There should have been two: Nursing care of parents experiencing the perinatal death of a twin

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WITH EACH PREGNANCY the question, “Could it be twins?” receives at least a moment’s attention. Often, an emotional entanglement of joy, fear, and excitement accompanies the fantasy. Several prenatal occasions provide the stimulus to consider the possibility of twins by both the parent and professional: when first listening for fetal heart tones, during the first ultrasound scan, and when assessing a maternal size-to-dates discrepancy. For some parents the expectation is well founded and the transition to the status of “parents of twins” is realized. For many of these parents of twins, however, the anticipated outcome of having two children is never realized.

This article examines parents’ experience with the loss of one twin during the perinatal period. Particular emphasis will be placed on the parental dilemma of simultaneously grieving the death of one twin while developing an attachment to the
survivor. A model of caring to guide nursing intervention is also proposed.

PERINATAL LOSS OF A TWIN

Early fetal demise

Up to 70% of twin pregnancies diagnosed prior to ten weeks' gestation will result in a singleton birth. The majority of the "vanished twins" actually die in early pregnancy and subsequently spontaneously abort, undergo resorption, or are retained and birthed as a fetal papyraceous (remains of the dead twin fetus that have been flattened by the growing co-twin in utero).

Prior to the current, near-ubiquitous use of ultrasound, most twin pregnancies would not even have been realized by the mother. Historically the spontaneously aborted single-twin fetus might have been viewed as an early miscarriage or passed off as a "late heavy period" followed by the "premature birth" of a full-term infant eight months later. Alternatively the spontaneous abortion of one twin might have been dismissed as unexplained first trimester bleeding in which the supposedly singleton pregnancy continued uneventfully. Conversely, if the nonsurviving twin remained in utero and was delivered at birth as a fetus papyraceous and if the birth attendants did not alert the mother of the presence of tissue, the mother would again be unaware of her twin conception. Lastly, if the fetus underwent resorption, the twin conception would have remained undiscovered. Given the high rate of early fetal loss in twin conceptions, the sense of disruption experienced by parents when diagnosed with twins, and the grief experienced when informed of the loss of one of the twins, questions can be raised about the risk of ushering parents through an emotional roller coaster when an early ultrasound scan is done.

Later fetal death

As Dudley and D'Alton summarized, the incidence of intrauterine single-fetal death ranges from 0.5% to 6.8% in twin pregnancies, with the likelihood of such loss being three times higher in monochorionic than dichorionic twins. To add to this tragic event, the reported incidence of neurologic sequelae for the co-twin survivor ranges from 20% to 46%. Some of the potential causes of intrauterine single-twin fetal death include cord accidents, twin-to-twin transfusion syndrome, placental abruption, and umbilical stricture.

Stillbirth and neonatal death

The risk of perinatal loss in a twin gestation is three times that in a singleton gestation. In Rutgers' 11-year study of 228 twin pregnancies, there were 38 perinatal deaths of at least one twin. Of the 38 deaths, 30 were the result of both twins dying. Mortality was significantly correlated with prematurity and sex of the infant. Low birth weight and being a male were both risk factors for twin perinatal death. In the study by Keith and colleagues of 588 twin pregnancies, 86 of the infants died in the perinatal period, with the highest incidence of loss being associated with low birth weight. The mortality rate for second twins was higher (8.5/100) than for first twins (6.1/100). Maternal risk factors of age and parity were also identified. The loss rate was highest among women aged 15 to 20 years (21.2/100) and lowest in women in their early 30s. After the age of early 30s the rate of twin loss rose again. Parity risk assumed a similar pattern: the rate of twin loss for nulliparous women was highest.
and lowest for a parity of three to four (4.3/100). For a parity of five or greater the loss rate rose again (6.8/100).

THE HUMAN EXPERIENCE

Parental response to the prenatal news of twins is often ambivalent. For many couples it takes considerable "getting used to the idea." A new world with some mystery and the special status of parenting twins opens up for the parents. Both the mother and father begin to imagine how they will parent two children of the same age at the same time. Breastfeeding, playtime, and the fantasies associated with the anticipated joys of twins begin to preoccupy the parents' thoughts. As one mother explained:

I can never describe how wonderful it felt to know I was carrying twins. Just the idea made other people smile with anticipation. Despite a rough time physically, I felt so special and looked forward to the joys and the tremendous responsibility the coming days would bring.

In time, the thought of having twins, although still somewhat scary, becomes exciting, desirable, and a source of pride. Soon friends and relatives get caught up in the momentum. Plans are made, two of everything is purchased, and some parents contact the local Parents of Twins Club. As the mother's abdomen grows larger and the birth draws near, the family prepares to welcome its two new members.

