.[3,4] Nurses who care for these parents must understand the range and intensity of reactions that are unique to this type of loss. In this article, we will draw from the literature to describe parents' grief responses and to identify nursing interventions.[3,4] Specifically, we will discuss the care of parents who are hospitalized and whose infants have died perinatally.

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PARENTS' EXPERIENCE OF LOSS

Arguably, the most widely known theory of grief is the Kubler-Ross model, which consists of five stages: denial, anger, bargaining, depression, and acceptance.[5] While earlier models demystified the experience of death and loss, they were limited in clinical usefulness. Current models frame grief not simply in stages, but as a complex individualized process.[6] Response to loss depends on many factors, yet what matters most is what the loss means to the individual.[7] One of us (KK) has coauthored a more complete review of current grief models elsewhere.[8]

Research findings indicate that there are differences in grief responses according to sex.[9-11] Mothers often experience intense responses, including extreme sadness; guilt; suicidal ideation; and feelings of emptiness, isolation, irritability, and anger.[11] We found that some mothers had difficulty being around pregnant women and infants or in situations such as holiday celebrations that reminded them of what might have been had their infant survived.[4] Fathers also experience a range of feelings, including isolation, restlessness, anger, sadness, and powerlessness.[4,11-14] Fathers are often concerned for their partner's emotional well-being.[3,4,13,14] Thus, health care professionals and other family members may overlook fathers' needs.[9,15]

PROVIDING SUPPORTIVE CARE TO PARENTS

Palliative care is becoming more available to parents whose infant is diagnosed with a life-limiting or life-threatening condition,[16-19] emphasizing the importance of planning for the limited time families will have with their infants. Nurses can help prepare parents for the birth of their baby by let-

Illustrated by Christine Murphy

ting them know what to expect regarding delivery and possible outcomes.

Nurses who care for bereaved parents should become familiar with the rights of both parents and the infant (see Tables 1 and 2, page 76).[20] Nurses may also want to familiarize themselves with Swanson's middle-range theory of caring.[21, 22] According to Swanson, caring is a "nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility."[21] The goal of caring is to enable parents to achieve well-being, regardless of what circumstances they endure or the pain they feel after the loss of a baby. Swanson's theory can apply to all areas of nursing and has provided a framework for perinatal bereavement support. Eliciting, listening to, and respecting parents' needs and wishes must be paramount. The following are guidelines, not absolutes, because there will be exceptions; for example, some parents may not

Table 1. Rights of Parents When an Infant Dies

- To be given the opportunity to see, hold, and touch their infant at any time before and after death, within reason.
- To have photographs taken of their infant, and made available to the parents or held in a secure place until the parents wish to see them.
- To be given as many mementos as possible—for example, crib card, baby beads, ultrasound or other photos, lock of hair, foot- and handprints, and measurement records.
- To name their child and bond with him or her.
- To observe cultural and religious practices.
- To be cared for by empathetic staff who will respect their feelings, thoughts, beliefs, and individual requests.
- To be with each other throughout hospitalization as much as possible.
- To be given time alone with their infant, allowing for individual needs.
- To request an autopsy. In the case of miscarriage, to request to have or not to have an autopsy or pathology examination as determined by applicable law.
- To have information presented in understandable terminology regarding their infant's status and cause of death, including autopsy and pathology reports and medical records.
- To plan a farewell ritual, burial, or cremation in compliance with local and state regulations and according to their personal beliefs or religious or cultural traditions.
- To be provided with information on resources that assist in the healing process—for example, support groups, counseling, reading material, and perinatal loss newsletters.

Adapted with permission from National Share Office. *Rights of parents who experience an early pregnancy loss.* http://www.nationalshareoffice.com/resources_rights.shtml.

Table 2. Rights of the Infant

- To be recognized as a person who was born and has died.
- To be named.
- To be seen, touched, and held by the family.
- To have the end of life acknowledged.
- To be put to rest with dignity.

Adapted with permission from National Share Office. *Rights of parents who experience an early pregnancy loss.* http://www.nationalshareoffice.com/resources_rights.shtml.

want mementos or to spend time with their infant after his death.

