

Psychological Issues in Advancing and Terminal Illness



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CHAPTER OUTLINE

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Death Education

At the first assembly of freshman year in a suburban high school, the principal opened his remarks by telling the assembled students, “Look around you. Look to your left, look to your right, look in front of you, and look in back of you. Four years from now, one of you will be dead.” Most of the students were stunned by this remark, but one boy in the back feigned a death rattle and slumped to the floor in a mock display of the principal’s prophecy. He was the one. Two weeks after he got his driver’s license, his car spun out of control at high speed and crashed into a stone wall.

The principal, of course, had not peered into the future but had simply drawn on the statistics showing that even adolescents die, especially from accidents. By the time most of us reach age 18, we will have known at least one person who has died, whether it be a high school classmate, a grandparent, or a family friend. Many of these causes of death are preventable. Many children die from accidents in the home. Adolescents, as well as children, die in car crashes often related to risky driving, drugs, alcohol, or a combination of factors. Even death in middle and old age is most commonly due to the cumulative effects of bad health habits, such as smoking, poor diet, lack of exercise, and obesity. Overall, the risk of dying at any given time has decreased for all age groups, especially at the younger ages, but stubborn causes of preventable death, such as obesity, smoking, and alcoholism, remain (Hoyert, 2012).

Moreover, overall, gains in longevity have slowed; and one group, namely middle-aged white men and women, have shown an increase (Tavernise, 2015). This increase appears to be due primarily to suicides and drug poisonings (Case & Deaton, 2015). Declines in mental health and the ability to work, and poor liver functioning (often due to alcohol or drug abuse) and increases in pain can prompt self-medication through alcohol and drugs, which over time, can result in death. Poorly educated men and women are more likely to show this pattern.

■ DEATH ACROSS THE LIFE SPAN

Comedian Woody Allen is said to have remarked on his 40th birthday, “I shall gain immortality not through my work but by not dying.” A mere 100 years ago, people died primarily from infectious diseases, such as tuberculosis, influenza, or pneumonia. Now those illnesses are

TABLE 12.1 | Deaths: Leading Causes in the United States, 2014

Rank and Cause	Number of Deaths
1. Heart disease	614,348
2. Cancer	591,699
3. Chronic respiratory diseases	147,101
4. Accidents (unintentional injuries)	136,053
5. Stroke (cerebrovascular diseases)	133,103
6. Alzheimer’s disease	93,541
7. Diabetes	76,488
8. Influenza/pneumonia	55,227
9. Nephritis*	48,146
10. Intentional self-harm (suicide)	42,773

*Includes nephrotic syndrome and nephrosis.

Source: Centers for Disease Control and Prevention, 2016, April.

much less widespread because of substantial advances in public health and preventive medical technologies that were developed in the 20th century. Just since the 1960s, death rates have declined 43 percent (MacDorman & Mathews, 2009).

This figure presents a falsely positive picture, however. The United States has substantial racial and ethnic disparities in life expectancy, with the result that we are falling behind in life expectancy faster than any other nation (Kulkarni, Levin-Rector, Ezzati, & Murray, 2011).

On average, people in the United States can currently expect to live about 78.8 years (Xu, Kochanek, Murphy, & Arias, 2014). When death does come, it will probably stem from a chronic illness, such as heart disease or cancer, rather than from an acute disorder, as Tables 12.1 and 12.2 indicate. This fact means that, instead of facing a rapid, unanticipated death, the average American may know what he or she will probably die of for 5, 10, or even more years.

Understanding the psychological issues associated with death and dying first requires a rather grim tour of death itself. What is the most likely cause of death for a person of any given age, and what kind of death will it be?

