Learning Objectives

After studying this chapter, you should be able to:
1. Discuss the concepts of loss, grief, and end-of-life care.
2. Describe at least three types of losses that an individual can experience.
3. Explain the grief process.
4. Differentiate between normal and unresolved or dysfunctional grief.
5. Define advance care planning.
6. Articulate the needs of dying persons and their survivors.
7. State the rationale for The Dying Person’s Bill of Rights.
8. Compare the perceptions of death by children during various growth stages.

Key Terms

Advance care planning
Advance directive
Bereavement
Durable health care power of attorney
Dying declaration exception to hearsay
Dying Person’s Bill of Rights
Dysfunctional grief
End-of-life care
Grief
Grief process
Health care directive
Health care proxy
Hospice care
Living will
Loss
Mourning
Palliative care
Patient Self-Determination Act
Suffering
Unresolved grief

People are complex, biopsychosocial beings. When they become ill, undergo diagnosis for altered health states, experience a loss, or progress into the end stage of life, their responses are the result of the complex interaction of biopsychosocial changes that occur. Because we live in a culture marked by dramatically different responses to the experiences of loss and grief, nurses often feel inadequate in planning interventions to facilitate grief management and the healing process.
This chapter provides information to familiarize the student with the concepts of loss, grief, and end-of-life care as they are experienced by individuals, families, and/or their significant others.

**Loss**

The concept of **loss** can be defined in several ways. The following definitions have been selected to familiarize the student with the concept of loss:

- Change in status of a significant object
- Any change in an individual's situation that reduces the probability of achieving implicit or explicit goals
- An actual or potential situation in which a valued object, person, or other aspect is inaccessible or changed so that it is no longer perceived as valuable
- A condition whereby an individual experiences deprivation of, or complete lack of, something that was previously present

Everyone has experienced some type of major loss at one time or another. Clients with psychiatric disorders, such as depression or anxiety, commonly describe the loss of a spouse, relative, friend, job, pet, home, or personal item.

**Types of Loss**

A loss may occur **suddenly** (eg, death of a child due to an auto accident) or **gradually** (eg, loss of a leg due to the progression of peripheral vascular disease). It may be **predictable** or occur **unexpectedly**. Loss has been referred to as **actual** (the loss has occurred or is occurring), **perceived** (the loss is recognized only by the client and usually involves an ideal or fantasy), **anticipatory** (the client is aware that a loss will occur), **temporary**, or **permanent**. For example, a 65-year-old married woman with the history of end stage renal disease is told by her physician that she has approximately 12 months to live. She may experience several losses that affect not only her, but also her husband and family members, as her illness gradually progresses. The losses may include a predictable decline in her physical condition, a perceived alteration in her relationship with her husband and family, and a permanent role change within the family unit as she anticipates the progression of her illness and actual loss of life. Whether the loss is traumatic or temperate to the client and her family depends on their past experience with loss; the value the family members place on the loss of their mother/wife; and the cultural, psychosocial, economic, and family supports that are available to each of them. Box 6-1 describes losses identified by student nurses during their clinical experiences.

**Grief**

**Grief** is a normal, appropriate emotional response to an external and consciously recognized loss. It is usually time-limited and subsides gradually. Staudacher (1987, p. 4) refers to grief as a “stranger who has come to stay in both the heart and mind.” **Mourning** is a term used to describe an individual’s outward expression of grief regarding the loss of a love object or person. The individual experiences emotional detachment from the object

