LEARNING OBJECTIVES

- Describe emotional, behavioral, cognitive, and physical responses commonly experienced during the grieving process associated with perinatal loss.
- Understand the personal and societal issues that may complicate responses to perinatal loss.
- Formulate appropriate nursing diagnoses for parents and their families experiencing perinatal loss.
- Identify specific nursing interventions to meet the special needs of parents and their families related to perinatal loss and grief.
- Differentiate among helpful and nonhelpful responses in caring for parents experiencing loss and grief.

KEY TERMS AND DEFINITIONS

bereavement The feelings of loss, pain, desolation, and sadness that occur after the death of a loved one.
bittersweet grief The resurgence of feelings and emotions that occur on remembering a loved one after the bereavement process has lessened.
complicated bereavement The persistent feelings of anger, guilt, loss, pain, and sadness over time that lead to feelings of hopelessness, helplessness, and diminishing self-worth.
grief Physical, emotional, social, and cognitive response to death of a loved one.
perinatal loss Death of a fetus or infant through the twenty-eighth day after birth.

ELECTRONIC RESOURCES

Additional information related to the content in Chapter 28 can be found on the companion website at http://evolve.elsevier.com/Lowdermilk/Maternity/
- NCLEX Review Questions
- WebLinks

or on the interactive companion CD
- NCLEX Review Questions
- Plan of Care—Fetal Death: 20 Weeks of Gestation

Becoming a parent is an important developmental milestone that is anticipated by most men and women in our society. However, loss can be associated with pregnancy and birth. During pregnancy, parents plan for the birth, imagine what the birth will be like, and develop an image of the appearance of the baby. The reality of childbirth may not be what the parents have dreamed of or hoped for. In particular, the experience of premature labor and preterm birth or cesarean birth all involve a loss of the expected pregnancy and birth plans. Parents may grieve over the sex or appearance of their child. For some parents, loss is associated with the birth of an infant who has a birth defect or chronic illness.

Although having children can be a strong desire for women and men, not everyone is successful in achieving parenthood. For some couples, infertility may thwart their plans and desires for parenthood and cause intense feelings of grief. When couples undergo infertility treatments, feelings of loss may intensify, especially when treatments fail and/or a pregnancy ends in a miscarriage. Women, in particular, experience high distress during this time.
Many women and their partners, whether infertile or not, experience miscarriage in the early months of pregnancy. Miscarriage affects the personal identity of the woman and causes guilt, depression, and anxiety. Others may have an ectopic pregnancy or experience a fetal death. Women and their partners also may suddenly be confronted with stillbirth, the birth of an infant who shows no signs of life. All of these experiences may be called perinatal loss. Others may experience intense grief after infant death. These others include women who give birth prematurely to an infant who survives only a few hours or who dies after days, weeks, or months in an intensive care unit. A woman may give birth to an infant with severe congenital anomalies or other serious health problems; these infants also may die after a few hours, days, weeks, or months in an intensive care unit.

The statistics on perinatal loss and death of an infant are grim. Approximately 2% of pregnancies are ectopic pregnancies, taking place outside the uterus, usually in a uterine tube. Ectopic pregnancies account for 9% of maternal deaths (Luciano, Jain, Roy, Solima, & Luciano, 2004). A miscarriage—a pregnancy that ends before 20 weeks of gestation—is reported to account for 10% to 15% of all pregnancies (Simpson, 2002). In addition, each year approximately 5 of every 1000 births end in stillbirth or fetal death (those occurring after 20 weeks of gestation). Newborn death, death of a baby born showing signs of life such as respiratory effort, heart rate, pulsating cord at birth, and/or muscle irritability, regardless of gestational age, accounts for approximately 28,000 deaths per year in the United States (Martin, Kodamak, Strobino, Guyer, & MacDorman, 2003). Of those, 20% die of congenital malformations and chromosomal abnormalities, 17% of short gestation and low birth weight (LBW), and 8% of sudden infant death syndrome (SIDS) (Martin et al., 2005). African American women experience pregnancy and infant loss at rates more than twice those of Caucasian women and women of other ethnic minority groups (Martin et al., 2005).

Parents can experience grief before or during the childbearing experience. Grief involves the painful emotions and related behavioral and physical responses to a major loss. Grief can be particularly difficult with perinatal losses for a number of reasons: the societal belief that there are no barriers to getting pregnant, and the expectation that once a woman is pregnant, the result will be a healthy live infant. As a result, our society tends to minimize perinatal loss and to lack understanding of the associated pain. Women and men who undergo perinatal losses struggle with these issues themselves, and because of these societal attitudes, they may not receive the support they need. In addition, many perinatal losses are hidden or private, in that others may not know about the infertility or the early pregnancy that ended in miscarriage.

Perinatal losses may be intensified for couples who delay pregnancy until the woman’s career and the family’s financial status are at the right point for the responsibilities of a child to be undertaken. Feelings of helplessness and loss of control can be very difficult when the couple experiences infertility or miscarriage. In many instances of perinatal loss, the lack of an identified cause for the loss can complicate grief. This is particularly difficult for women, who often feel personally responsible for infertility, miscarriage, and infant death. Some couples endure repeated losses; 4% of married women in the United States have had two fetal losses, and 3% have had three or more (Simpson, 2002). Such losses can be devastating. Furthermore, society allows far too little time for mothers grieving a perinatal loss and even less time for men. All of these issues can reduce the support to bereaved parents. Parents in a Canadian study reported that social support from families and friends fell short of expectations, and they interpreted this inattention as an indication that the death of their baby was not an important event. Some also reported a lack of understanding and support from healthcare professionals (Malacrida, 1999).

Nurses have a powerful influence on how parents experience and cope with perinatal loss (Corbet-Owen & Kruger, 2001; Saflund, Siegum, & Wredling, 2004). Nurses encounter these parents in a variety of settings, including the antepartum, labor and birth, neonatal, postpartum, and gynecologic units of hospitals, and obstetric, gynecologic, and infertility outpatient clinics and offices, as well as emergency rooms. In these settings, nurses have opportunities to provide sensitive and caring interventions to parents. Parents have reported that their nurses were an important resource in helping them cope with their grief.

Nurses in many inpatient settings have developed protocols that provide clear directions for nurses with regard to how to help parents through this difficult process. In some units, experienced nurses, social workers, or hospital chaplains who are particularly comfortable in helping bereaved parents are designated as perinatal grief consultants. They are available to help parents but also to help prepare the staff for their role with parents. In addition, many institutions now have follow-up programs involving telephone calls, home visits, and support groups that are effective in helping parents after discharge. It is important, then, that dealing with perinatal loss be included in nursing curricula and in-service training for staff nurses.

The focus of this chapter is to prepare the beginning nurse to provide sensitive, supportive, and therapeutic interventions to parents experiencing perinatal loss in a variety of settings. An overview of the grief process is presented as a guide for assessing and understanding the responses of bereaved women, men, and their families. Guidelines for intervention are given, and specific intervention approaches are discussed.

GRIEF RESPONSES

Grief or bereavement has been described as a cluster of painful responses experienced by individuals coping with the death of someone with whom they had a close relationship, generally a relative or close friend (Lindemann, 1944; Osterweis, Solomon, & Green, 1984; Parkes, 1972; Parkes &
Weiss, 1983). Many authors believe there are overlapping phases in the grief process, but most do not believe that grief is experienced in “stages.” There is an early period of acute distress and shock followed by a period of intense grief that includes emotional, cognitive, behavioral, and physical responses. The phase of reorganization is reached when the individuals return to their usual level of functioning in society, although the pain associated with the death remains. The duration of grief varies with the individual, but there is general agreement that grief is a long-term process that can extend for months and years. With a very close relationship such as with one’s baby, some aspects of grief never truly end. Another way of conceptualizing the grief process is through the achievement of certain tasks of mourning. Worden (1991) identified four tasks: (1) accepting the loss, (2) working through the pain, (3) adjusting to the environment, and (4) moving on. He proposed that these four “tasks of mourning” must be completed to resolve grief.

Miles (1984) and Miles and Demi (1986, 1997) proposed a conceptual model of parental grief, based on the work of Lindemann (1944), Parkes (1972), Parkes and Weiss (1983), and Worden (1991). The model proposes that the grief responses of a parent are closely linked to self-image as a mother or father. Parental grief responses occur in three overlapping phases of grief—acute distress, intense grief, and reorganization (Box 28-1).

**Box 28-1 Conceptual Model of Parental Grief**

**Phase of Acute Distress**
- Shock
- Numbness
- Intense crying
- Depression

**Phase of Intense Grief**
- Loneliness, emptiness, and yearning
- Guilt
- Anger, resentment, bitterness, irritability
- Fear and anxiety (especially about getting pregnant again)
- Disorganization
- Difficulties with cognitive processing
- Sadness and depression
- Physical symptoms

**Reorganization**
- Search for meaning
- Reduction of distress
- Reentering normal life activities with more enthusiasm
- Ability to make future plans, including decision about another pregnancy


### Acute Distress

The loss of a pregnancy or death of an infant is an acute and distressing experience for mothers and fathers who planned for and expected a normal healthy infant as the outcome. The loss encompasses a loss of their identity as a mother or father and the loss of their many dreams related to parenthood. The immediate reaction to news of a perinatal loss or infant death encompasses a period of acute distress. Parents generally are in a state of shock and numbness. They may feel a sense of unreality and confusion, as though they were in a bad dream or in a fog or trance-like state. Disbelief and denial can occur. However, parents also feel very sad and depressed. Intense outbursts of emotion and crying are common. However, lack of affect, euphoria, and calmness may occur and may reflect numbness, denial, or a personal way of coping with stress.

Much of the literature and research on grief after perinatal loss and infant death has focused on the mother. Likewise, much of the attention during the time of a loss is on the mother; the father is expected to be her main support but is often not acknowledged as grieving too. The response of fathers may be more variable than that of mothers and depends on the level of identification with the pregnancy. With early miscarriage or ectopic pregnancy, some fathers may not have a strong investment in the wished-for child. However, many fathers do grieve deeply for a miscarriage. Fathers are profoundly affected by a stillbirth or death of an infant. They have feelings of self-blame, a loss of identity and a need to hide feelings of grief and anger, and to appear strong (McCreight, 2004). Fathers also are distressed by the grief of the mother and often feel helpless with regard to how to help her with the intense pain. It is important to realize that fathers may be experiencing deep pain beneath their calm and quiet appearance and need help in acknowledging these feelings. Because fathers do not easily share feelings or ask for help, special efforts are needed to help them realize that they too have a right to support from others in their pain.