Death in Infancy and Childhood

Although the United States is one of the most technologically developed countries in the world, our **infant mortality rate** is still fairly high (5.97 per

TABLE 12.2 | Leading Causes of Mortality Among Adults, Worldwide, 2013

Mortality, Low-income Countries			Mortality, High-income Countries		
Rank	Cause	Deaths	Rank	Cause	Deaths
1	Lower respiratory infections	91	1	Ischaemic heart disease	153
2	HIV/AIDS	65	2	Stroke	95
3	Diarrheal diseases	53	3	Trachea, bronchus, lung cancers	49
4	Stroke	52	4	Alzheimer's and other dementias	42
5	Ischaemic heart disease	39	5	Chronic obstructive pulmonary disease	31
6	Malaria	35	6	Lower respiratory infections	31
7	Preterm birth complications	33	7	Colon and rectum cancers	27
8	Tuberculosis	31	8	Diabetes mellitus	20
9	Birth asphyxia and birth trauma	29	9	Hypertensive heart disease	20
10	Protein energy malnutrition	27	10	Breast cancer	16

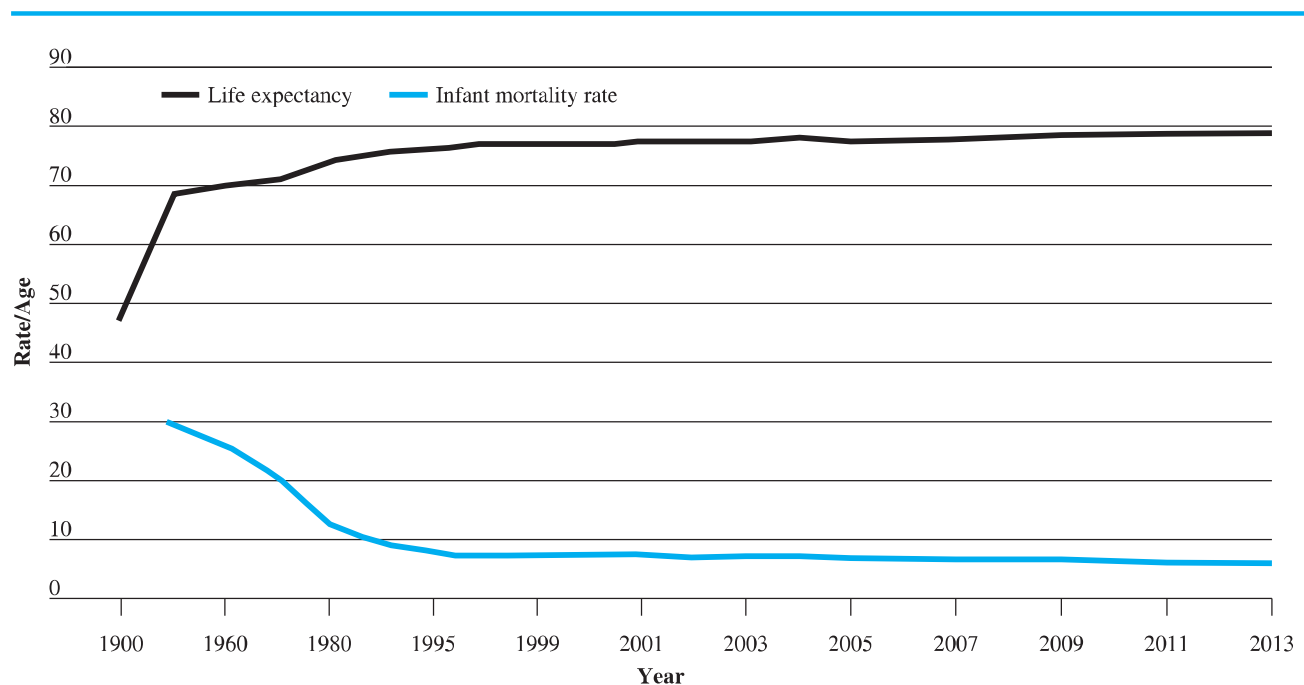
Source: World Health Organization, June 2011. Note: Table entries are yearly deaths per 100,000 people.

1,000) (Xu et al., 2014), higher than in most Western European nations. Although these figures represent a substantial decline in infant mortality since 1980 (from 12.6 per 1,000) (Centers for Disease Control and Prevention, 2012, January) (Figure 12.1), African American and Hispanic infants are still more than twice as likely to die during the first year as White infants are (Centers for Disease Control and Prevention, 2012, January).

Causes of Death The countries that have a lower infant mortality rate than the United States all have national medical programs that provide free or low-cost maternal care during pregnancy. When infants are born prematurely or die at birth, the problems can frequently be traced to poor prenatal care for the mother. We are one of the few developed nations without such a program, although that picture is now changing, due to health care reform.