<table>
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<tr>
<th>Examples of Losses Identified by Student Nurses</th>
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<tbody>
<tr>
<td>• Loss of spouse, friend, and companion. The client was a 67-year-old woman admitted to the psychiatric hospital for treatment of depression following the death of her husband. During a group discussion that focused on losses, the client stated that she had been married for 47 years and had never been alone. She described her deceased husband as her best friend and constant companion. The client told the student and group that she felt better after expressing her feelings about her losses.</td>
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<tr>
<td>• Loss of body image and social role as the result of a below-the-knee amputation. The client was a 19-year-old girl who was involved in a motorcycle accident. She had shared her feelings with the student nurse about her “new” body image and dating after hospitalization.</td>
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<tr>
<td>• Loss of a loved one owing to fetal demise or intrauterine death. The student nurse had been assigned to a young woman, who was in her twenty-eighth week of pregnancy and delivered a preterm newborn who died immediately after birth. The following day, the client expressed a sincere thanks to the student nurse for supporting her during such a difficult time in her life.</td>
</tr>
<tr>
<td>• Loss of physiologic function, social role, and independence because of kidney failure. A 49-year-old woman was admitted to the hospital for improper functioning of a shunt in her left forearm. She was depressed and asked that no visitors be permitted in her private room. She shared feelings of loneliness, helplessness, and hopelessness with the student nurse as she described the impact of kidney failure and frequent dialysis treatment on her lifestyle. Once an outgoing, independent person, she was housebound because of her physical condition and “resented what her kidneys were doing to her.”</td>
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</table>
or person, eventually allowing the individual to find other interests and enjoyments. Some individuals experience a process of grief known as bereavement (e.g., feelings of sadness, insomnia, poor appetite, deprivation, and desolation). The grieving person may seek professional help for relief of symptoms if they interfere with activities of daily living and do not subside within a few months of the loss.

**Grief Theory**

Grief theory proposes that grief occurs as a process. The grief process is all-consuming, having a physical, social, spiritual, and psychological impact on an individual that may impair daily functioning. Feelings vary in intensity, tasks do not necessarily follow a particular pattern, and the time spent in the grieving process varies considerably from weeks to years (Schultz & Videbeck, 2002).

Several authors have described grief as a process that includes various stages, characteristic feelings, experiences, and tasks. Staudacher (1987) states there are three major stages of grief: shock, disorganization, and reorganization. Westberg (1979) describes ten stages of grief work, beginning with the stage of shock and progressing through the stages of expressing emotion, depression and loneliness, physical symptoms of distress, panic, guilt feelings, anger and resentment, resistance, hope, and concluding with the stage of affirming reality. Kubler-Ross (1969) identifies five stages of the grieving process including denial, anger, bargaining, depression, and acceptance; however, progression through these stages does not necessarily occur in any specific order. Her basic premise has evolved as a result of her work with dying persons. Box 6-2 discusses Kubler-Ross’s five stages of the grief process.

**Unresolved or Dysfunctional Grief**

Unresolved or dysfunctional grief could occur if the individual is unable to work through the grief process after a reasonable time. The cause of dysfunctional grief is usually an actual or perceived loss of someone or something of great value to a person. Clinical features or characteristics include expressions of distress or denial of the loss; changes in eating and sleeping habits; mood disturbances, such as anger, hostility, or crying; and alterations in activity levels, including libido (sex drive). The person experiencing dysfunctional grief idealizes the lost person or object, relives past experiences, loses the ability to concentrate, and is unable to work purposefully because of developmental regression. The grieving person may exhibit symptoms of anxiety (Chapter 21), depression (Chapter 20), or psychosis (Chapter 18).

**Self-Awareness Prompt** Identify at least one loss that you or a member of your family has experienced. Was it an actual, perceived, or anticipated loss? How did you and/or members of your family respond to the loss? What type of support, if any, was offered to help you with the grief process? Was it sufficient to meet the needs of yourself and/or members of your family?
End-of-Life Care

The following statement was retrieved on August 22, 2002, from the Aging with Dignity organization’s Web site (http://www.agingwithdignity.org):

Something is terribly wrong: The majority of Americans want to die at home surrounded by family and friends, but most end up dying in the hospital or nursing home, cared for by strangers. Half of the Americans die in pain that could have been treated. Sick people have come to fear losing their dignity or burdening their families more than they fear death. And this is all happening in a country that is meant to prize the rights of individuals and champion respect for personal wishes.

End-of-life care refers to the nursing care given during the final weeks of life when death is imminent. The American culture is marked by dramatically different responses to the experience of death. On one hand, death is denied or compartmentalized with the use of medical technology that prolongs the dying process and isolates the dying person from loved ones. On the other hand, death is embraced as a frantic escape from apparently meaningless suffering through means such as physician-assisted suicide. Both require compassionate responses rooted in good medical practice and personal religious beliefs.