During this time of acute distress, parents face the first task of grief, accepting the reality of the loss. The pregnancy has ended or the baby has died, and their life has changed. Although parents are often required to make many decisions, such as having an autopsy, naming the infant, and funeral arrangements, normal functioning is impeded, and decisions are difficult to make. These decisions are especially painful and difficult for young couples who have limited or no previous experience with death. Grandparents are often called on to help make difficult decisions regarding funeral arrangements and/or disposition of the body because they have more life experience with taking care of these painful, yet required arrangements. However, some well-meaning grandparents and other family members may try to take over with all the decisions that must be made. It is critical that the nurse remember that a very important role is always to be a patient advocate and that the parents themselves should approve the final decisions.
Intense Grief

The phase of intense grief encompasses many difficult emotions, including loneliness, emptiness, yearning, guilt, anger, and fear: disorganization and depression; and physical symptoms. During this time, parents are working on two additional tasks of mourning: working through the pain and adjusting to life without the wished-for child. Being able to adjust to the environment after the loss means learning how to accommodate the changes that the loss has brought.

In the early months after the loss, parents often experience feelings of loneliness, emptiness, and yearning. The mother may report that her arms ache to hold or nurse her baby and that she wakes to the sound of a baby crying. When her milk comes in, it is particularly poignant when there is no baby to take to breast. Both mothers and fathers may be preoccupied with thoughts about the wished-for child. Some women cope with these feelings by avoiding memories and by not talking about the baby, whereas others want to reminisce and discuss their loss over and over. Deciding what to do about the nursery and baby clothes is particularly difficult during this period. Some women want the room taken down before they go home, whereas others want the room left intact until they have had time to grieve their loss. It is not unusual for a grandparent or other family member to want to rush home to take down the nursery with the thought that they would be sparing additional painful grief. In fact, their actions might only complicate the grief if parents were not involved in the decision. The bereaved parents, in their own time frame, must go through these types of experiences so that healing can take place.

During this phase of intense grief, guilt may emerge from the deep feelings of helplessness in not somehow preventing the pregnancy loss or the death of the infant. Mothers are particularly vulnerable to feel guilt because of their sense of responsibility for the well-being of the fetus and baby. With many perinatal losses, there is no clear cause of the event, leaving the woman to speculate about what she might have done or not done to cause the loss. Guilt also may be intense if a mother thinks she is being punished for some unrelated event such as having had a prior induced abortion. Such self-blame is torture for mothers, and they need repeated emotional reassurance that they were not at fault. Guilt can occur when one is enjoying life again and experiencing happiness despite the loss of the infant.

Another common response during this phase of grief is anger, resentment, bitterness, or irritability. Anger is particularly poignant if the loss is perceived as senseless, and there is a felt need to blame others. Anger may be focused on the health care team who failed to save the pregnancy or infant. For some parents, anger is vented toward a God who allowed the loss to occur. This can lead to a spiritual crisis. Anger also occurs toward family, friends, and peers when they do not provide the support bereaved parents need and want. Some parents focus their resentment on parents who do not appreciate their children or who neglect and abuse them. A sense of bitterness or generalized irritability, rather than frank anger, may be another response.

Fear and anxiety can occur during the grief process as a profound worry that something else bad might happen to another. Fear and anxiety are particularly poignant when the couple thinks about another pregnancy. Whereas some parents, especially mothers, are almost obsessed with the desire to become pregnant again, others struggle with whether they can cope with another potential loss. A prior loss increases parents’ stress in a subsequent pregnancy; parents experience a mixture of hope and fear (Armstrong, 2004).

Deep sadness and depression occur when the parent is faced with the full awareness of the reality of the loss. This often occurs several months after a perinatal loss and can continue for some time. Sadness and depression are often accompanied by disorganization and problems with cognitive processing. This leads to behavioral changes such as difficulty in getting things done, an inability to concentrate, restlessness, confused thought processes, difficulty in solving problems, and poor decision making. Disorganization and depression often cause difficulties in keeping up with work and family expectations. Additionally, parents returning to work face issues such as handling well-meaning but painful comments or the silence of co-workers.

Physical symptoms of grief include fatigue, headaches, dizziness, or backaches. Parents are at risk for developing health problems, such as colds or hypertension. The grieving process makes it difficult for bereaved parents to sleep. Their appetites may be depressed or voracious. Lack of sleep and inadequate nutrition and fluids can complicate other grief responses.

Grief responses are very personal, ongoing, and difficult to cope with. Some parents may suppress or deny their feelings because of societal indifference toward pregnancy loss and infant death. Suppression of feelings may, on the surface, be more socially acceptable. However, denying the pain of grief may lead to eventual physical and emotional distress or illness. Many parents, especially mothers, want to tell their story over and over. This helps them actualize the loss and face their feelings. Sometimes parents begin to think they are the only individuals who have ever had such a rough time and that they may be going crazy. Although bereaved parents have many ups and downs for many months and even years after a child’s death, few parents actually become mentally ill or commit suicide. Knowing that these feelings are normal and that others have felt the same is helpful. The grief process during this phase is often difficult for fathers. Some may continue to have difficulty sharing their feelings. A rift can occur if one parent, usually the mother, wants to talk about the loss and pain, and the other parent, often but not always the father, withdraws. Other signs of problems of the father include reliance on alcohol and drugs, extramarital affairs, prolonged hours at work, and overinvolvement in diversional and other activities outside the home as an escape. The Perinatal Grief Scale is an instrument that can be used to quantify the grief parents experience (Fig. 28-1).
EVIDENCE-BASED PRACTICE
Measuring the Unmeasurable: Perinatal Grief Scale

BACKGROUND
• With the decrease in infant mortality during the last century and increased parental expectations, response to perinatal loss became a topic for investigation. Cultural changes in the 1970s created increased patient expectations of control during childbirth, self-help movements, and increased awareness of the stages of dying and grieving. With increasing interest in understanding the grief of perinatal loss, social scientists faced the challenge of measuring this powerful and profound emotion. Since the introduction of the Perinatal Grief Scale (PGS) in 1988, it has been used in many studies to quantify and predict the impact of perinatal loss. The PGS is a 33-item test, using Likert-type responses (“strongly agree” to “strongly disagree”) to various statements of grief (see Fig. 28-1).

OBJECTIVES
• The original authors’ goals were to compare the internal consistency of the tool, establish normative ranges so as to be able to identify the parent who may be experiencing extreme duress, and compare groups across cultures and times.

METHODS
Search Strategy
• The reviewers searched PsycLit, SciSearch, and Social SciSearch. Keywords included pregnancy-loss and grief. Every article that referenced the original publications about PGS was evaluated. The reviewers also searched WorldCat for relevant dissertations and followed up on all studies that had requested the use of the PGS tool.
• The authors identified 22 empirical studies, presented from 1988 to 1999, representing 1803 women and 654 men (total 24571) from the United Kingdom, the Netherlands, and Germany. The types of losses included miscarriage, stillbirth, newborn loss, elective abortion, and ectopic pregnancy, adoption, and elective abortion.

Statistical Analysis
• Metaanalysis indicated strong internal consistency (all items seem to measure the same phenomenon similarly) and external validity (generalizability) of the PGS tool. The number of subjects enabled the establishment of a normal range of grief by determining that 97.5% of newly bereaved parents’ scores fell below 91. Therefore a score above 91 was accepted as reflecting severe distress.
• High benchmarks were also set for the three subscale groups that showed progressive psychologic decline: active grief, difficulty coping (more severe), and despair (most severe).

FINDINGS
• Between-group comparisons revealed that women’s scores exceeded men’s scores, but not to the level of significance. Grief does decrease across 2 years. There were significantly higher grief scores in groups recruited from grief groups or advertisements than from parents referred by health care workers. This may account for the significantly higher scores in the U.S. samples, who were mostly recruited through advertisements and groups, as compared to the European cohorts, who were mostly referred from hospitals. Strong marriages and the perception of social support were consistently related to lower grief scores. Preloss poor mental health, such as neuroticism, led to significantly higher grief. Grief scores showed a pattern of increasing with increasing gestation, but not to the level of significance. In the United States, low socioeconomic status was significantly associated with higher grief scores; this disparity was less marked in Europe.

LIMITATIONS
• Diversity was lacking in the U.S. samples, which were largely composed of Caucasian and middle class subjects. Groups and advertisements may attract people seeking relief from more severe grief; this sample bias may confound the comparison of scores in the United States and Europe. Cultural bias and wording may also influence results.

CONCLUSIONS
• The PGS is a valuable tool for clinical and research purposes, across time and countries.

IMPLICATIONS FOR PRACTICE
• Nurses can identify those at risk for poor adaptation and can counsel bereaved parents that healing will take years, and requires much marital and social support. Patients with high PGS scores that do not improve across time or who seem to be slipping into measurable despair on the subscale can be referred to grief specialists.

IMPLICATIONS FOR FUTURE RESEARCH
• Deeper understanding would be derived from more diverse cohorts and from exploring the grief patterns of men and other family or support members. Researchers can explore the lower end of the grief scale to distinguish functional results from denial, which may prove to be a bigger problem later. Research can determine whether those seeking groups have higher baseline scores or whether self-help groups are not as effective for alleviating grief as some hospital interventions. In-depth research is still needed on ectopic pregnancy, second trimester abortions for genetic abnormalities, and elective abortion.

Presents Thoughts and Feelings About Your Loss

Each of the items is a statement of thoughts and feelings that some people have concerning a loss such as yours. There are no right or wrong responses to these statements. For each item, circle the number that best indicated the extent to which you agree or disagree with it at the present time. If you are not certain, use the “neither” category. Please try to use this category only when you truly have no opinion.