Whether the news of the death of an expected twin is given prenatally, at birth, or shortly after birth, it is received as a physical blow to most parents. The following account describes one mother's feelings:

At 30 weeks, during a routine sonogram, my doctor drove to the hospital to see for himself if the radiologist was correct. "Rightie" had died. We didn't know why—we didn't know when.

We stared in disbelief at the doctor when he explained that I would have to carry a dead child for several more weeks. This plan would give "Leftie" a better chance at survival. The idea seemed almost cruel to me. How could I stand the waiting and wondering? My tiny son who had died was trapped inside of me, possibly poisoning his twin brother and me with his slowly decomposing body?

Immediately set into motion is a confusing desire to fill an empty space, to complete a missing whole, or to finish an incomplete feeling. This feeling may and often does recur throughout the parents' lives. Although the intensity of the sense of incompleteness may diminish over time, it is unlikely that it will ever disappear.

In the study of Wilson et al, which compared parents who lost a singleton to stillbirth with parents who lost a twin to stillbirth, no significant difference was found between the groups in amount of depression at 15 months postbirth. Neither the presence of a surviving twin nor the rapid, subsequent birth of a replacement child seems to make up for the death of the co-twin. The surviving twin will always be a single twin. Parents will continue to be the "parents of twins, one of whom died at birth."

Parents get through the loss of a twin; they do not get over it. The presence of the living co-twin is a flesh and blood reminder of the dead child. The resurgence of grief at anniversaries and special occasions is a common aspect of grieving. With the loss of a twin, however, the actual number of "occasions" are increased exponentially by

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witnessing growth markers in the surviving twin. Some of those markers include first time at the breast, first day home from the hospital, first smile, first tooth, first step, first birthday, and so on for the remainder of the surviving twin’s life. The surviving twin is ironically the never-ending reminder of what could have been.

When one twin dies perinatally, mothers and fathers have a very confusing, ambivalent induction into new parenthood. Congratulations and condolences, birth and death announcements, baptismal gowns and caskets are all a part of the first few postpartum weeks. While trying to attach to the surviving twin, parents are also experiencing the need to grieve the dead twin. As one parent states:

Brian came home two weeks later with what was to become a four-month case of colic. We were both exhausted and had no time to finish our grieving. In temperament Brian was a challenge until he was about a year old. All the feeling I thought had been resolved resurfaced…. My concern is raising Brian in a way that we can acknowledge our sadness in losing Thomas, without forcing Brian to live in the shadow of his lost twin.5

For many parents, the real, immediate needs of the live infant become an easy way to avert the painful energy necessary for grieving. This tendency to turn away from death and toward life is often encouraged by well-meaning friends and family. Unfortunately grieving, an essential part of being, if not given its full attention, tends to linger right beneath the surface. Marris6 refers to loss as a disruption in the meaning that one has built up around an event. Unless parents who lose a twin perinatally tend to that disrupted meaning and struggle to build a new acceptable meaning, their lives may become stuck in the disrupted, confusing feelings of early parenthood.

The “replacement child” phenomenon has been described by Poznanski.9 It involves the rapid subsequent conception and birth of a child to replace the one previously lost through stillbirth or neonatal death. The replacement child, like the surviving co-twin, is born into a time of confusion and fear. Parents, in their efforts to get past the painful loss of one child, often remain blind to the burdens they place on the subsequent child or surviving co-twin. Parents who have not addressed their grief and who focus only on what they have left are all too often cheated out of the opportunity to experience a full nurturing relationship with the surviving child. If parents have not given totally into their bereavement needs, the much-wanted, too-soon-conceived “replacement” child or the surviving co-twin may ironically become the focus of the parents’ rage, depression, and fears. These feelings may be expressed through such maladaptive parenting modes as overprotection, abuse, or emotional abandonment.10,11

A decision of particular challenge to parents of twins, one of whom died at birth, is whether or not to acknowledge the surviving twin as a twin. In western society twins and parents of twins enjoy a somewhat special status. As Cassill12 describes, the relationship between twins is a special bond that is believed to occur on a psychic as well as physical level. When one twin dies in the perinatal period, little is understood about how much, if any, imprint that loss has on the psyche of the co-twin survivor. Guidelines are unavailable for determining how much twin emphasis is too much, when the attention to the lost twin borders on being morbid, or when the surviving twin loses the message that “you are special” and instead gets the message that “you are not enough.”