The Patient Self-Determination Act (PSDA), passed in 1990, states that every competent individual has the right to make decisions about his or her health care and is encouraged to make known in advance directives (AD; legal documents specifying care) end-of-life preferences, in case the individual is unable to speak on his or her own behalf (Allen, 2002; Robinson & Kennedy-Schwarz, 2001).

Advance Care Planning

Advance care planning is a thoughtful, facilitated discussion that encompasses a lifetime of values, beliefs, and goals for the client and family. Advance care planning often involves completion of an advance directive. The two most common forms of advance directives are the living will or the health care directive and the durable health care power of attorney or health care proxy (Allen, 2002; Norlander, 2001).

The living will is a document filled out by the client with specific instructions addressing issues of cardiopulmonary resuscitation (CPR); life support systems such as the use of a ventilator or intubation; tube feedings or artificial nutrition and hydration; and emergency measures such as surgery, blood transfusion, or antibiotics to treat end-stage diseases.

A durable health care power of attorney permits an individual to name a health care decision-maker or surrogate to make medical decisions in the event that the individual is unable to make these decisions or give informed consent. If a health care power of attorney or surrogate has not been named, the law allows a health care proxy to be appointed to act on behalf of the client (eg, an individual has a stroke and is unable to communicate his wishes). Examples of health care proxies include spouses, guardians, or parents.

A unique form of advance directive, the dying declaration exception to hearsay allows statements referred to as “death bed declarations” to be honored by the medical and nursing staff. For example, a client, who is aware that death is imminent and has not completed a living will, may inform the nursing staff that he wants all medication, including intravenous (IV) therapy, to be discontinued. Such a request can be honored if documented (Scanlon, 2003).

Ethnic Considerations and Cultural Sensitivity

Nurses need to acknowledge that their view of end-of-life care might be quite different from views held by clients and their families or significant others. Ethnicity and race significantly influence end-of-life decisions and treatments. Cultural competence demands that nurses view clients through their own eyes and the eyes of the client and family. Many culturally diverse clients and families have had negative experiences with health care providers as a result of the lack of attention to cultural needs, or they have experienced additional stressors such as limited financial resources and health coverage. Such influences could have profound effects upon establishing trust with a client when planning end-of-life care (Mazanec & Tyler, 2003).

Andrews and Boyle (2002) discuss stages of grief and bereavement observed in culturally diverse clients such as Native Americans, Buddhists, Mexican-Americans, Puerto Ricans, and Eurasians. The magnitude of stress and its meaning to such individuals vary significantly cross-culturally. Contemporary grieving practices of various cultural groups demonstrate a wide range of expression of emotion related to personal losses. Hindering or interfering with the practices that the culturally diverse client and family find meaningful can disrupt the grieving process and precipitate physical or psychological symptoms that may lead to serious physical illness or even death.

Palliative Care and Hospice Care

The terms palliative care and hospice care are associated with end-of-life care. According to the World Health
Organization, **palliative care** is the active total care of clients whose disease is not responsive to curative treatment. The Institute of Medicine emphasizes that palliative care seeks to prevent, relieve, reduce, or soothe the symptoms of disease or disorder without effecting a cure. Nursing outcomes focus primarily on promoting quality of life while emphasizing the relief of pain, suffering, and symptom management; and assisting clients and families to reach personal goals, reconcile conflicts, and derive meaning from their experiences at end of life. Palliative care can and should exist outside of hospice programs because not all clients who receive palliative care are near the end of life. Palliative care may be provided in the early stages of a chronic disease or terminal illness (Ferrell & Coyle, 2002; Norlander, 2001; Puntillo, 2001).

**Hospice care** refers to a program that supports the client and family through the dying process and the surviving family members through the process of bereavement. Although clients can receive hospice care in a variety of settings, most clients are cared for in the home or in a nursing home. Almost one third of hospice clients die within 7 days of admission to the program (Ferrell & Coyle, 2002).