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel depressed.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. I find it hard to get along with certain people.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. I feel empty inside.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. I can’t keep up with my normal activities.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. I feel a need to talk about the baby.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. I am grieving for the baby.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. I am frightened.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. I have considered suicide since the loss.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. I take medicine for my nerves.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. I very much miss the baby.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. I feel I have adjusted well to the loss.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. It is painful to recall memories of the loss.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. I get upset when I think about the baby.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. I cry when I think about him/her.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. I feel guilty when I think about the baby.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. I feel physically ill when I think about the baby.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. I feel unprotected in a dangerous world since he/she died.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. I try to laugh, but nothing seems funny anymore.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. Time passes so slowly since the baby died.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20. The best part of me died with the baby.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>21. I have let people down since the baby died.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>22. I feel worthless since he/she died.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>23. I blame myself for the baby’s death.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>24. I get cross at my friends and relatives more than I should.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>25. Sometimes I feel like I need a professional counselor to help me get my life back together again.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>26. I feel as though I’m just existing and not really living since he/she died.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>27. I feel so lonely since he/she died.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>28. I feel somewhat apart and remote, even among friends.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>29. It’s safer not to love.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>30. I find it difficult to make decisions since the baby died.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>31. I worry about what my future will be like.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>32. Being a bereaved parent means being a “Second Class Citizen.”</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>33. It feels great to be alive.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Scoring Instructions

The total PGS score is arrived at by first reversing all of the items except 11 and 33. By reversing the items, higher scores now reflect more intense grief. Then add the scores together. The result is a total scale consisting of 33 items with a possible range of 33-165.

The three subscales consist of the sum of the scores of 11 items each, with a possible range of 11-55.

**Fig. 28-1** The Perinatal Grief Scale (33-item Short Version).

Reorganization

From the time of the pregnancy loss or infant death, parents attempt to understand "why?" This leads to a long and intense "search for meaning." At first the "why" is focused on the cause of death. Finding few good answers, parents focus next on "why me, why mine?" These questions lead some parents into an existential search about the meaning of life and death. "What does my loss mean to my life?" "What is life all about?" "What do I do with the rest of my life?" This search continues into the phase of reorganization and may lead to profound changes in the parents' views about the fragility of life. Internal (hardiness) and external (marital support and social support) factors are predictors of health in bereaved parents (Lang, Goulet, & Amesl, 2004).

Time helps to ease slowly the painful feelings of grief. Over time the pain becomes less frequent. Reorganization occurs when the parent is better able to function at home and work, experiences a return of self-esteem and confidence, can cope with new challenges, and has placed the loss in perspective. Reorganization begins to peak sometime after the first year as parents begin to achieve the task of moving on with their lives. Enjoying the simple pleasures of life without feeling guilty, nurturing self and others, developing new interests, and reestablishing relationships are all signs of moving on. For some women and families, another pregnancy and the birth of a subsequent child is an important step in moving on with their lives; however, the term "recovery" is used because the grief related to perinatal loss can continue in varying degrees for life. Parents have shared that they will never forget the baby who has died, and they are not the same persons as before the loss. The term "bittersweet grief," invented by Kowalski (1984), refers to the grief response that occurs with reminders of the loss. This typically happens at special anniversary dates related to the loss (Box 28-2). Grief feelings also can be triggered after a subsequent live birth.

Resuming the sexual relationship is an extremely important aspect of recovery but can be very complicated. Many parents are comforted with the belief that their babies were conceived in love, lived in love, and died in love. The result of love and intimacy created this child, and parents may believe that they may never experience joy and closeness again. Once the doctor has given permission for resumed sexual activities, parents may find it emotionally very difficult. Some couples may have an increased need for sexual activity in an attempt for closeness and healing, whereas others have a decreased desire for sexual intimacy. It is important that parents be aware of some possible deep need from inside themselves to stop the emotional pain. Difficulties arise when the needs of the couple differ. Sexuality also brings with it decisions about a future pregnancy. Some couples are eager to have another child, although one child cannot replace the one who died, and the grief will continue despite pregnancy. Other parents have a deep fear of experiencing the pain of loss again, which can make the resumption of sexual activity difficult. These ambivalent feelings are normal, and couples will find themselves moving back and forth between the emotions of exhilaration and fear. The subsequent pregnancy after a loss is often filled with guarded emotions and great anxiety. The excitement that many others experience with a pregnancy is very different for previously bereaved parents. Fathers also reported anxiety about the outcome of the next pregnancy and increased their vigilance (Armstrong, 2001). Couples often mark the progress of the pregnancy in terms of fetal development, waiting anxiously until the number of weeks before the previous loss have passed. In some cases the fear of repeated loss, especially after a stillbirth, is so great that induction of labor is considered if lung maturity studies can confirm that the baby is mature. Parents may have anxiety in caring for the surviving infant. Burkhammer, Anderson, and Chiu (2004) reported assisting a young, anxious mother whose first child was stillborn and the second born alive, but small-for-dates, to use skin-to-skin breastfeeding to overcome her grief, guilt, and anxiety when feeding difficulties emerged.

BOX 28-2

Bittersweet Grief

To Jessica Mayo—on her eleventh birthday

Sunday, November 18, 1990

"The child who is born on the Sabbath day, is bonny and blithe and good and gay."
Sundays are special days.
. . . a day of rest, a day to play.
A day to reflect on days past.
. . . a day to thank God for all that we bless.
I bless your memory.
I wish you were here.
On your eleventh birthday I still want to share.
. . . Your dreams of the future.
. . . Our memories past.
My baby's first cry.
My daughter's first laugh.
I was told you were an angel in heaven above.
Eleven years later, I’m an expert . . .
At long-distance love.
On your third birthday I wrote my first poem to you.
Eight years later, it's still true
. . . no birthday cake,
no presents unwrapped . . .
no pictures of you in your party hat.
But the candles are lit,
Never to go out
For they burn forever in my heart.
Love, Mom"

Kathie Rataj Mayo
1990

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ment. Several key areas to address include the following:

- **Assessment and Nursing Diagnoses**
  - The nature of the parental attachment with the pregnancy or infant, the meaning of the pregnancy and infant to the parents, and the related losses they are experiencing. Each pregnancy and birth has a special meaning to parents. Whether a woman has experienced a miscarriage or ectopic pregnancy, stillbirth, or death of an infant, it is important to gain some understanding of parents’ perceptions of their unique loss. The meaning of the loss is determined by familial and cultural systems of the parents. In one study, feelings about perinatal loss ranged from devastation to relief (Corbet-Owen & Kruger, 2001). Listening to parents tell their stories and being sensitive to the language used to describe their experience can help one gain an understanding of the meaning of the loss. Open-ended questions are helpful: “Tell me about your labor and birth with Mia.” Or “When did you know you were miscarrying?” Mothers who have had a previous pregnancy loss may feel less attached, which can increase their feelings of guilt when a loss occurs.
  - The circumstances surrounding the loss, including the level of preparation for the loss and the parents’ level of understanding about the cause of the loss or death, and any related unresolved issues are important. While listening to the parents’ stories, it is important to uncover any special experiences that may make their losses even more poignant. A history of infertility, repeated pregnancy losses, a previous stillbirth, or infant death can make this loss even more painful. In addition, other life circumstances such as illness of another family member, loss of a job, or other family stresses can increase the distress of parents. It also is helpful to know whether the mother and father perceived the loss to be totally unexpected or whether they had some forewarning or preparation.
  - The immediate response of the mother and father to the loss, whether their responses are complementary or problematic, and how their responses match with their past experiences, personalities, and behavioral and cultural backgrounds. An understanding of the usual responses to grief described earlier can be helpful in attempting to understand the unique grief responses of the mother and father and other family members. As nurses work with families, they may uncover information about how the individual or family responded to a previous loss, or a personality or behavioral trait that may interact in their responses to this grief. In particular, it is important to know about any history of infertility, previous pregnancy losses, or infant deaths and evaluate how that might affect parental responses. It also is important to be sensitive to different expectations during grief for men and women from different cultural groups (see section on cultural and spiritual needs of parents later in this chapter).

- **CARE MANAGEMENT**
  - Nursing care of mothers and fathers experiencing a perinatal loss begins the first time the parents are faced with the potential loss of their pregnancy or death of their infant. Supportive interventions are important both at the time of the loss and after the parents have returned home.

- **Family Aspects of Grief: Grandparents and Siblings**
  - It is extremely important for the nurse taking care of these parents to keep in mind that they have an entire family to minister to, including especially grandparents and siblings. Grandparents have hopes and dreams for a grandchild; these have been shattered. The grief of grandparents is often complicated by the fact that they are experiencing intense emotional pain by witnessing and feeling the immense grief of their own child. It is extremely difficult to watch their son or daughter experience unimaginable emotional trauma with very few ways to comfort and end their pain. As a result, the grief response may be complicated or delayed for grandparents. On occasions, some grandparents experience immense “survival guilt” because they feel the death is out of order. They are angry that they are alive and their grandchild is not.
  - The siblings of the expected infant also experience a profound loss. Most children have been prepared for having another child in the family once the pregnancy is confirmed. These children come in all ages and stages of development, and this must be considered in understanding how they view the event and their loss experience. A young child will respond more to the response of their parents, picking up on the fact that they are behaving differently and are extremely sad. This can cause clinging, altered eating and sleeping patterns, or acting-out behaviors, yet it is a time when parents have limited patience for responding to and meeting the needs of the child. Older children have a more complete understanding of the loss. School-aged children may be frightened by the entire event, whereas teens may understand fully but feel awkward in responding. Older siblings need to be included in grieving rituals to the extent the parents and the child feel comfortable. They may need to see the baby to actualize the loss. Nurses need to have a basic understanding about how children view death and grieve to reach out to siblings in an appropriate and sensitive manner. Nurses also need to help parents understand and be sensitive to the needs of their other children despite their own deep pain.

- **C H A P T E R 2 8**
  - Perinatal Loss and Grief

- **Diagnoses**
  - The social support network of the parent (e.g., extended family, friends, co-workers, church) and the extent to which it has been activated. Support during a perinatal loss is important to most couples. However,
it is important to assess the amount of support and the type of support from others that a couple wants. Some prefer to handle the tragedy alone for a time. Others want assistance in calling other family members, friends, and clergy to be with them and to help them with decisions.