FIGURE 12.1 | Life Expectancy and Infant Mortality in the United States, 1900–2013

(Source: National Vital Statistics Reports, 2016, February).



During the first year of life, the main causes of death are congenital abnormalities and **sudden infant death syndrome (SIDS)**. The causes of SIDS are not entirely known—the infant simply stops breathing—but epidemiologic studies reveal that it is more likely to occur in lower-class urban environments, when the mother smoked during her pregnancy, and when the baby is put to sleep on its stomach or side (Lipsitt, 2003). Mercifully, SIDS appears to be a gentle death for the child, although not for parents: The confusion, self-blame, and suspicion from others who do not understand this phenomenon can exact an enormous psychological toll on the parents.

After the first year, the main cause of death among children under age 15 is accidents, which account for 40 percent of all deaths in this group. In early childhood, accidents are most frequently due to accidental poisoning, injuries, or falls in the home. In later years, automobile accidents take over as the chief cause of accidental death (Centers for Disease Control and Prevention, 2015, September).

Cancer, especially leukemia, is the second leading cause of death in youngsters age 1–15, and its incidence is rising. Leukemia is a form of cancer that strikes the bone marrow, producing an excessive number of white blood cells and leading to severe anemia

and other complications. Because of advances in treatment, including chemotherapy and bone marrow transplants, over 80 percent of those treated for cancer survive the disease for 5 years or more (American Cancer Society, 2012a). Unfortunately, these procedures, especially bone marrow transplants, can be painful and produce unpleasant side effects. Overall, the mortality rates for most causes of death in infants and children have declined.

Children’s Understanding of Death The child’s idea of death appears to develop quite slowly. Up to age 5, most children think of death as a great sleep. Children at this age are often curious about death rather than frightened or saddened by it, partly because they may not understand that death is final and irreversible. Rather, the dead person is thought to be still around, but in an altered state, like Snow White or Sleeping Beauty waiting for the prince (Bluebond-Langner, 1977).

Between ages 5 and 9, the idea that death is final develops, although most children do not have a biological understanding of death. For some of these children, death is personified into a shadowy figure, such as a ghost or the devil. They may, for example, believe that death occurs because a supernatural being comes



A huge decline in child mortality is now occurring throughout Africa. Broad economic growth and public health policies such as the use of insecticide-treated bed nets to discourage mosquitoes and improvements in diet are among the reasons for this good news. Source: The Economist, May 19, 2012

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One of the chief causes of death among adolescents and young adults is vehicle accidents.

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to take the person away. The idea that death is universal and inevitable may not develop until age 9 or 10. At this point, the child typically has some understanding of the processes involved in death (such as burial and cremation), knows that the body decomposes, and realizes that the person who has died will not return (Bluebond-Langner, 1977; Kastenbaum, 1977).

Death in Adolescence and Young Adulthood

When asked their view of death, most young adults envision a trauma or fiery accident. This perception is realistic. Although the death rate in adolescence is low (about 0.95 per 1,000 for youths age 15–19), the major cause of death in this age group is unintentional injury, mainly involving automobiles (Centers for Disease Control and Prevention, 2016, April). Homicide is the second leading cause of death overall and the leading cause of death for young black men, approximately 1.3 times more likely for that of young

white men (Centers for Disease Control and Prevention, 2016, February). Suicide, largely through firearms, is the third leading cause of death in this age group, with cancer the fourth. Heart disease and AIDS account for most of the remaining deaths in this age group.

Reactions to Young Adult Death Next to the death of a child, the death of a young adult is considered the most tragic. Not surprisingly, when young adults do receive a diagnosis of a terminal illness, such as cancer, they may feel shock, outrage, and an acute sense of injustice. Partly for these reasons, medical staff often find it difficult to work with these patients. They can be angry much of the time and, precisely because they are otherwise in good health, may face a long and drawn-out period of dying. For them, unlike older people, there are fewer biological competitors for death, so they do not quickly succumb to complications, such as pneumonia or kidney failure.