Typically, to qualify for hospice care, Medicare or other insurance companies require that the individual be terminally ill, have a medical prognosis with a life expectancy of 6 months or less if the illness runs its normal course (eg, end-stage chronic obstructive pulmonary disease or cancer), and no longer wishes to pursue aggressive treatment options (Klimkiewicz, 2001).

Both palliative care and hospice care address issues related to the manifestations of suffering including physical and emotional responses, pain, and the act of dying.

**Manifestations of Suffering**

**Suffering** has been described as a process or state of severe distress associated with injury or events that threaten the composure, integrity, and fulfillment of our intentions. Manifestations of suffering may be behavioral (eg, withdrawal or avoidance of contact with family or caregiver), emotional (eg, anger or depression), physical (eg, impaired sleep or fatigue), or spiritual (eg, a sense of alienation or emptiness) (Norlander, 2001; Rushton, 2001). After the nurse has identified the source of suffering, a holistic plan of care can be implemented based on the client’s needs. (Chapters 8 and 9 address the nursing process.) Box 6-3 lists common responses associated with suffering at the end of life.

**BOX 6.3**

**Common Responses Associated With Suffering at End of Life**

- **Behavioral**: Avoidance, controlling, distancing
- **Emotional**: Anger, anxiety, depression, emotional outbursts, frustration, guilt, sarcasm, emotional withdrawal from family or friends
- **Physical**: Fatigue, fluctuation in vital signs, impaired sleep, impaired mental processes such as confusion or delirium, persistent physical symptoms such as pain, weight gain or loss
- **Spiritual**: Verbalization of a sense of hopelessness, emptiness, or meaninglessness


**Pain**

The Agency for Health Care Policy and Research (AHCPR; 1994, p. 12) defined pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage.” Box 6-4 lists the ABCDE mnemonic of pain assessment and management as stated by AHCPR.

**BOX 6.4**

**ABCDE Mnemonic of Pain Management**

- **A**: Ask about the client’s pain regularly and assess the pain systematically.
- **B**: Believe the client, family, and/or significant other in their reports of pain and what relieves it.
- **C**: Choose pain-control options that are appropriate for the client, family, or significant other. Consider the setting in which the client is receiving care.
- **D**: Deliver nursing interventions in a timely, logical, and coordinated fashion.
- **E**: Empower the client, family, and/or significant other. Enable client to control his or her course to the greatest extent possible.

In 1996, the World Health Organization (WHO; 1996) developed an Analgesic Ladder that outlines the principles of analgesic selection and titration as well as the use of adjunctive drug therapy to ease pain or to counteract adverse effects in the treatment of clients with cancer. For example, control of mild pain may be achieved with the use of a non-narcotic analgesic. As the severity of pain increases, a narcotic analgesic would be given. In the case of severe or persistent pain, a combination of medications such as an opioid and non-narcotic analgesic or opioid and salicylate would be used. Additional medication may be added to relieve adverse effects secondary to the use of pain medication or to relieve clinical symptoms of anxiety or depression.

In 1991, the American Nurses Association issued a position statement regarding the promotion of comfort and relief of pain in dying clients. It maintained that efforts to relieve pain and other symptoms in dying patients are the obligations of the nurse and may require increasing titration of medication to achieve adequate symptom control. Although such aggressive measures may interfere with maintaining life and may hasten death, these nursing interventions are considered to be ethically justified. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) recently issued pain treatment standards mandating pain assessment in all hospitalized clients, including those in the psychiatric setting. These guidelines have helped to alleviate the fear prevalent among health care professionals that the use of analgesic or sedative medications will promote tolerance or addiction to pain medication, hasten death, or be viewed as an act of euthanasia.

The Act of Dying

Although death is inevitable, clients do have a choice regarding the medical procedures, drugs, and nutritional or respiratory support that they can receive during the final stage of life, referred to as the act of dying. Supporting Evidence for Practice 6-1 highlights a study on end-of-life ethical concerns. Bad deaths, those accompanied by unnecessary and severe suffering, are often the result of the clinician’s failure to follow recommended end-of-life guidelines for the care of dying clients. Few clinicians outside of hospice and palliative care programs have the skills necessary to manage the dying process (LaDuke, 2001). Early recognition of impending death and the recognition of a client’s life choices can lead to a good death.