Nursing diagnoses may include physiologic and psychosocial problems experienced by the mother or father or problems occurring within the couple or family because of the loss and subsequent grief. Examples of nursing diagnoses include the following:

- Anxiety related to
  - lack of experience regarding how to manage the loss
  - worry about the partner
  - intense concern over not achieving a pregnancy
  - becoming pregnant again with risk of another loss
- Ineffective family or individual coping related to
  - inability to make decisions as a family
  - difficulties in communication within the family
  - conflicting coping patterns between mother and father
- Powerlessness related to
  - high risk pregnancy and birth
  - inability to prevent the infant’s death
- Interrupted family processes related to
  - maternal depression leading to changes in role function
  - inadequate communication of feelings between the grieving mother and father
  - lack of expected support from family
  - behavioral and emotional reactions of siblings
  - grief within the family system including grandparents and other relatives
- Ineffective sexuality patterns between the mother and father related to
  - guilt and fear associated with sexuality
  - loss of pleasure in sexual intercourse
  - differences in desires of each partner
  - fear of getting pregnant again
- Fatigue and disturbed sleep pattern related to
  - inability to fall asleep because of grief
  - waking in the night and thinking about the loss
  - loss of sleep
- Dysfunctional grieving related to
  - prolonged denial or avoidance of the loss
  - intense guilt related to the loss
  - continued anger about the loss
  - serious depressive symptoms and despair
  - loss of self-esteem
  - intense grieving patterns that continue for more than a year
- Social isolation resulting from grief
- Situational low self-esteem related to
  - prolonged feelings of poor self-worth because of the loss
  - feeling unworthy of having a child
- Spiritual distress related to
  - anger with God
  - confusion about why prayers were not answered
- Disturbed thought processes related to
  - difficulty making decisions
  - inability to get organized
  - poor work performance
  - confused thinking

Expected Outcomes of Care

Expected outcomes are set and priorities assigned in patient-centered terms according to the mutual goals chosen by the patient and the nurse. Nursing actions are then selected to meet the expected outcomes, which may include that the woman or family will do the following:

- Actualize the loss
- Share experiences and verbalize feelings of grief as much as is culturally and personally appropriate
- Understand the normal grief responses they and others in the family may experience at the time of and after the loss
- Demonstrate increasing independence in participating in and making decisions that meet their needs and reflect their religious and cultural beliefs
- Identify family, spiritual, health care, and community resources for support
- Discuss problems or issues involving relationships with each other and family
- Verbalize satisfaction with the care and support provided by their health care professionals

Plan of Care and Interventions

Interventions and support for parents from the nursing and medical staff before and after a perinatal loss or infant death are extremely important in their healing. Although parents often cannot recall details of their experiences at the time of death, they may recall vividly minor events that were perceived as particularly painful or particularly helpful. When parents know before birth that the baby will not survive, they can make arrangements to spend time with the baby, even if for just a short time (Cole, 2004). However, care must be individualized to each parent and family. Parents appreciate the opportunity to make choices about their needs. Providers should not try to influence parents or make presumptions that would limit their choices or force them to make choices they do not want. Furthermore, the cultural and spiritual beliefs and practices of individual parents and families must be considered. The interventions discussed later are general ideas about what may be helpful to parents.
Help the mother, father, and other family members actualize the loss

When a loss or death occurs, the nurse should be sure that parents have been honestly told about the situation by their physician or others on the health care team. It is important for their nurse to be with them during this time. With infant death, caregivers must use the words “dead” and “died,” rather than “lost” or “gone,” to assist the bereaved in accepting this reality. Parents need opportunities to tell their story about the events, experiences, and feelings surrounding the loss. This can help them come to terms with the reality of their loss. Listening to their pain and allowing time for them to absorb the information are important.

One way of actualizing the loss is to tell the parents the sex of the baby (if not already known) and give them the option of naming the fetus or to help them to name an infant who has died. Choosing a name helps make the baby a member of their family so that the baby can be remembered in a special way. Once the baby is named, the nurse should use the name when referring to the baby. Although naming can be helpful, it is important not to create the sense that the parents have to name the “baby,” especially in the case of a miscarriage when the sex is not known.

NURSE ALERT A caution about naming is important. Cultural taboos and rules in some religious faiths prohibit the naming of an infant who has died. It is very important to be sensitive to this possibility and not impose naming on such parents.

It may be helpful for mothers and fathers to see the fetus or baby. Many professionals, based on vast clinical experiences with parents, believe that seeing the fetus or baby helps parents face the reality of the loss, reduces painful fantasies, and provides an opportunity for closure. This has been questioned as the result of a longitudinal study of a small group of mothers in England (Hughes, Turton, Hopper, & Evans, 2002). These authors suggest that the wishes of the parents should be respected. Parents should never be made to feel they “should” see or hold their baby when this is something that they do not really want. Encouraging reluctant parents to hold or see their dead child by telling them that not seeing the child could make mourning more difficult is inappropriate. Obviously, this subject must be approached very carefully. A question such as, “Some parents have found it helpful to see their baby. Would you like time to consider this?” Because the need or willingness to see also may vary between the mother and father, it is extremely important to determine what each parent really wants. This should not be a joint decision made by one person or a decision made for the parents by grandparents or others. It is a good policy for the nurse to first tell them about this option and then give them time to think about it. Later the nurse can return and ask each parent individually what they decided. In preparation for the visit with the baby, parents appreciate explanations about what to expect. Descriptions of how their baby looks is important. For example, babies may have red, peeling skin like a bad sunburn, dark discoloration similar to bruises, molding of the head that makes the head look soft and swollen, or birth defects. The nurse should make the baby look as normal as possible, and remember that parents and health care professionals view the baby differently. Bathing the baby, applying lotion to the baby’s skin, combing hair, placing identification bracelets on the arm and leg, dressing the baby in a diaper and special outfit, sprinkling powder in the baby’s blanket, and wrapping the baby in a pretty blanket convey to the parents that their baby has been cared for in a special way. The use of powder and lotion stimulates the parent’s senses and provides pleasant memories of their baby.

It is more complicated if the fetus died several days or weeks before birth or if decapitation or dismemberment occurred. Consultation with a local funeral director can help the nurse prepare the baby to be seen by his or her parents. If the baby has been in the morgue, he or she can be placed underneath a warmer for 20 to 30 minutes and wrapped in a warm blanket before being brought to the parents. Cold cream rubbed over stiffened joints can help in positioning the baby.

When bringing the baby to the parents, it is important to treat the baby as one would a live baby. Holding the baby close, touching a hand or cheek, using the baby’s name, and talking with the parents about the special features of their child convey that it is all right for them to do likewise. If a baby has a congenital anomaly, the nurse can desensitize the family by pointing out aspects of the baby that are normal. Nurses can help parents explore the baby’s body as they desire. Parents often seek to identify family resemblance. A good question might be: “Who in your family does Michael resemble?”

Some families may like to have the opportunity to bathe and dress their baby. Although the skin may be fragile, parents can still apply lotion with cotton balls, sprinkle powder and lotion stimulates the parent’s senses and provides pleasant memories of their baby.

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Some families may like to have the opportunity to bathe and dress their baby. Although the skin may be fragile, parents can still apply lotion with cotton balls, sprinkle powder, tie ribbons, fasten the diaper, and place amulets, medals, rosaries, or special toys or mementos in their baby’s hands or alongside their baby. They may want to perform other parenting activities, such as combing hair, dressing the baby in a special outfit, wrapping the baby in a blanket, or placing the baby in a crib.

Parents need to be offered time alone with their baby if they wish. They also need to know when the nurse will return and how to call if they need anything. If at all possible the family should be placed in a private room, and when possible the room should have a rocking chair for the parents to sit in when holding their baby. This offers the mother and father special time together with their baby and with other family members (Fig. 28-2). Marking the door to the room with a special card can be helpful for reminding the staff that this family has experienced a loss (Fig. 28-3).

It is difficult to predict how long and how often parents will need to spend time with their baby. These moments are
the only ones they will have to parent their child while their child’s physical presence is still with them. Some parents need only a few minutes; others need hours. It is extremely painful for some parents to say good-bye to their baby. They will tell the nurse when they are ready verbally and nonverbally. The nurse should watch for cues that the parents have had enough time with their baby, such as when parents are no longer holding their child close to them or have placed the baby back in the crib. Asking parents whether they have had enough time may make parents feel that the nurse thinks they have had enough time, which may not be the case. When a baby is taken too soon from parents, it leaves them feeling as though the baby was “ripped from their arms too soon.” Heiman, Yankowitz, and Wilkins (1997) found that 85% of parents in their study would have appreciated additional opportunities to see their baby, and 44% felt they did not have adequate time with the baby. Therefore sensivity to parental needs in actualizing the loss and coping with the reality of the death is essential for their healing.

Grandparents should be offered the same opportunities to hold, rock, swaddle, and love their grandchildren so that their grief is started in a healthy way.

Help the parents with decision making

At the time of a perinatal loss, and especially if the loss was of an infant, parents have many decisions to make when they are experiencing great distress. Mothers, fathers, and extended families look to the medical and nursing staff for guidance in knowing what decisions they must and can make and in understanding the options related to those decisions. Therefore it is a primary responsibility of the nurse to help them and to advocate for them because decisions made during the time of their loss will provide their memories for a lifetime.

One decision might be related to conducting an autopsy (Box 28-3). An autopsy can be very important in answering the question "why" if there is a chance that the cause of death can be determined. This information can be helpful in processing grief and perhaps preventing another loss. However, the cost of an autopsy must be considered. Autopsies may not be covered by insurance and are expensive. However, if the autopsy is done under the jurisdiction of the medical examiner’s office, there is no charge. Some parents may feel that their baby has been through enough and prefer not to have further information about the cause of death. Some religions prohibit autopsy or limit the choice to times when it may help prevent another loss. Options for the type of autopsy, such as excluding the head, are available to parents. Parents may need time to make this decision. There is no need to rush them, unless there was evidence of contagious disease or maternal infection at the time of death.