Death in Middle Age

In middle age, death begins to assume more realistic and, in some cases, fearful proportions, both because it is more common and because people develop chronic health problems that may ultimately kill them. The fear of death may be symbolically acted out as a fear of loss of physical appearance, sexual prowess, or athletic ability. Or it may be focused on one's work: the realization that one's work may be meaningless and that many youthful ambitions will never be realized. The abrupt life changes that are sometimes made in middle age—such as a divorce, remarriage to a much younger person, or radical job change—may be viewed partly as an effort to postpone death (Gould, 1972).

Premature Death The main cause of **premature death** in adulthood—that is, death that occurs before the projected age of 79—is sudden death due to heart attack or stroke. When asked, most people reply that they would prefer a sudden, painless, and nonmutilating death. Although sudden death has the disadvantage of not allowing people to prepare their exit, in some ways it facilitates a more graceful departure, because the dying person does not have to cope with physical deterioration, pain, and loss of mental faculties. Sudden death is, in some ways, kinder to family members as well. The family does not have to go through the emotional torment of witnessing the person's worsening condition, and finances and other resources are not as severely taxed. A risk is that families may be poorly prepared financially to cope with the loss, or family members may be estranged, with reconciliation now impossible.

Overall, death rates in the middle-aged group have declined, due in large part to a 60 percent drop in smoking-related lung cancer, although as noted, the death rate in this age group has recently showed a startling uptick (Case & Deaton, 2015). Heart disease and stroke have declined over the past decade (American Heart Association, 2012). Despite the overall increases in life expectancy, whites still live longer than blacks by nearly 2 years (for men) and 1 year (for women) (Centers for Disease Control and Prevention, 2016, April). One factor that accounts for this difference is that socioeconomic status is a strong determinant of age of death: the higher one's socioeconomic status, the longer one lives. Relative to whites, blacks are also more likely to have diabetes,

obesity, and hypertension, which can lead to heart attacks and strokes.

Death in Old Age

Dying is not easy at any time during the life cycle, but it may be easier in old age. The elderly (over age 65) are generally more prepared to face death than are the young. The elderly have seen friends and relatives die and may have thought about their death and have made some initial preparations.

Typically, the elderly die of degenerative diseases, such as cancer, stroke, or heart failure, or simply from general physical decline that predisposes them to infectious disease or organ failure. The terminal phase of illness is generally shorter for them because there is often more than one biological competitor for death.

Why do some individuals live only into their 60s and others live into their 90s or longer? Health psychologists have investigated the factors that predict mortality in the elderly. Obviously, new illnesses and the worsening of preexisting conditions account for many of these differences. But changes in psychosocial factors are also important. Poor mental health and reduced satisfaction with life predict decline among the elderly (Myint et al., 2007; Rodin & McAvay, 1992; Zhang, Kahana, Kahana, Hu, & Pozuelo, 2009), whereas a sense of purpose is tied to a longer life (Boyle, Barnes, Buchman, & Bennett, 2009). Close family relationships are protective of health.

In part because of such findings, health goals for the elderly now focus less on reducing mortality and more on improving quality of life. In the United States, people age 65 and up are healthier due to lifestyle changes. However, the worldwide picture is quite different. People are living longer, about 64 years in third-world countries, but the prevalence of chronic diseases due to smoking, poor diet, sedentary lifestyle, and alcohol abuse means that many older people live poor-quality lives.

One curious fact about the elderly is that women typically live longer than men—women to age 81 and men only to age 76 (Centers for Disease Control and Prevention, 2016, February). Box 12.1 explores some of the reasons for this difference in mortality rates between men and women. Table 12.3 provides a formula for roughly calculating personal longevity. A more recent website that offers projections about how likely you are to live is www.livingto100.com.

On average, women live nearly 5 years longer than men in the United States, a difference that also exists in most other industrialized countries (The World Factbook, 2009). Only in underdeveloped countries, in which childbirth technology is poorly developed, or in countries where women are denied access to health care, do men live longer. Why?

Women seem to be biologically more fit than men. Although more male than female fetuses are conceived, more males are stillborn or miscarried than are females, and male babies are more likely to die than females. In fact, the male death rate is higher at all ages, so that there are more females than males left alive by the time young people reach their 20s. Exactly what biological mechanisms make females more fit are still unknown. Some factors may be genetic; others may be hormonal. For example, women's buffered X chromosome may protect them against certain disorders to which men are more vulnerable.