The act of dying is a very personal matter and end-of-life care such as hospice offers a final respite, and a time for acceptance and peace for both the client and the client’s family or significant other (Klimkiewicz, 2001). Holst (1984) created a list of needs experienced by dying persons and their survivors while they face conflicts and dilemmas during this critical time in their lives. These needs are summarized in Table 6-1.

In 1975, a bill of rights for the dying person was developed (Box 6-5). Every nursing unit should have this bill

<table>
<thead>
<tr>
<th>SUPPORTING EVIDENCE FOR PRACTICE 6.1</th>
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<tr>
<td>Providing Interventions for End-of-Life Ethical Concerns of Clients in the Psychiatric–Mental Health Clinical Setting</td>
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**PROBLEM UNDER INVESTIGATION:** Elders discuss ethical concerns related to aging and end-of-life issues

**SUMMARY OF RESEARCH:** Eighteen elders between the ages of 70 years to 92 years of age, ten of their children, and two of their grandchildren were interviewed by a nurse researcher to explore end-of-life ethical concerns and how they and their family members responded to the concerns. Ethical concerns included issues such as personal health and caregiver burden; maintaining spirituality; ethnic identity; worry about the health of a loved one; concern about the loved one’s death; and facing death. Researchers concluded that most elders wanted to avoid pain and discomfort, to avoid being a burden on their families, and to achieve a natural, peaceful death. Family members described the importance of positive interpersonal family relationships and the need to assist elders in resolving conflicts.

**SUPPORT FOR PRACTICE:** Planning of nursing interventions for ethical concerns and unresolved conflicts of elders and their family members should focus on the promotion of healthy and positive choices for quality-of-life and end-of-life decision-making.

**Source:** Cameron, M.D. (2002). Older persons’ ethical problems involving their health. Nursing Ethics, 9, 537–556.
TABLE 6.1 Needs of Dying Persons and Survivors

<table>
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<tr>
<th>DYING PERSON'S NEEDS</th>
<th>SURVIVOR'S NEEDS</th>
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<tr>
<td>Vent anger and frustration</td>
<td>Provide a quality of life for the dying person while preparing for a life without that loved one</td>
</tr>
<tr>
<td>Share the knowledge that the end is near</td>
<td>Be available to offer comfort and care even though the survivor feels like running away to escape the pain of death</td>
</tr>
<tr>
<td>Ensure the well-being of loved ones who will be</td>
<td>Hope that the loved one will somehow live in spite of obvious deterioration and inability to function. At this time the survivor may pray for the peace of death.</td>
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<tr>
<td>left behind, because the person resents the fact</td>
<td>Vent feelings or irritation and guilt over the dying person’s demands and increased dependency needs</td>
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<td>that life will go on without him or her</td>
<td>Live and appreciate each day as one plans for a future without the loved one</td>
</tr>
<tr>
<td>Vent feelings or irritation at omissions or neglect</td>
<td>Reassure the dying person that the survivor will “continue in his or her footsteps” by holding the family together, raising the children, or managing the business, while knowing that such talk about the future is painful to the dying client</td>
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<td>although the person feels guilty over the pain</td>
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<tr>
<td>this causes</td>
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<td>Remain as independent as possible, fearing he or</td>
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<td>she will become unlovable</td>
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<tr>
<td>Be normal and natural at a time when nothing</td>
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<tr>
<td>appears to be normal or natural. The dying client</td>
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<td>generally experiences the fears of pain, loss of</td>
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<td>control, and dying alone. The client has a need to</td>
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<tr>
<td>maintain security, self-confidence, and dignity.</td>
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Spiritual Needs

As stated earlier, people suffer many types of loss, including the loss of health. When this happens, the individual reaches out for support from significant others, such as friends, family, or the clergy.