Organ donation can be an aid to grieving and an opportunity for the family to see something positive associated
Autopsies are the best method to investigate perinatal deaths. However, the improvement in diagnostic techniques may make the autopsy seem unnecessary to the clinician (Steigman, 2002). Autopsies are expensive, and third-party payers do not pay hospitals or pathologists directly for them; payment is bundled into general hospital payments. Current charge for an autopsy is $3200 (Vidal Herrera, personal communication, May 25, 2005).

The rate of neonatal autopsies remains higher than that for adults, with the rate ranging from 59% to 81% (Brodlie, Laing, Keeling, & McKenzie, 2002). Parents agree to an autopsy to answer questions about “Why?” and to help others. Parents may refuse autopsy because they do not want the child mutilated and feel that the baby has already been through enough and when they have no questions that were not answered (Lyon, 2004). Rankin, Wright, and Lind (2002) investigated the experience and views of autopsy by parents. They found that 7% of parents who agreed to the examination and 14% who refused the examination regretted their decision.

When parents refuse autopsy, magnetic resonance imaging is a noninvasive alternative with the major disadvantage of a lack of tissue sampling (Huisman, 2004). In cases of the death of a neonate with congenital anomalies, the probability of identifying the etiologic diagnosis is increased when clinical geneticists and fatal pathologists work together (Cernach, Patricio, Galera, Moron, & Brunoni, 2004). Nurses may be involved in seeking consent for autopsy or in answering parents’ questions about the examination. They can provide support for the decision the parents make. They should be aware of agency policies where they are employed and pertinent regulations dictated by the community.

BOX 28-3

Autopsies

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LEGAL TIP: Defining Live Birth

Laws in all states govern what constitutes a live birth. In most states a live birth is considered to be any products of conception expelled from a woman that show any signs of life. Signs of life are considered to be any muscle irritability, respiratory effort, or heart rate, regardless of gestational age. All nurses should be knowledgeable about their state laws regarding what constitutes a live birth and what forms must be completed and filed in the case of fetal death, stillbirth, or newborn death.

Provide postmortem care

Preparation of the baby’s body and transport to the morgue depends on the procedures and protocols developed by individual hospitals. The Joint Committee on Accreditation of Healthcare Organizations requires that we offer appropriate care to the body after death. A sensitive and respectful approach for taking the fetus or infant to the morgue is the use of a “burial cradle” (Fig. 28-4). These miniature coffins have a quilted lining and replace wrapping the baby in a Chux pad (see Resources at end of chapter). Postmortem care can be an emotional and sometimes difficult task for the nurse. However, nurses may find that providing postmortem care helps them find closure in their own grief related to a perinatal loss. This is particularly true for neonatal...
reavement. However, it is difficult for parents to know ex-
be the foundation for the development of complicated be-
many needs. Unmet needs can form the basis of “if only”
have been shattered with a perinatal loss; thus they may have
will be done by the facility conducting the cremation.
face desires cremation, they may want to have the option of
ily desires cremation, they may want to bury
have decisions about what funeral home to call and where
children in their hometown or family cemetery. If the fam-
many couples may be living in an area dis-
tant from their family homes, and they may want to bury
the meaning it has for their lives and to share their emotional
should acknowledge the loss with a simple but sincere com-
with them. These are the first steps toward their own journey.
be scattered; many states have regulations regarding
plot, or in a mausoleum. Ashes also may be scattered in a
designated area; many states have regulations regarding
where ashes can be scattered. A local funeral director or a
the state’s rules, codes, and regulations regarding live births,
burial requirements, transportation of the deceased by par-
etal hours, days, or weeks.
mostly in the comfort of their home and contact the hospital in the
some cases the mother may be discharged home before these
decisions are made. Then the family can think about them in the
comfort of their home and contact the hospital in the following
to give their answers.

Help the bereaved to acknowledge and express their feelings
One of the most important goals of the nurse is to vali-
date the experience and feelings of the parents by encour-
aging them to tell their stories and to listen with care
(Corbet-Owen & Kruger, 2001). At the very least, the nurse
should acknowledge the loss with a simple but sincere com-
ment such as “I’m sorry about the baby,” or “I’m sorry about
your loss.” Helping the parents to talk about their loss and
the meaning it has for their lives and to share their emotional
pain is the next step. “Tell me about what happened.” Be-
cause nurses tend to be very focused on the physical and
emotional needs of the mother, it is especially important to
ask the father directly about his views of what happened and
his feelings of loss.

The nurse should listen patiently during the story of loss
or grief, but listening is hard work and can be painful for the
helper. The feelings and emotions of expressed grief can over-
whelm health care professionals. Being with someone who
is terribly sad and crying or sobbing can be extremely dif-
ficult. The initial impulse to reduce one’s sense of help-
lessness is to say or do something that you think will reduce
their pain. Although such a response may seem supportive
at the time, it can stifle the further expression of emotion.
Bereaved parents have identified many unhelpful responses
made to them by well-meaning health care professionals,
family, and friends. The nurse should resist the temptation
to give advice or to use clichés in offering support to the be-
reaved (Box 28-4). Nurses need to be comfortable with their
own feelings of grief and loss to support and care for be-
reaved persons effectively. The nurse should have a presence
of self, the willingness to be alongside, quietly supporting
the bereaved in whatever expressions of feelings or emotions
are appropriate for them. This presence leaves parents feel-
that they were cared for. Leaning forward, nodding the
head, and saying “Uh-huh” or “Tell me more” is often en-
couragement enough for the bereaved person to tell his or her story. Sitting through the silence can be therapeutic; silence gives the bereaved person an opportunity to collect thoughts and to process what he or she is sharing. Furthermore, careful assessment is important before using touch as a therapeutic technique. For some, touch is a meaningful expression of concern, but for others it is an invasion of privacy.

Bereaved parents have many questions surrounding the event of their loss that can leave them feeling guilty. This is particularly true for mothers. Such questions include “What did I do?” “What caused this to happen?” “What do you think I should have, could have done?” Part of the grief process for bereaved parents is figuring out what happened, their role in the loss, why it happened to them, and why it happened to their baby. The nurse should recognize that the answers to these questions must be answered by the bereaved themselves; it is part of their healing. For example, a bereaved mother might ask, “Do you think that this was caused by painting the baby’s room?” An appropriate response might be, “I understand you need to find an answer for why your baby died, but we really don’t know why she died. What are some of the other things you have been thinking about?” Trying to give bereaved parents answers when there are no clear answers or trying to squelch their guilt feelings by telling them they should not feel guilty does not help them process their grief. In reality, many times there are no definite answers to the question of why this terrible thing has happened to them. However, factual information, such as data about the frequency of miscarriages in pregnant women or the fact that there usually is no clear cause for a stillbirth, can be helpful.

Stillbirth can create intense feelings of incompleteness and failure. There may be culturally bound taboos against talking about death, taking part in events related to death, or expressing grief in public that can influence the grieving process (Hsu, Tseng, Banks, & Kuo, 2004). Feelings of anger, guilt, and sadness can occur immediately but often become more problematic in the early days and months after a loss. When a bereaved person expresses feelings of anger, it can be helpful to identify the feeling by simply saying, “You sound angry,” or “You look angry.” The nurse’s willingness to sit down and listen to these feelings of anger can help the bereaved move past those surface feelings into the underlying feelings of powerlessness and helplessness in not being able to control the many aspects of the situation.

Normalize the grief process and facilitate positive coping

While helping parents share their feelings of pain, it is critical to help them understand their grief responses and feel they are not alone in these painful responses. Most parents are not prepared for the raw feelings that they experience or the fact that these painful, complex feelings and related behavioral reactions continue for many weeks or months. Reassuring them of the normality of their responses and preparing them for the length of their grief is important. The nurse can help the parent be prepared for the emptiness, loneliness, and yearning; for the feelings of helplessness that can lead to anger, guilt, and fear; and for the cognitive processing problems, disorganization, difficulty making decisions; and sadness and depression that are part of the grief process. Books and pamphlets about grief, if short and sensitive, can be given to parents to take home. Many parents have reported feelings of fear that they were going crazy because of the many emotions and behavioral responses that leave them feeling totally out of control in the months after the loss. It is essential for the nurse to reassure and educate bereaved parents about the grief process, including the physical, social, and emotional responses of individuals and families. Offering health teaching on the bereavement process alone is not enough, however. In the initial days after a loss, other strategies might include follow-up phone calls, referrals to a perinatal grief support group, or provision of a list of publications or websites intended to help parents who have experienced a perinatal loss (see Community Activity). As with any referral, however, the nurse should first read the material or check out the websites (see Resources at the end of the chapter).

To reduce relationship problems that can occur in couples who are grieving, it is particularly important to help...
them understand that they may respond and grieve in very different ways. Differences in grieving can lead to serious marital problems and be a risk factor for complicated bereavement. Remind the couple of the importance of being understanding and patient with each other. Nurses can reinforce positive coping efforts and attempt to prevent negative coping. They can remind the parents of the importance of being patient and being good to themselves during the grief process. In particular, nurses should discourage dependence on drugs and alcohol.

Meet the physical needs of the postpartum bereaved mother

Coping with loss and grief after childbirth can be an overwhelming experience for the woman and her family. One particularly difficult aspect of the loss is the sound of crying babies and the happiness of other families on the unit who have given birth to healthy infants. The mother should be given the opportunity to decide if she wants to remain on the maternity unit or be moved to another hospital unit. She also should be helped to understand the advantages and disadvantages of each choice. Postpartum care as well as grief support may not be as good on another hospital unit where the staff are not experienced in postpartum and bereavement care. The physical needs of a bereaved mother are the same as those of any woman who has given birth. The cruel reality is that their milk may come in with no baby to nurse, their afterpains remind them of their emptiness, and gas pains feel as though a baby is still moving inside. The nurse should ensure that the mother receives appropriate medications to reduce these physical signs and symptoms. Adequate rest, diet, and fluids must be offered to replenish her physical strength. Mothers need postpartum care instructions on discharge. They also need ideas about how to cope with problems with sleep such as decreasing food or fluids that contain caffeine, limiting alcohol and nicotine consumption, exercising regularly, using strategies for rest, taking a warm bath or drinking warm milk before bedtime, doing relaxation exercises, listening to restful music, or getting a massage. Furthermore, the couple needs to be encouraged and supported in maintaining their relationship and keeping open channels of communication. They also need to be prepared for some of the issues related to resuming sexual intimacy after perinatal loss.