Being present for parents by understanding and accepting a wide range of responses can help determine appropriate interventions. Parents may not understand the many emotions that can constitute grieving, so it's important to give anticipatory guidance.[4,11,23-25] Since it may be difficult to differentiate between grief and depression, a consultation with a mental health professional is recommended when there's concern about a parent's grief response (for example, if a parent describes a plan for suicide).[26]

Parents may not be ready to talk immediately after the loss. A nurse can be supportive by sitting quietly next to them. Nonverbal support is communicated through eye contact, attentive listening, and concerned facial expressions. Research by one of us (KK) has found that parents appreciate the opportunity to talk about family resemblances regardless of the infant's gestational age or physical condition.[4]

Any statements that minimize parents' loss; impose personal, moral, or religious values; judge the parents; or increase guilt should be avoided. The words used to describe the infant should be nontechnical and personal. Referring to the infant by name or as "your baby" conveys respect for the infant as a human being. Words such as "fetus," "it," "micropreemie," or "nanopreemie" should never be used with parents. Statements such as "I know exactly how you feel" or "Your baby would have suffered anyway" should also be avoided; they aren't comforting and may be viewed as presumptuous or insensitive.[27]

When nurses are at a loss for what to say, it's often best to listen empathetically and attentively to the parents. Nurses are perceived as caring if they check on parents often, allow family members unrestricted visiting, use empathetic touch, and visit the parents even when they aren't assigned to care for them.[3,4] Parents consider such actions as "giving special attention" and appreciate them, even though they rarely have the opportunity to say so.[4]

Helping parents create cherished memories. Parents often want tangible mementos of their

'I Wish I Had Understood What It Meant, Leaving You That Last Time'

Twenty-five years later, a mother recalls her infant's last day.

Editor's note: On April 16, 1981, three-week-old Vincent Cass developed necrotizing enterocolitis in the neonatal ICU at Albany Medical Center in Albany, New York. Vincent had been born 14 weeks early, and in three weeks he had overcome several small obstacles common to premature infants. But on that April morning he required intubation, his abdomen became distended, and surgery was performed to repair a perforated colon. Despite the surgery and an emergency blood transfusion, he died that afternoon. His mother, AJN *clinical editor Karen Roush, was a nursing student at the time. She recounts her response to Vincent's last moments of life.*

I thought you would live. When you went into surgery, the doctor told us that your chances of making it through were nil. That's what he said, "The chances of him making it through this are nil." But you did. And so I thought you would live. Even when your hands and feet started turning blue, when the blue started creeping up your arms and legs. I watched your heart rate on the monitor slowing and your blood pressure dropping, and still I thought you would live. It's like that, you know, when something unimaginable is happening, like watching your baby die.

They decided to try an exchange transfusion as a last effort to save you, but halfway through your heart rate fell and the doctor said, I remember his words exactly, "Let's stop everything now and let the family be together." And that's what they did. Disconnected everything. The syringe got stuck in the tubing and broke off as they handed you to me, and blood poured out over my hands. They became so upset, wanted to take you away and wash you off, but I said no, no, I wanted to hold you those last moments of your life, I didn't want you to die in a stranger's hands and be brought back to me cold and still.

I rocked you. I held you against my chest, pressing your face against mine. Sometimes when I'm missing you I'll hold my arms like I did then, remembering how it felt.

The nurse crouched next to us, her arm tight around my shoulders, physically holding me together. I lowered you to my lap, and she touched your face and hair. "He was such a beautiful baby," she said. I've always been thankful for those words. You were beautiful.

I don't know how long I rocked you before handing you to your father. The doctor led me to the sink and washed your blood from my hands and face. He was crying and saying how sorry he was. How unexpected it was, what a good baby you were. I remember agreeing, calmly, saying I know, we never expected it either. I didn't cry. Later I wondered if he thought I was heartless, that I didn't love you. But he probably knew I was in shock.

I didn't know. I remember thinking how it didn't even hurt that much. Your father guided me through the halls, crying hard, but I remained emotionless. I carried the bag they had given me with your things, a blue bag with big print saying "Patient's Belongings." Inside were the stuffed bunny, Thumper, your blankets, and the gowns I had sewn for you. There was the small yellow squeaky bear, and the music box that played "It's a Small World" that you would turn toward whenever I wound it up and placed it next to you. You didn't like the squeaky bear; you'd frown and draw away when your brother squeezed it for you. I had them put the bunny and the music box in the casket with you. I had them dress you in the blue gown with the tiny white flowers and wrap you in your blankets. Later, I wished I had kept something, Thumper or one of your blankets. Something of you I could hold. The squeaky bear I made a place for next to your headstone. Your brother would squeeze it for you whenever he came there with me. It lasted through years of weather, fading in the summer sun, frozen in winter's snow, until one spring when I found it in pieces; a groundskeeper must have caught it in his lawnmower. I cried for hours. I keep the pieces in a drawer next to my bed.

The nurse crouched next to us, her arm tight around my shoulders, physically holding me together.