BOX 6.5

The Dying Person’s Bill of Rights*

I have the right to:

Be treated as a living human being until I die.
Maintain a sense of hopefulness however changing its focus may be.
Be cared for by those who can maintain a sense of hopefulness, however changing this might be.
Express my feelings and emotions about my approaching death in my own way.
Participate in decisions concerning my care.
Expect continuing medical and nursing attention even though “cure” goals must be changed to “comfort” goals.
Not die alone.
Be free from pain.

Have my questions answered honestly.
Not be deceived.
Have help from and for my family in accepting my death.
Die in peace and with dignity.
Retain my individuality and not be judged for my decisions, which may be contrary to beliefs of others.
Discuss and enlarge my religious and/or spiritual experiences, whatever these may mean to others.
Expect that the sanctity of the human body will be respected after death.
Be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.

(Taken from the American Journal of Nursing, January, 1975, p. 99)

*The Dying Person’s Bill of Rights was created at a workshop on “The Terminally Ill Patient and the Helping Person” in Lansing, Michigan, sponsored by the Southwestern Michigan Inservice Education Council and conducted by Amelia J. Barbus, Associate Professor of Nursing at Wayne State University in Detroit, Michigan.
Although hospice and most palliative care programs address the spiritual issues of dying clients and their families and/or significant others, not all clients receive palliative or hospice care. Becoming familiar with the attitudes and requirements of various religious groups is crucial to address the spiritual needs of their clients, families, and/or significant others.

Clients may not verbalize their desire or need for spiritual support. Pumphrey (1977, p. 64) discusses how clients search for an understanding listener and spiritual support by sending out feelings or making remarks such as “I haven’t gone to church much lately” or “My pastor is so busy, I hate to bother him while I’m in the hospital.” Ideally, the nurse should be able to respond to each client’s spiritual needs as naturally as he or she responds to the client’s physical needs. If addressing various spiritual concerns is uncomfortable, the nurse can suggest that the client talk to the hospital chaplain, the client’s own clergy, members of his or her congregation, or other clients with similar religious beliefs. If none of these options seems appropriate, the nurse can provide quiet time for private meditation or prayer (Cohen & Koenig, 2002).

Culture also can impact a client’s spiritual needs. Andrews and Hanson (2002, p. 432) discuss the assessment of spiritual needs in culturally diverse clients who are actively dying. Four areas to be explored include the environment, behavior, verbalization, and interpersonal relationships. For example, are religious objects visible? Does the client or family wear clothing that has religious significance? Are special dietary requests made? Such observations enable the nurse to address spiritual needs of the client.

**Children and Death**

Although children’s growth varies both physically and emotionally, books that discuss children and the impact of dying outline general growth stages, citing the needs and understanding of children in each phase of development.

Preschool children between the ages of 3 and 5 years have a fear of separation from their parents and are unable to think of death as a final separation. They perceive death as a temporary trip to heaven or some other place in which the person still functions actively by eating, sleeping, and so forth. If a child displays guilt feelings because the child “wished something awful would happen when angry at mommy or daddy,” he or she needs to be told that wishes do not kill. Conversely, the well-adjusted child who appears to be brave and displays little emotion while appearing to accept a parent’s death should be seen by a professional counselor to ensure no psychological problem is developing.

Children between the ages of 5 and 6 years see death as a reversible process that others experience, whereas children from 6 to 9 years of age begin to accept death as a final state. Death is conceptualized as a destructive force, a frightening figure, a bogey monster, or an angel of death who comes during the night “to get bad people.” Children of this age believe they will not die if they avoid the death figure.

By the age of 10 years, some children begin to realize that death is an inevitable state that all human beings experience because of an internal process. They also believe that the body of a dead person slowly rots until only bones remain as insects infest the coffin and prey on the body. The child may verbalize words such as afterlife, cremation, rebirth, and reunion at this age.

Adolescents are able to intellectualize their awareness of death although they usually repress any feelings about their own death. Adolescents often hide the fact that they are mourning. They are inexperienced in coping with a stressor and may not shed tears or voice their emotions regarding their loss.