Assist the bereaved in communicating with, supporting, and getting support from family

Providing sensitive care to bereaved parents means including their families in the grief process. Grandparents and siblings are particularly important when a perinatal loss has occurred. However, it is up to the parents to decide to what extent they want family involved in their grief process. If it is the parents’ desire, children, grandparents, extended family members, and friends should be allowed to be involved in the rituals surrounding the death, such as seeing and holding the baby. Such visits afford others the opportunity to become acquainted with the baby, to understand the parents’ loss, to offer their support, and to say good-bye (see Fig. 28-2). This experience helps parents explain to their surviving children who their brother or sister was and what death means, offers the children answers to their questions in a concrete manner, and helps the children in expressing their grief. Involving extended family and friends enables the parents to mobilize their social support system of people who will support the family not only at the time of loss but also in the future. Parents also need information about how grief affects a family. They may need help in understanding and coping with the potential differing responses of various family members. Frustrations may arise because of the insensitive or inadequate responses of other family members. Parents may need help in determining ways to let family members know how they feel and what they need.

Create memories for parents to take home

Parents may want tangible mementos of their baby to allow them to actualize the loss. Some may want to bring in a previously purchased baby book. Special memory books, cards, and information about grief and mourning are available for purchase by parents or hospitals or clinics through national perinatal bereavement organizations (Fig. 28-5). The nurse can provide information about the baby’s weight, length, and head circumference to the family. Footprints and handprints can be taken and placed with the other information on a special card or in a memory or baby book. Sometimes it is difficult to obtain good handprints or footprints. Application of alcohol or acetone on the palms or soles can help the ink adhere to make the prints clearer, es-
Chapters 28

Perinatal Loss and Grief

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Critical Thinking Exercise

The Bereaved Couple

Marsha gave birth to a stillborn 17-week fetus. This is her second miscarriage. She has been diagnosed with prematurity dilation of the cervix. She and her husband, Andrew, are in the LDRP room 1 hour after the birth. Both are crying softly. Andrew has his arm around Marsha and is trying to comfort her. You have just come on duty and are assigned to care for the couple. When you enter the room, Marsha says, “Why did this happen? I want a baby so badly. I did everything right; I did exactly what the doctor told me to do. My sister has five children and she didn’t even want the last one. What is the matter with me? Why is God doing this to us?” How should you respond to Marsha’s questions? What can you do to comfort the couple? Should they see the baby?

1. Evidence—Is there sufficient evidence to draw conclusions about factors interfering with healthy bereavement? About appropriate support related to accepting the death of the baby? Is the fact that this is Marsha’s second miscarriage a factor in her grief?
2. Assumptions—What assumptions can be made about the following factors?
   a. A diagnosis of prematurity dilation of the cervix
   b. A second miscarriage
   c. The importance of the father’s support
   d. Andrew’s need for an outlet for his grief
3. What implications and priorities for nursing care can be drawn at this time?
4. Does the evidence objectively support your conclusion?
5. Are there alternative perspectives to your conclusion?

Communicate using a caring framework

Mothers, fathers, and extended families look to the nursing staff for support and understanding during the time of loss. Nurses have an important role in providing sensitive care to parents at the time of a perinatal loss. The nurse needs to take the time to understand the meaning of the loss to the woman and her family. The nurse provides physical care, comfort, and safety for the woman and her family. Others of information, anticipatory guidance, choices for decision making, and support during hospitalization and after discharge help the family feel more in control of a situation in which they feel very much out of control. The woman and her family are encouraged to believe in their own ability to begin the process of healing. The nurse spends time with the family, learns their inner strengths and coping abilities, and begins the process of healing. The nurse spends time with the family are encouraged to believe in their own ability to take the time to understand the meaning of the loss to the family and personalizes the mementos. The nurse should ask parents if they wish to have these articles before giving them to the parents. A lack of hair may be another important keepsake. Parents must be asked for permission before cutting a lock of hair, which can be removed from the nape of the neck where it is not noticeable.

For some, pictures are the most important memento. Photographs should be taken whenever there is an identifiable baby and when it is culturally acceptable to the family. It does not matter how tiny the baby is, what the baby looks like, or how long the baby has been dead. Pictures should include close-ups of the baby’s face, hands, and feet. Pictures should be taken of the baby clothed and wrapped in a blanket as well as unclothed. If there are any congenital anomalies, close-ups of the anomalies should also be taken. Flowers, blankies, stuffed animals, or toys can be placed in the background to make the picture more special. Parents may want their pictures taken holding the baby. Keeping a camera nearby and taking pictures when parents are spending special time with their baby can provide special memories. Some parents may have their own camera or video camera and would like the nurse to record them as they bathe, dress, hold, or diaper their baby.

Communicate using a caring framework

Mothers, fathers, and extended families look to the nursing staff for support and understanding during the time of loss. Nurses have an important role in providing sensitive care to parents at the time of a perinatal loss. The nurse needs to take the time to understand the meaning of the loss to the woman and her family. The nurse provides physical care, comfort, and safety for the woman and her family. Others of information, anticipatory guidance, choices for decision making, and support during hospitalization and after discharge help the family feel more in control of a situation in which they feel very much out of control. The woman and her family are encouraged to believe in their own ability to begin the process of healing. The nurse spends time with the family, learns their inner strengths and coping abilities, and points out these inner resources to the family by saying, “I know this is a difficult time for you, but I have seen some of your inner strength and know that you will be able to make it through all of this.”

Be concerned about cultural and spiritual needs of parents

Parents who experience perinatal loss can be from widely diverse cultural and ethnic groups. In addition, parents belong to many different religious groups. Many of the responses that are described and the interventions suggested in this chapter are based on European-American views of perinatal grief and loss. Although it is thought that there are no particular differences in the individual, interpersonal experiences of grief based on culture, ethnicity, or religion, many differences are found in mourning rituals, traditions, and behavioral expressions of grief that are often ignored or misunderstood. Therefore the practices suggested earlier may not be appropriate for parents from other cultural, ethnic, and religious groups, and the nurse must consider the potential unique responses and needs of parents from different groups. This involves understanding the cultural orientation and beliefs of the individual parent, the partner, the extended family, and the larger community to which they belong.

Cultural and religious differences can affect the way parents respond to a perinatal loss. This includes their way of...
communicating with health care professionals, as well as their emotional and behavioral responses and family interaction patterns. Some groups, such as Orthodox Jews, may not support the notion of grieving for perinatal loss because the fetus or stillborn infant is not considered a person. Some African-American women were found to use self-healing strategies that reflect inner processes, resources, and remedies (Van, 2001). Mothers from some cultural groups may have intense somatic symptoms. In some cultures, such as the Muslim culture, decisions are communal (Arshad, Horsfall, & Yasin, 2004). Expressions of grief may range from quiet and stoic to dramatic and hysterical for different Native American groups. Native Americans from many tribes would not respond well to an “interviewing” or “questioning” approach (Lawson, 1990). Mexican mothers may be very demonstrative in their grief, while also struggling with the view that hardship is “God’s will” (Lawson, 1990).

With perinatal loss, culture and religious beliefs can affect issues such as seeing the child, naming the child, and taking pictures. Some cultural and religious groups do not believe in naming an infant who dies before 30 days of age. Picture taking can conflict with beliefs of some cultures, such as some Native American, Eskimo, Amish, Hindu, and Muslim cultures. Families from these cultures should be sensitively offered this opportunity but not pushed into having a picture taken.

Many different taboos and expectations are related to death for different religious groups. Autopsies are not allowed by some religions except under unusual circumstances. Cremation is forbidden by the Jewish religion, Bahá’ís, and the Greek Orthodox Church (Harakas, 1999). It is discouraged or allowed only under unusual circumstances in the Church of Jesus Christ of Latter-Day Saints. Embalming is not allowed for Jews, Bahá’ís, and Muslims.

Culture and religious beliefs also influence the customs surrounding death. Many religious groups have rituals, such as prayers, ritualistic washing and shrouding, or anointing with oil, that are performed at the time of death. Baptism is extremely important for Roman Catholics and some Protestant groups. Baptism can be performed by a lay person, such as a nurse, in an emergency situation when a priest cannot be there in a timely fashion (Box 28-5).

Many Protestant groups believe that baptism is conducted at the age of reason, and parents from these religions would not want their baby baptized. When bereaved parents need a referral for grief counseling, cultural considerations are paramount. Native Americans, for example, are best referred to native healers and counselors rather than to Western biomedical therapists (Lawson, 1990).

**Provide sensitive care at and after discharge**

When leaving the hospital, mothers are often taken out in a wheelchair. This can be a devastating experience for the mother who has experienced a pregnancy loss. Leaving the hospital without a baby in her arms is a very empty and painful experience. It is especially difficult if others are seen leaving with babies; therefore the discharge of mothers and fathers who have experienced a perinatal loss should be done with great sensitivity to their feelings. They should not be discharged at a time when other mothers with live babies are leaving. Giving the mother a special flower to carry in her arms can be a thoughtful gesture.

The grief of the mother and her family does not end with discharge; rather it really begins once they return home, attend the funeral, and start to live their lives without their baby. Follow-up phone calls after a loss may be helpful to some parents. However, it must be determined when parents do not want a follow-up call, which often is the case after early loss. Follow-up calls let the parents know they are still thought of and cared about. The calls are made at predictable difficult times such as the first week at home, 1 month to 6 weeks later, 4 to 6 months after the loss, and at the anniversary of the death. Families who experienced a miscarriage, ectopic pregnancy, or death of a premature baby may appreciate a phone call on the estimated date of birth. The calls provide an opportunity for parents to ask questions, share their feelings, seek advice, and receive information to help them in processing their grief.

A grief conference can be planned when parents return for an appointment with their doctor, nurses, and other health care providers. At the conference, the loss or death of the infant is discussed in detail, parents are given information about the baby’s autopsy report and genetic studies, and they have opportunities to ask the questions that have arisen since their baby’s death. Parents appreciate the opportunity to review the events of hospitalization, go over the baby’s and/or mother’s chart with their primary health care provider, and talk with those who cared for them and their baby during hospitalization. This is an important time to help parents understand the cause of the loss, or to accept the fact that the cause will forever be unknown. This gives health care professionals the opportunity to assess how the grief is progressing and to provide support if needed.
family is coping with their loss and provide additional information and education on grief.