Another reason why men die earlier than women is that men engage in more risky behaviors (Williams, 2003). Chief among these is smoking, which accounts for as much as 40 percent of the mortality difference between men and women. Men are exposed to more occupational hazards and hold more hazardous jobs, such as construction work, police work, or firefighting. Men's alcohol consumption is greater than women's, exposing them to liver damage and alcohol-related

accidents, and they consume more drugs than do women. Men are more likely to participate in hazardous sports and to use firearms recreationally. Men's greater access to firearms, in turn, makes them more likely to use guns to commit suicide—a method that is more effective than the methods typically favored by women (such as poison). Men also use automobiles and motorcycles more than women, contributing to their high death rate from accidents. Men's tendencies to cope with stress through fight (aggression) or flight (social withdrawal or withdrawal through drugs and alcohol) may thus also account for their shorter life span; women are more likely to tend and befriend instead (Taylor, Kemeny, Reed, Bower, & Gruenewald, 2000). Men engage in less preventive healthcare, and this is more true of men with strong masculinity beliefs (Springer and Mouzon, 2011). Macho men, then, live shorter lives.

Social support may be more protective for women than for men. On the one hand, being married benefits men more than women (Kiecolt-Glaser & Newton, 2001). However, women have more close friends and participate in more group activities, such as church or women's groups, that may offer support. Social support keeps stress systems at low levels and so may prevent some of the wear and tear that men, especially unattached men, sustain. All of these factors seem to play a role in women's advantage in longevity.

TABLE 12.3 | How Long Will You Live?

Longevity calculators are rough guides for calculating your personal longevity. Although many longevity calculators exist, one of the most popular is Vitality Compass. This calculator asks questions such as:

Compared with a year ago, how has your overall health changed?

During the past month, how many days have you felt sad or depressed?

In the past week, during how many days did you exercise or engage in rigorous physical activity for at least 20 minutes?

On average, how many hours a night do you sleep?

On average, how many alcoholic drinks do you have in a typical day?

During the past week, how many servings of fresh vegetables did you eat?

During the past week, how many times did you consume sweets or fast food?

How satisfied are you with your work life?

How often do you attend religious activities?

After these questions are answered, you are provided with four scores: your biological age (your body's age given your habits), your life expectancy, your healthy life expectancy (years free of cancer, heart disease, and diabetes), and your accrued years (how many years you are gaining or losing as a result of your habits).

To get your score, go to <http://apps.bluezones.com/vitality>.

Source: Vitality Compass, <http://apps.bluezones.com/vitality>.

■ PSYCHOLOGICAL ISSUES IN ADVANCING ILLNESS

Although many people die suddenly, many people who are terminally ill know that they are going to die for some time before their death. As a consequence, a variety of medical and psychological issues arise for the patient.

Continued Treatment and Advancing Illness

Advancing and terminal illness frequently bring the need for continued treatments with debilitating and unpleasant side effects. For example, radiation therapy and chemotherapy for cancer may produce discomfort, nausea and vomiting, chronic diarrhea, hair loss, skin discoloration, fatigue, and loss of energy. The patient with advancing diabetes may require amputation of extremities, such as fingers or toes. The patient with advancing cancer may require removal of an organ to which the illness has now spread, such as a lung or part of the liver. The patient with degenerative kidney disease may be given a transplant, in the hope that it will forestall further deterioration.

There may, consequently, come a time when the question of whether to continue treatments becomes an issue. In some cases, refusal of treatment may indicate depression and feelings of hopelessness, but in many cases, the patient's decision may be supported by thoughtful choice.

Is There a Right to Die? In recent years, the right to die has assumed importance due to several legislative and social trends. In 1990, Congress passed the Patient Self-Determination Act, requiring that Medicare and Medicaid health care facilities have written policies and procedures concerning patients' wishes for life-prolonging therapy. These policies include the provision of a Do Not Resuscitate (DNR) order, which patients may choose to sign or not, in order to provide explicit guidance regarding their preferences for medical response to cardiopulmonary arrest.