Children and adolescents are capable of feeling the great loss of a loved person one moment and yet becoming fully absorbed in something funny the next. Adults need to be aware of this capability so that they do not misinterpret such behavior as disrespect or lack of love for the deceased person. In addition, as a child matures and his or her concept of death changes, the child may have to mourn a loss more than once. For example, a child may lose a parent while at the age where he or she believes that death is not permanent; thus the child believes that he or she will see the parent again. However, after the child matures, he or she may mourn the loss again and in a new way.

Various studies have been done to evaluate children and their responses to death. Christ (2001) reports the findings of a qualitative intervention study regarding the understanding of death by 157 children ages 3 to 17 years of age and their ability to mourn the death of a parent from cancer. According to Christ, most children and adolescents can adapt effectively to the death of a parent and even learn and grow from the experience; however, they cannot do it alone. The findings of the study and
developmental conceptions of death, behavioral responses, and interventions are summarized in Table 6-2.

### Table 6.2 Research Results: Mourning the Death of a Parent From Cancer

<table>
<thead>
<tr>
<th>AGE GROUP</th>
<th>DEVELOPMENTAL CONCEPTIONS, RESPONSES, AND INTERVENTIONS</th>
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<tr>
<td>Age 3–5 years</td>
<td>Children did not understand that death was permanent and irreversible. Mourning was nonspecific and included behaviors such as irritability, toileting regression, nightmares, and somatic symptoms. Play bereavement groups helped to improve communication and to decrease clinical symptoms.</td>
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<tr>
<td>Ages 6–8 years</td>
<td>Children had difficulty understanding the circumstances that lead to the death of a parent. They focused on themselves as the cause when something bad happened. Mourning behaviors included joyful reminiscences of the parent, with sporadic crying and sadness. Children believed the parent was in a place such as heaven and were convinced that the deceased parent could see them and still care for them. Play bereavement groups, contact with peers with similar losses, reminiscences of parent, and rituals such as visiting the parent’s gravesite were considered to be therapeutic.</td>
</tr>
<tr>
<td>Ages 9–11 years</td>
<td>Behaviors included spending time with peers and looking for ways to be helpful with caretaking functions. Mourning included compartmentalization of their emotions, and intellectualization of their feelings by writing reports about cancer and treatment options. Children responded favorably to encouragement of appropriate reminiscences of the deceased parent and structural family rituals.</td>
</tr>
<tr>
<td>Ages 12–14 years</td>
<td>Behaviors included marked egocentrism (concern about self) and fluctuating emotional responses and needs. Mourning occurred in private areas such as their bedrooms; however, they did talk about dreams and speaking with the deceased parent. Limit-setting and formal family reminiscence experiences enabled the children to express feelings that they avoided in informal discussions.</td>
</tr>
<tr>
<td>Ages 15–17 years</td>
<td>Behaviors included the presence of anticipatory grief during the parent’s terminal illness. The teenagers acknowledged that their family’s future would be changed. Mourning symptoms for most of the teenagers were similar to those of adults but shorter in duration. Clinical symptoms included lack of interest, sleeping problems, and inability to concentrate. Sharing of grief experiences with their peers who had lost their parents to death or divorce appeared to be beneficial. The teens were encouraged to maintain independent functioning.</td>
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### Key Concepts

- Loss has been described as a condition whereby an individual experiences deprivation of, or complete lack of, something that was previously present such as a job, pet, home, personal item, or loved one. The individual may experience an actual loss, perceive that a loss has occurred, or anticipate that a loss will occur.
- Grief is a normal, appropriate emotional response to an external and consciously recognized loss. Failure to work through the grief process could result in unresolved or dysfunctional grief.
- End of life refers to the final weeks of life when death is imminent. The Patient Self-Determination Act of 1990 states that every competent individual has the right to make decisions about his or her health care. This includes the use of advance directives such as the living will and durable health care power of attorney. These documents address the issues of CPR, life support, artificial nutrition and hydration, and emergency measures to treat end-stage diseases.
- Acknowledging that our view of end-of-life care might differ from views held by our clients and their families or significant others is important. Lack of knowledge regarding the ethnicity, culture, and race of a client could have a profound effect on establishing trust with a client when planning end-of-life care.
- Palliative care seeks to prevent, relieve, reduce, or soothe the symptoms of disease or disorder without effecting a cure. Palliative care may be provided in the early stages of a chronic disease or terminal illness. Hospice care supports the client and family during the dying process (medical prognosis of 6 months or less) and the surviving family members through the process of
bereavement. Both palliative care and hospice care address issues related to the manifestations of suffering including physical and emotional responses, pain, and the act of dying.