Some parents are very interested in finding a perinatal or parental grief support group. They appreciate the opportunity to talk with others who have been through similar experiences. A grief support group also can be helpful for sharing feelings and gaining an understanding of the normality of the grief process. An online perinatal loss listserve is a way to connect women who are geographically distant but share similar stories and pain (Capitulo, 2004). A group for women experiencing pregnancy after loss is also useful (Coste-Arsenault & Freije, 2004).

Over time, a support group may be the only place where bereaved parents can talk about the wished-for child and their grief. However, not all parents find such groups helpful. When referring to a group, it is important to know something about the group and how it operates. For example, if a religious parent would not be likely to find the group helpful, then they might feel overwhelmed with the grief of parents whose older children have died of cancer, suicide, or homicide. In addition, their grief might be minimized by participants; therefore the needs of the parents must be matched with the focus of the group.

**Evaluation**

The evaluation of nursing care is made more difficult by the shock and numbness of the bereavement process and the varied grief responses of the parents and other family members during hospitalization. The achievement of expected outcomes is assured when the positive integration of the perinatal loss is expressed by the family (Plan of Care).

One approach to evaluation is the use of checklists. Many hospitals have checklists used in providing care, mobilizing members of the multidisciplinary health care team, communicating the family's needs, and keeping track of all the details in meeting the needs of bereaved parents (Fig. 28-6). Such checklists may be a permanent part of the chart. Documentation in the nursing notes of primary concerns, grief responses, health teaching, health care advice, and any referrals of the mother or other family members is essential to ensure continuity and consistency of care.

**PLAN OF CARE**

### Fetal Death: 20 Weeks of Gestation

#### NURSING DIAGNOSIS

**Dysfunctional grieving related to fetal death, as evidenced by intense expressions of grief for prolonged period of time**

**Expected Outcome** Parents will identify appropriate ways to deal with grief.

**Nursing Interventions/Rationales**

- Prepare family for viewing fetus by cleaning body and wrapping in clean blanket to initiate and support the grieving process in a supportive setting.
- Allow family quiet time to hold and view fetus. Take pictures for family to keep to provide sense of reality regarding the death and support the grieving process.
- Provide a certificate for the family with vital statistics, along with identification bands, lock of hair, and footprints to emphasize reality of situation and support the grieving process.
- Provide spiritual support as needed to assist with religious services such as baptism and memorial services to provide spiritual support and assist with religious practices.
- Refer to appropriate community support groups to facilitate grieving with group input and to share experiences.

#### NURSING DIAGNOSIS

**Situational low self-esteem related to fetal death as evidenced by mother’s or family’s intense feelings of guilt**

**Expected Outcome** Mother and family will exhibit positive self-image and adapt to death of fetus in a timely manner.

**Nursing Interventions/Rationales**

- Provide private time for expressions of feelings through therapeutic communication and active listening to validate feelings.
- Identify mother’s and family’s perception and feelings about fetal death to correct any misconceptions and alleviate guilt.
- Assist mother and family to identify positive coping mechanisms and support systems to promote feelings of self-worth.
- Refer to appropriate health professionals for further evaluation and counseling, such as social service, to provide ongoing assistance as needed.
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- Refer to appropriate health professionals for further evaluation and counseling, such as social service, to provide ongoing assistance as needed.

#### NURSING DIAGNOSIS

**Spiritual distress related to perinatal loss**

**Expected Outcome** Parents will verbalize a decrease in spiritual distress.

**Nursing Interventions/Rationales**

- Assist parent’s spiritual preference to reinforce parent’s own beliefs.
- Assist with spiritual rituals for parents and infant to promote comfort for parents.
- Provide opportunity for parents to express feelings about perinatal loss to facilitate the grieving process.
- Assist parents in contacting the facility’s chaplain or personal spiritual advisor to provide spiritual support.

#### NURSING DIAGNOSIS

**Ineffective family coping**

**Expected Outcome** Family will use coping strategies to accept death of fetus.

**Nursing Interventions/Rationales**

- Encourage parents to seek emotional support from each other to improve coping ability.
- Assist grandparents to participate in grieving with their son/daughter to demonstrate understanding and support.
- Refer parents to grief support group to provide ongoing assistance and support.
- Listen to parents’ expressions of grief to enhance understanding of factors creating distress and give direction to support.
### RTS Bereavement Services

**SAMPLE CHECKLIST FOR ASSISTING PARENT(S) EXPERIENCING STILLBIRTH OR NEWBORN DEATH**

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Comments</th>
<th>Initials</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tbody>
</table>

- Notify/Assign RTS counselor: [ ] Yes [ ] No
- Pastoral Care notified: [ ] Yes [ ] No
- Family Burial: [ ] Yes [ ] No
- Saw baby when born and/or after delivery: [ ] Mother [ ] Father
- Touched and/or held baby: [ ] Mother [ ] Father
- Offered private time with their baby: [ ] Yes [ ] No
- Baptism offered: [ ] Yes [ ] No
- Remembrance of Blessing offered: [ ] Yes [ ] No
- Given option to transfer off Maternity Unit: [ ] Yes [ ] No
- Patient’s room flagged with door card: [ ] Yes [ ] No
- Genetic studies: [ ] Yes [ ] No
- Genetic Associate notified: [ ] Yes [ ] No
- Autopsy: [ ] Yes [ ] No
- Section of Fetal monitor strip: [ ] Given to parents [ ] On file
- ID Bands/Crib cards/Tope measure: [ ] Given to parents [ ] On file
- Footprints/Handprints/Weight/Length recorded on "In Memory Of" sheet: [ ] Given to parents [ ] On file
- Lock of hair offered: [ ] Yes [ ] No
- Given to parents [ ] On file
- Given to aunts [ ] On file
- Family Burial: [ ] Yes [ ] No
- Siblings: [ ] Yes [ ] No
- Genograms: [ ] Yes [ ] No
- Friends: [ ] Yes [ ] No
- Baby’s name:
- Children's name(s):
- Support people:
- Attending MD &/or Pediatrician:
- Notify Peds Nurse Practitioner:
- RTS Bereavement Services:
- RTS Counselor:
- Phone number:
- Date/Time delivered:
- Baby’s name:
- Children’s name(s):
- Age:
- Sex:
- Religion:
- Optimal call time:
- Phone number:
- Date/Time death:
- Patient’s name:
- Address:
- Phone number:
- Date of birth:
- Address:
- Father’s name:
- Phone number:
- Date of delivery:
- Mother’s name:
- Address:
- Phone number:
- Date of death:
- Age:
- Parity:
- L.C.:
- Due date:
- Previous loss:
- Date:
- Time:
- Comments:

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**Fig. 28-6** Sample checklist for assisting parents experiencing stillbirth or newborn death. (Used with permission of Bereavement Services. Copyright Lutheran Hospital-La Crosse, Inc., A Gundersen Lutheran Affiliate, La Crosse, WI.)
Prenatal Diagnoses with Negative Outcome

Early prenatal diagnostic tests such as ultrasonography, chorionic villus sampling, and amniocentesis can determine the well-being of the embryo or fetus. Reasons for prenatal testing include history of chromosomal abnormality in the family; three or more miscarriages; maternal age over 35 years; lack of fetal growth, movement, or heart beat; and diabetes mellitus or other chronic illnesses. If the health care provider is certain that the baby has a serious genetic defect that would lead to death in utero or after birth (congenital anomalies incompatible with life or genetic disorders with severe mental retardation), the choice of interruption of a pregnancy may be offered. Abortion is controversial, and this may prevent parents from sharing this decision with other family members or friends. This limits their support systems after their loss.

The decision to terminate a pregnancy paves the way for feelings such as guilt, despair, sadness, depression, and anger. The nurse’s role is to be a good listener. It is important to assess how these families feel about the experience and to offer options for their memories as appropriate. Healing can

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Comments</th>
<th>Initials</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Informed about postponing funeral until mother is able to attend: ☐ Yes ☐ No</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Services/Funeral arrangements, options discussed: ☐ Self-transport ☐ Gravesite service ☐ Visitation ☐ Hospital chapel ☐ Cremation ☐ Funeral home ☐ Burial at foot or head of relative’s grave ☐ Specific area for babies in cemetery ☐ Plan own service</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Funeral arrangements made by: ☐ Mother ☐ Father</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Discussed: ☐ Seeing baby at funeral home ☐ Taking pictures there ☐ Providing outfit/hay for baby ☐ Dressing baby at funeral home</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Grief information packet given to: ☐ Mother ☐ Father</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Discussed grief process/incongruent grief with: ☐ Mother ☐ Father</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Discussed grief conference: ☐ Yes ☐ No</td>
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<tr>
<td></td>
<td></td>
<td>RTS Parents Support Group brochure given to: ☐ Mother ☐ Father</td>
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<tr>
<td></td>
<td></td>
<td>RTS business card given to: ☐ Mother ☐ Father</td>
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<td></td>
<td></td>
<td>Pregnancy &amp; Infant Loss Card sent to RTS secretary: ☐ Yes ☐ No</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Follow-up calls: 1 week: ___________________________ Due date: ___________________________ 6-10 months: ___________________________ Anniversary date: ___________________________</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Grief conference planned with parents: Date: ____________ Time: ____________ Place: ___________________________</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Letter of confirmation sent: ☐ Yes ☐ No</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Parent Support Group, first meeting attended: Date: ____________</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Follow-up meetings attended: Dates: ___________________________</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Would like another parent to call: ☐ Yes ☐ No ☐ Ask later</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Parent contact: ______________________________________________</td>
<td></td>
</tr>
</tbody>
</table>

Forms Needed: 
- Report of fetal death (Photocopy and save for mother.)
- Autopsy if ordered
- Record of death
- Genetics protocol (folder) if ordered
- Notice of removal of a human corpse from an institution
- Final disposition form
- If funeral home involved - Final disposition will be completed by them.
- Original certificate of death (for NB death only)

Note: Family Burial - Check with your funeral home.