An important social trend affecting terminal care is the right-to-die movement, which maintains that dying should become more a matter of personal choice and personal control. Derek Humphry's book *Final Exit* virtually leaped off bookstore shelves when it appeared in 1991. A manual of how to commit suicide or assist in suicide for the dying, it was perceived to give

back to dying people the means for achieving a dignified death at a time of one's choosing.

Receptivity to such ideas as suicide and assisted suicide for the terminally ill has increased in the American population. In a 1975 Gallup Poll, only 41 percent of respondents believed that someone in great pain with no hope of improvement had the moral right to commit suicide, whereas, as of 2013, about two-thirds of adults did; however, that is fewer than the 71% who supported euthanasia in 2007 (Reyes, 2013). Many European countries, as well as Australia and Canada, have much higher levels of support for assisted dying, with several approaching 90% (*The Economist*, October 20, 2012). Although some experts found that these preferences may change when people realize that they are facing death (Sharman, Garry, Jacobson, Loftus, & Ditto, 2008), declines in functioning appear to lead to reduced interest in life-sustaining treatments (Ditto et al., 2003) (see Box 12.2).

Moral and Legal Issues Increasingly, societies must struggle with the issue of **euthanasia**, that is, ending the life of a person who is suffering from a painful terminal illness. *Euthanasia* comes from the Greek word meaning "good death" (Pfeifer & Brigham, 1996). Terminally ill patients most commonly request euthanasia or assisted suicide when they are experiencing extreme distress and suffering, often due to inadequate relief from pain.

In 1994, Oregon became the first state to pass a law permitting physician-assisted dying. To exercise this option, the patient must be mentally competent and have a terminal illness with less than 6 months to live. He or she must also be informed about alternatives, such as pain control and hospice care. He or she must make the request at least 3 times, and the case must be reviewed by a second physician for accuracy and to ensure that family members are not pressuring the patient to die (*The Economist*, October, 2012). Typically, if these conditions are met, the physician provides a lethal dose of medication or sleeping pills that the patient can then ingest to end his or her life. Statistics show a steady increase in the number of people taking advantage of the law, with 71 Oregonians choosing assisted suicide in 2011. Many other patients obtain the drugs but do not use them (Oregon Department of Human Services, 2011). Although a 1997 Supreme Court ruling did not find physician-assisted dying to be a constitutional right, the Court nonetheless left legislation to individual states, and so the

(This is an example of the kind of letter that might be given by a patient to his or her physician.)

Dear Dr. _____.

I wish to maintain the last weeks of my life with dignity and to die an appropriate death.

To that end, I ask:

- That my health care choices (or those of the person designated to choose for me) be respected.
- That if palliative care is warranted, you will recommend a plan or facility.

- That I may be allowed to die with dignity and that extraordinary life-saving measures will not be taken.
- That my “do not resuscitate” request will be honored.

I appreciate the opportunity to communicate my wishes with respect to the end of my life and your willingness to honor my requests so as to minimize the burden on me and my family.

Sincerely,

Signature

Date

1997 Oregon Death with Dignity Act became official, with the first physician-assisted death occurring in 1998 (Sears & Stanton, 2001). Currently, 5 other states also have physician assisted dying procedures legally in place (Lovett & Pérez-Peña, 2015).

More passive measures to terminate life have also received attention. A number of states have now enacted laws enabling people with terminal diseases to write a **living will**, or provide advance directives, requesting that extraordinary life-sustaining procedures not be used if they are unable to make this decision on their own. Advance directives provide instructions and legal protection for the physician, so that life-prolonging interventions, such as use of respirators, will not be indefinitely undertaken in a vain effort to keep the patient alive. This kind of document also helps to ensure that the patient’s preferences, rather than a surrogate’s (such as a relative), are respected (Ditto & Hawkins, 2005; Fagerlin, Ditto, Danks, Houts, & Smucker, 2001). Overall, 88 percent of hospice care patients, 65 percent of nursing-home residents, but only 28 percent of home healthcare patients have filed at least one advanced directive with their physicians, usually a do not resuscitate order or a living will (Jones, Moss, & Harris-Kojetin, 2011).