- Not all clients receive palliative or hospice care. Nurses need to familiarize themselves with the attitudes and requirements of various religious groups so that they can address the spiritual needs of their clients, families, and/or significant others.

- The concept of death changes as children undergo various developmental stages. Preschool children fear separation from their parents and are unable to think of death as a final separation. Five- and 6-year-olds see death as a reversible process, whereas 6- to 9-year-olds begin to accept death as a final state. By the age of 10 years, some children begin to realize that death is an inevitable state. Adolescents are able to intellectualize their awareness of death although they usually repress any feelings about their own death.

For additional study materials, please refer to the Student Resource CD-ROM located in the back of this textbook.

**Internet Resources**

Advance Care Planning: Project Grace: http://www.p-grace.org/
Aging With Dignity: http://www.agingwithdignity.org/
Hospice Foundation of America: http://www.hospicefoundation.org/
Last Acts Campaign: http://www.lastacts.org/
National Hospice and Palliative Care Organization: http://www.nhpco.org/

**Selected References**


Suggested Readings


CRITICAL THINKING QUESTIONS

1. Your best friend hasn’t been herself lately; in fact, you are becoming increasingly worried about her. It has been 18 months since her father died of lung cancer. She is smoking more, missing class, and reacting angrily when questioned. You feel her grief is dysfunctional at this point. How might you help her?

2. Mrs. Kessler, a 78-year-old widow, has been under your care for several days. She has openly spoken about her wishes for a dignified death, with “none of that mechanical stuff.” You have just overheard her son and doctor planning additional surgery for her without her involvement in the decision. What action should you take and why?

REFLECTION

A new neighbor tells you that his wife of 30 years was killed in an automobile accident 3 months ago and he is having difficulty adjusting to living alone. Reflect on the chapter opening quote by Abraham Lincoln. How would you interpret the meaning of this quote? What significance does it have in relation to the neighbor’s disclosure about the loss of his wife?

MULTIPLE CHOICE QUESTIONS

1. A 27-year-old male client who recently lost his wife due to terminal cancer relates that he and his wife discussed her end-of-life wishes including her burial service. The client states that he is now unable to sleep; has a poor appetite; and feels sad even when in the company of their two children, ages 5 and 7 years. Which of the following responses to the death of his wife is the client experiencing?
   a. Mourning
   b. Anger
   c. Acceptance
   d. Bereavement

2. A woman diagnosed with terminal breast cancer discusses with her husband her wishes for end-of-life care, including her funeral. Which type of loss is this couple experiencing?
   a. Perceived loss
   b. Anticipatory loss
c. Temporary loss
d. Sudden loss

3. A client whose husband died last month of a sudden cardiac arrest tells you that her 4-year-old child asks “When is Daddy coming home?” When explaining to the mother about the child’s concept of death, which of the following would you include?
   a. Death is an irreversible process.
   b. Death is a final state.
   c. Death is a destructive force.
   d. Death is a temporary separation.

4. Palliative care differs from hospice care because palliative care:
   a. may be provided in the early stages of a chronic disease
   b. requires that a client is a Medicare recipient
   c. does not provide care for hospitalized clients
   d. does not provide spiritual support for family members

5. Several health care agencies have addressed the issue of pain management for terminally ill clients. In 1991, which of the following issued a position statement regarding the promotion of comfort and relief of pain in dying clients?
   a. The Agency for Health Care Policy and Research
   b. The Joint Commission on Accreditation of Healthcare Organizations
   c. The American Nurses Association
   d. The World Health Organization