** You may wish to list your hospital and state forms that are necessary, as required by your state laws and your institution.

Fig. 28-6 cont’d

SPECIAL LOSSES

Prenatal Diagnoses with Negative Outcome

Early prenatal diagnostic tests such as ultrasonography, chorionic villus sampling, and amniocentesis can determine the well-being of the embryo or fetus. Reasons for prenatal testing include history of chromosomal abnormality in the family; three or more miscarriages; maternal age over 35 years; lack of fetal growth, movement, or heart beat; and diabetes mellitus or other chronic illnesses. If the health care provider is certain that the baby has a serious genetic defect that would lead to death in utero or after birth (congenital anomalies incompatible with life or genetic disorders with severe mental retardation), the choice of interruption of a pregnancy may be offered. Abortion is controversial, and this may prevent parents from sharing this decision with other family members or friends. This limits their support systems after their loss.

The decision to terminate a pregnancy paves the way for feelings such as guilt, despair, sadness, depression, and anger. The nurse’s role is to be a good listener. It is important to assess how these families feel about the experience and to offer options for their memories as appropriate. Healing can
take place when words can be given to feelings and needs can be met.

The parent who decides to continue the pregnancy also requires emotional support. The time of labor and birth can be particularly difficult. The nurse should remember that parents may be grieving not only the loss of the perfect child but the loss of expectations for their child's future.

Loss of One in a Multiple Birth

The death of a twin or baby in a multifetal gestation during pregnancy, labor, or birth or after birth requires parents to parent and grieve at the same time. Such a death results in a confusing and ambivalent induction into parenthood. Parents feel that they cannot do anything right. They cannot parent their surviving child with all the joy and enthusiasm of new parents because their surviving child reminds them of what they have lost. They cannot give over completely and grieve in the manner they need to because their surviving child demands their attention. These parents are at risk for altered parenting and complicated bereavement.

It is important to help the parents acknowledge the birth of all their babies. Parents should be treated as bereaved families, and all the options previously discussed should be offered. Pictures should be taken of the babies, and parents should be offered the opportunity to hold their babies in their arms and have time to say goodbye to the baby who has died.

Bereaved parents should be warned that well-meaning family members or friends may say, “Well, at least you have the other baby,” implying that there should be no grief because they are lucky to have one at all. Parents need to be able to anticipate insensitivity to their loss and be empowered to say to others, “That is how I feel.” By simply setting a boundary on what their feelings are, they are able to acknowledge the baby who died and then have an opportunity to share more about their feelings if they so choose.

Bereaved parents of multiples have special problems in coping with life without their anticipated “extra special” family, telling their surviving child about his or her twin, dealing with the possibility of that child’s feelings of survivor guilt, and deciding on how to celebrate birthdays, death days, or special holidays.

Adolescent Pregnancy

Adolescent pregnancy accounts for many births in the United States. Each year, many adolescents experience perinatal loss, including as elective abortion or miscarriage. Although adolescent participants have been included in the samples of research done in all areas of perinatal bereavement, their unique responses to perinatal loss have not been identified. Adolescents grieve the loss of their babies and need the emotional support from the nurses who care for them. However, nurses and other health care professionals, as well as family members, often believe that the adolescent’s loss of her baby was for the best, so that the adolescent can move on with her life. Adolescent girls, then, may not receive the support they need from staff and family. In addition, adolescent girls usually do not have the support from the father of the baby as compared with older women who have a perinatal loss; therefore there is a great need to provide sensitive care to all adolescents who experience any type of perinatal loss.

The first step for the nurse in caring for a bereaved adolescent is to acknowledge the significance of giving birth, no matter what the mother’s age. Second, the nurse should make additional efforts to develop a trusting relationship with the adolescent. Third, the nurse should offer options for saying goodbye, anticipatory guidance, support, and information to meet the adolescent at the point of her need. It may take longer for adolescents to process their grief because of their level of cognitive and emotional maturation. Being patient, saving mementos, and giving the adolescent information on how to contact the nurse are interventions that can help the adolescent accept the reality of the loss and process her grief.

COMPPLICATED BEREAVEMENT

Although most parents cope adequately with the pain of their grief and return to some level of normal functioning, some parents have extremely intense grief reactions that last for a very long time; this response is complicated bereavement. Other parents have grief from one loss that is exaggerated or intensified by other past losses. A long preloss pregnancy (e.g., the fetus died in late gestation), a psychiatric personality, more preexisting psychiatric symptoms, and a lack of other living children are important risk factors for stronger grief reactions for either parent (Janssen, Cuisinier, de Graauw, Hoogevein, 1997).

Evidence of complicated grief includes continued obsession with yearning and loneliness, intense and continued guilt or anger, relentless depression or anxiety that interferes with role functioning, abuse of drugs (including prescription medications) or alcohol, severe relationship difficulties, continued feelings of inadequacy and low self-esteem, and suicidal thoughts or threats. Feelings of inadequacy, in particular, were strongly and positively related to distress after 4 years (Hunfeld, Wladimiroff, & Pachter, 1997). Parents showing signs of complicated grief should be referred for counseling. It is the responsibility of a qualified mental health professional to determine whether the parents are experiencing a normal, albeit intense grief response or whether they are also having a serious mental health problem such as depression. However, it is important to refer to a therapist or counselor who is experienced in grief counseling and knows how to help the bereaved, because some therapists and counselors do not have an understanding of the special needs related to grief.

Therapy is a big step. The highest number of cancellations and “no shows” in a therapist’s practice are intakes, or first visits; therefore, anything the nurse can do for a family or
individual to help with that major hurdle would be useful. However, it also is important to remember that people may have symptoms but may not, for whatever reason, be ready to deal directly with these symptoms or may not have the energy to make the call. Enlisting a family member to encourage parents to seek such assistance may be helpful.

COMMUNITY ACTIVITY

1. Identify community resources and support groups for parents who have experienced the following:
   a. Infertility
   b. Birth of a less-than-perfect child
   c. Death of a baby through miscarriage, stillbirth, or newborn death.
   What services do each of these resources or groups provide?

2. Interview a mother, father, or couple who have experienced a perinatal loss.
   a. Ask them to tell you their story and then listen intently for their story lines.
   b. Ask them who or what helped them the most.
   c. Ask who or what made their experience more difficult.
   d. Ask what they would want nursing students caring for such parents to know so they may help parents.

Key Points

- Parental and infant attachment can begin before pregnancy with many hopes and dreams for the future.
- The gestational age of the baby influences neither the severity of the grief response nor the bereavement process.
- When a baby dies, all members of a family are affected, but no two family members grieve in the same way.
- When birth represents death, the role of the nurse is critical in caring for the woman and her family, regardless of the age of the woman or stage of gestation.
- An understanding of the grief process is fundamental in the implementation of the nursing process.

Answer Guidelines to Critical Thinking Exercise

The Bereaved Couple

1. Yes, there is sufficient evidence to draw conclusions about factors interfering with healthy bereavement. Manisha may feel guilty about the death of her baby in spite of the fact that many stillbirths are unexplainable. She also may feel shame or incomplete as a woman because of the inability of her cervix to stay closed to permit pregnancy to continue. Women who have previously experienced a stillbirth have higher stress and anxiety than other pregnant women. There are excellent sources on appropriate support related to accepting the death of the baby and suggestions for what to say and what not to say (see Resources).

2. a. Some women with premature dilation of the cervix experience pregnancies that attain a longer gestation each time until finally a viable infant is born. She may be a candidate for a cerclage.
   b. Women who have experienced miscarriage often are anxious until the current pregnancy exceeds the gestation at which the previous miscarriage occurred.
   c. Support of the father is very important, as is that of the family.
   d. Andrew will also need support and understanding. He needs to be able to be vulnerable and express his feelings about the loss. Parents may express grief differently; they require good communication and understanding to resolve their differences.

3. The priority for nursing care at this time is to allow the couple to express their feelings: grief, anger, and sadness. They should be offered the opportunity to view, hold, and care for the baby. A memory kit should be assembled. The couple should be given the choice of moving off the maternity floor to another one. They may need assistance with contacting clergy, arranging for burial, etc. (A 17-week fetus does not have to be buried, but the parents may choose to do so.)

4. There is considerable information derived from research on death and dying, including appropriate support for bereaved parents.

5. Various cultures and religions may view a 17-week baby as a fetus and may not choose to name the baby, have it baptized, or buried. Some parents may choose cremation.
Resources

American Association of Pastoral Counselors (AAPC)
www.aapc.org

Bay Memorials
321 S. 15th Street
Escanaba, MI 49829
www.baymemorialsbabycaskets.com
906-786-2609

The Compassionate Friends (self-help organization for bereaved parents and siblings)
www.compassionatefriends.org

Griefnet (collection of resources of value to those who are experiencing loss and grief)
www.griefnet.org

Growth House, Inc. (grief related to pregnancy, including miscarriage, stillbirth, termination of pregnancy, and neonatal death)
www.growthhouse.org

Hannah’s Project (Christian support for fertility challenges)
www.hannah.org

Houston’s Aid in Neonatal Death (HAND): Supporting grieving parents in the greater Houston area with the rest of the world via the Internet
www.hern.org/~hand

Hygeia (online journal for pregnancy and neonatal loss: Dr. Michael Berman)
www.connex.com/~hygeia/

Miscarriage Support and Information Resources (comprehensive resource list)
www.painelandpress.com/support/miscarriage.html

NAME, the National Association of Medical Examiners
430 Pryor St., 3W
Atlanta, GA 30312
404-730-4780 (fax)
www.thename.org

OB/GYN.net (list of resources for loss and bereavement)
www.obgyn.net/woman/loss/loss.htm

Pen-Patients, Inc. (international nonprofit support network for bereaved parents)
www.pen-patients.org

The Process Group (web site of the Process Group, Inc.)
www.processgroup.org

SHARE (Support and Hope for All Resources Everywhere)
www.share-net.org

SIDS NETWORK
Sudden infant death syndrome (SIDS) information website
www.sidsnetwork.org

U.S. Department of Health and Human Services
1-800-Autoopsy.com
1-800-autopsy (1-800-288-6779)
info@1-800 autopsy.com

References