I wish I had understood what it meant, leaving you that last time. The finality of it. I would have rocked you longer. I would have gotten a lock of your hair. When the nurse explained that after we left they would bathe you and dress you in one of your gowns, I would have asked to do it, if only I had thought it was a possibility. I would have taken care of you. I wouldn't have missed those last loving acts of a mother.—*Karen Roush, MSN, FNP, RN, clinical editor: karen.roush@wolterskluwer.com*

Table 3. Perinatal Loss: Online Resources for Parents and Professionals

Center for Loss in Multiple Birth, Inc.
www.climb-support.org

Centering Corporation and *Grief Digest*
www.centering.org

The Compassionate Friends, Inc.
www.compassionatefriends.org

Hygeia Foundation, Inc.
http://hygeia.org

The MISS Foundation
www.missfoundation.org

Pregnancy Loss and Infant Death Alliance
www.plida.org
(For information about the October 2006 conference, see
www.perinatalbereavementconference.org)

RTS Perinatal Bereavement Program
www.bereavementprograms.com

Share: Pregnancy and Infant Loss Support, Inc.
www.nationalshareoffice.com

Association for Death Education and Counseling
www.adec.org

Perinatal Hospice
http://perinatalhospice.org

infant and are generally grateful for pictures.[4, 17, 28, 29] If possible, pictures should be taken while the infant is alive and after death; it's preferable that no equipment be attached to the infant. The infant should be clothed, wrapped in a blanket with hat and gown, and pictures should be taken with the parents and important others. Items can be placed in the background to make the picture less stark, and black-and-white film may be preferred if the infant's skin is discolored. Other possible mementos include a note with the infant's weight, length, and head circumference; a lock of hair; or footprints, handprints, or casts of feet and hands. Parents treasure items, such as blankets, that have come into contact with the infant. These should be given to the parents unwashed, so that they retain the infant's smell.

When a parent expresses a need for a specific ritual, even if it sounds unusual, the nurse must try to meet the request, particularly if it stems from their cultural traditions or religious beliefs. Nurses can create an environment that allows parents to generate long-lasting memories. Parents, siblings (regardless of age), friends, and extended family members should have unrestricted time with the infant before and after the death and the opportunity to perform caregiving activities, such as bathing and dressing.[4, 17] Parents cherish the time they spend with the infant, and appreciate nurses who allow the infant to remain in the room until the mother's hospital discharge.[4] Some parents may request a hospital chaplain or other clergyperson to provide support or conduct a prayer service, especially if no other memorial service will be held.

Guiding parents in making decisions about autopsy and burial. Parents must make many irreversible decisions at the time of their infant's death, particularly those regarding autopsy, memorial service, and burial.[3, 4, 23, 30, 31] Parents in crisis often don't comprehend or remember all of the information they receive, and many are uncertain of their rights. Nurses can help by anticipating their need for information, offering explanations more than once, and being patient.

Nurses themselves need to be informed and provide written information about burial, autopsy, and organ donation options within their institution and community. Parents generally choose between a private or hospital burial. The latter typically does not include a memorial service or individual burial. The mode of hospital burial may differ depending on the institution. Private or individual options include burial in a special place in a cemetery designated for children or in a family burial plot. One of us (KK) found that parents based their decision regarding infant burial on what they felt was best for them and their infant, not always on economic factors or the perceived stress of arranging a private service.[4]

Follow-up visits are an important aspect of care, and phone calls should be made within one week of a loss and again several weeks later. A follow-up consultation can also occur in conjunction with the mother's postpartum appointment.[4, 23, 24] Parents often have medical, spiritual, and philosophical questions. All parents should have the opportunity to meet with a physician for a postpartum appointment to ask questions, to clarify the events that led to the infant's death, and how it might affect future pregnancies. During the follow-up call or visit, the nurse should clarify information, validate parents' feelings, and provide sources of support,[26] including support groups, Web sites, books, and national organizations (see Table 3, at left).

NURSES' RESPONSE TO LOSS

Nurses may also grieve. Working with many bereaved families in a

short period of time can lead to chronic, compounded grief, which may limit nurses' ability to continue caring for these families.[32] Nurses are encouraged to take care of themselves, seek out personal and professional support, and participate in educational activities to learn more about their own feelings, such as the National Perinatal Bereavement Conference organized by the Pregnancy Loss and Infant Death Alliance (www.plida.org). Self-care may involve exercise, relaxation techniques, or private therapy. Mental health services are an option for nurses, especially when self-care activities are not adequate to relieve stress.[33] Hospitals may have a program in place to help health care professionals cope with loss, but if not, nurses can be instrumental in trying to promote such a program within their institution.

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These strategies can help nurses continue to provide optimal care to parents and can make a substantial difference in how parents experience the tragic loss of an infant. ▼

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