At present there are few resources or
support groups that parents can turn to for assistance with their decisions. A notable exception to this is a recently published networking newsletter for parents who have experienced the perinatal death of a twin. The newsletter, published by Jean Kollantai and the Anchorage Parents of Twins and Multiples Club, is entitled Our Newsletter. In their first newsletter, Kollantai wrote the following:

Though we are scattered all over the country and are in many circumstances, we all know what it is to suddenly go from being proudly pregnant with two babies—to having a baby who died and a baby who lived... and raising our surviving baby in the midst of grief for our baby who died, and for our twins... And all too often with people acting like the baby who died didn't exist or wasn't important, and telling us how lucky we are to have one baby... This newsletter is one way of sharing with each other and reaching out to others who are out there feeling alone.13

NURSING CARE OF PARENTS EXPERIENCING PERINATAL LOSS OF A TWIN

Nurses who practice in perinatal settings are in a key position for humanizing parents' experience with the loss of a twin. Whether the setting is an ambulatory outpatient clinic, an in-hospital birthing center, or a neonatal intensive care unit (NICU), the nurse should focus on the parents' response to their simultaneous experience with life (expectancy, birth, and attachment to a live twin) and death (fetal demise, intrauterine death, stillbirth, or neonatal death). Whatever the mode of twin loss, the caregiver must ask: What is the meaning of this event to these parents at this point in time?

A potential model to guide perinatal practice in the event of twin loss is the caring model, which is based on a study of women who experienced miscarriages. This model was further refined through a subsequent study of caregivers in the neonatal intensive care unit.14,15

The caring model consists of five categories: (1) knowing, (2) being with, (3) doing for, (4) enabling, and (5) maintaining belief. Nursing practice in this model is focused on the parents' reality.

The first category, knowing, is defined as, striving to understand the event as it has meaning in the life of the parents. Caregivers who practice from a stance of knowing are perceived as sensitive, knowledgeable, and appropriate. When practice is not based on knowing, caregivers often appear distant, abrupt, and mechanical. Knowing the meaning that the loss of a twin has in a parent's life can be enhanced by:

- discarding any personally held assumptions about the loss of a twin (ie, what should be, what is normal);
- remaining aware that meanings that people attribute to birth and death are highly individualized;
- using all senses to thoroughly assess where each parent is with their experience;
- using broad opening statements and questions when approaching parents (How are you doing now?; How has all of this been for you?);
- recognizing parents' postpartum need to focus on the stillborn or dying infant even if it appears to be at the expense of the living infant (this may be the parents only chance to care for their dying or dead infant; the survivor will have a lifetime of attention);
- including both parents in the plan of care, fathers are often expected to act responsibly (ie, funeral arrangements)
at a time when they too have lost a child;
- including siblings and grandparents in caregivers' attempts to understand and be sensitive; and
- avoiding platitudes and trite condolences.

The next caring category, being with, is defined as being emotionally present to the parents. Being with takes a personal commitment on the part of the nurse to be willing to enter into the pain and joy of another human being. The sharing of another's emotional experience must, however, be done with a sense of responsibility toward the self and toward the other. An essential part of nursing others through difficult life events is knowing when it is time to withdraw and practice self-care. Such self-monitoring enhances the nurse's capacity to be genuinely with a client who is experiencing a painful event such as the loss of a twin. The ambivalence and emotional turmoil engendered by the death of one twin and the birth of the other are particularly challenging experiences for both parents and nurses to face. The tendency to want to flee from death and turn toward life must be curtailed. As every perinatal nurse knows, when a reproductive casualty occurs, remaining physically and emotionally present with the parents takes a tremendous amount of personal energy. Perinatal care providers are probably among the very few who have witnessed the prenatal or postnatal existence of the dead twin. This validation of the parents' perception makes the perinatal caregiver a very special part of their lives. The personal energy expended in being with is a nursing intervention that parents always remember.

The third caring category, doing for, involves doing for the parents as they would do for themselves if it were possible. Doing for involves providing physical care that is anticipatory, competent, and comforting. This is a fundamental nursing action. Doing for is based on clinical knowledge and human compassion (knowing and being with).

When a perinatal loss of a twin occurs, few parents have a repertoire of actions or words available to them, since they are novices at perinatal loss. Relatively speaking the nurse is an expert by virtue of previous experience and learning. Using this expertise the nurse does for the parents what they would do for themselves if they had planned on the simultaneous birth and death. Nursing actions should include the following:
- providing parents opportunities for privacy;
- giving a verbal or nonverbal message that the nurse is always available (a nonverbal message of the nurse's willingness to do for is to go ahead and "just do" [i.e., find parents chairs by the isolette, get the mother tea or ice water, hand a parent the call bell before leaving the room, etc.]);
- handling the dead infant with respect and compassion (the nurse should carry the infant close to his or her own body as he or she hands the parents their infant); and
- anticipating a parent's needs before he or she even has to ask (i.e., having Kleenex available everywhere, offer-
The fourth caring category, enabling, is most applicable to the loss of a twin. Enabling means facilitating the parents' passage through life transitions and unfamiliar events. The events of birth and death are life's two greatest transitions. When they occur simultaneously, they create an unfamiliar situation. Nursing care that is enabling must give attention to both the attachment and grieving needs of parents. The following nursing actions are suggested to enable parents' attaching to and grieving for the dead or dying twin:

- Recognize that parents need to have the life of the dead twin acknowledged. Attachment is a lifelong process that begins long before birth. The twin lost perinatally was at one time, prenatally or postnatally, a very significant vital being in his or her parents' lives.
- Help to make memories of the twin's brief life (ie, take footprints and photographs; if they are available, give parents ultrasound photographs or videotapes of the twins together; save identification bracelets and swaddling blankets; and suggest that parents bring in clothes for the infant).
- Acknowledge that the mother did conceive, carry, and give birth to the dead twin.
- Encourage parents to name the child. A name is the birthright of every person, and having a name provides the dead twin with a permanent, distinct identity.
- Acknowledge that the parents are parents of twins.
- Encourage parents to seriously consider a funeral or some meaningful ceremony to say goodbye to the dead twin.
- Give parents books on perinatal loss, and for future reference tell them where they may purchase bereavement books in the community.
- Assist parents in contacting other parents who have experienced the same or similar losses (ie, support groups such as Compassionate Friends); or assist parents to connect with the Our Newsletter network by writing to Mrs. Jean Kollantai, PO Box 1064, Palmer, Alaska 99645.

The final caring category, maintaining belief, is defined as sustaining faith in the parents' capacity to get through an event or transition and face a future of fulfillment. This category is particularly salient with respect to parents' needs to attach to and foster the growth of the surviving co-twin. Parents often feel as if there is no light at the end of the tunnel; consequently, they need those around them to believe in their ability to get through. Parents need to believe that one day meaning will be restored in their lives. The key point is assisting parents to see that things will never again be as they were but that a life with new meaning and fulfillment is possible. Parents need to reach a point of peace in their own time. The nurse's job is not to judge but to allow parents to be where they are and, whenever possible, to assist them to take control and make decisions about how to face a future without one twin.

Attaching to and nurturing the surviving co-twin will often not be an easy experience. Parents will always be faced with the challenge of enjoying the surviving co-twin as the individual he or she is. At times parents may feel resentful that this twin...
lived and the other did not. Parents may compare this child to what might have been. Furthermore, parents will often experience the sense that this is only half the pleasure to which they are entitled. These are common responses. Parents who have lost a twin should be encouraged to express these feelings and should be forewarned that such feelings may occur. Parents must be assured that it is normal to have occasions on which they may be acutely aware of their loss (ie, the twins' birthdays). Anticipatory guidance consists of helping parents to be aware of and plan for such occasions.

A key aspect of maintaining belief in parents who have lost a twin perinatally is to accept that parents are doing the best parenting job they can, given the resources available to them. The nurse must be one of the potential resources whom parents can turn to as they solve such problems as whether or not to raise the surviving twin as a twin; how to inform the surviving twin of his or her co-twin's existence; or how to handle the unsolicited advice of others as to “what is the right thing to do for this child.” Currently there are minimal, if any, guidelines as to how to raise a child whose twin has died at birth.

For nurses the challenge is to facilitate the parents in their ability to grieve for the loss of one twin while developing a relationship with the surviving twin. This goal of clinical practice requires further research to guide nursing interventions.

To my daughter

| I do have good days       | I had to carry you for another two months |
| I do smile and laugh     | It's not fair I yelled                    |
| I have learned a lot     | the Dr. just stared.                     |
| Through tears I can praise God the most high | What could he say, |
| But it still hurts deep inside | No one seemed to care. |

And now

| when I am all alone       | ...                                   |
| All I do is cry.          | ...                                   |

| Some people try to tell me | ...                                   |
| that two babies would     | ...                                   |
| have been too hard to handle | BUT I COULD HAVE MANAGED |
| A friend told me once     | ...                                   |
| that God knew I couldn’t handle twins. | ...                                   |
| You mean to say           | ...                                   |
| I can handle this better  | ...                                   |

REFERENCES