Unfortunately, research suggests that many physicians ignore the wishes of their dying patients and needlessly prolong pain and suffering. One study (Seneff, Wagner, Wagner, Zimmerman, & Knaus, 1995) found that although one-third of the patients had asked not to be revived with cardiopulmonary resuscitation, half the time this request was not indicated

on their charts. Thus, at present, the living will and related tools are not completely successful in allowing patients to express their wishes and ensure that they are met. Box 12.3 presents a case of assisted suicide.

The complex moral, legal, and ethical issues surrounding death are relatively new to our society, prompted in large part by substantial advances in health care technologies. These issues will assume increasing importance in the coming decades with the aging of the population.

Psychological and Social Issues Related to Dying

Advancing and terminal illness raises a number of important psychological and social issues.

Changes in the Patient’s Self-Concept Advancing illness can threaten the self-concept. As the disease progresses, patients are increasingly less able to present themselves effectively. It may become difficult for them to maintain control of biological and social functioning. They may be incontinent (unable to control urination or bowel movements); they may drool, have distorted facial expressions, or shake uncontrollably. None of this is attractive either to the patient or to others.

These patients may also be in intermittent pain, may suffer from uncontrollable retching or vomiting, and may experience a shocking deterioration in appearance due to weight loss, the stress of treatments, or the sheer drain of illness. Even more threatening to

May Harvey, age 60, was dying slowly and painfully of gastric cancer. She no longer had the energy to see friends and needed help for every daily activity, including basic hygiene. She decided to take her own life and asked her physician to help her. He refused, explaining that the law was very clear about not assisting a suicide. She turned to her husband who had been a medic overseas, but he also refused. He would lose his license to practice nursing and could go to prison.

So May decided she would have to do it herself. She began hoarding her sleeping pills and complained of insomnia, so her physician would increase the dosage. One day, May decided she had accumulated enough pills, and so she swallowed them all with water, expecting to slip into sleep and away from life. Instead, within the hour she threw them all up.

Frantic, she gathered them up, dried what remained off, and put them away for another try. Soon she had accumulated a few more pills. She picked a day when she was feeling better and swallowed them all again. The same thing happened. This time her husband realized what she was trying to do. He informed her physician who reduced her sleep medication. It did not matter because May was now too weak to try it a third time.

A few days later, May's daughter came in to help, and May told her what she had tried to do. "I don't see why they can't help me. When they put the dog to sleep, it was so easy and painless. Why can't they do the same for me?" May lived a few more weeks until finally she got the death she sought.

some patients is mental regression and the inability to concentrate. Cognitive decline accelerates in the years prior to death (Wilson, Beck, Bienias, & Bennett, 2007). Losses in cognitive function may also be due

either to the progressive nature of disease or to the tranquilizing and disorienting effects of painkillers and other medications.



In recent years, grassroots movements expressing the rights to die and to physician-assisted suicide have gained strength in the United States.

© AP Photo/Richard Sheinwald

Issues of Social Interaction These issues spill over into social interactions. Although terminally ill patients often want and need social contact, they may be afraid that their obvious mental and physical deterioration will upset visitors. Thus, patients may begin a process of social withdrawal, whereby they gradually restrict visits to only a few family members. Family and friends can help make this withdrawal less extreme: They can prepare visitors in advance for the patient's state so that the visitor's reaction can be controlled; they can also screen out some visitors who cannot keep their emotions in check.

Some disengagement from the social world is normal and may represent the grieving process through which the final loss of family and friends is anticipated. This period of anticipatory grieving may compromise communication because it is hard for the patient to express affection for others while simultaneously preparing to leave them.

Communication Issues As long as a patient's prognosis is favorable, communication is usually open; however, as the prognosis worsens and treatment



Many terminally ill patients who find themselves repeated objects of intervention become worn out and eventually refuse additional treatment.

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becomes more drastic, communication may break down. Medical staff may become evasive when questioned about the patient's status. Family members may be cheerfully optimistic with the patient, but confused and frightened when they try to elicit information from medical staff. Each person involved may believe that others do not want to talk about the death. Death itself is still a taboo topic in our society. The issue is generally avoided in polite conversation; little research is conducted on death; and even when death strikes within a family, the survivors often try to bear their grief alone. The right thing to do, many people feel, is not to bring it up.

The Issue of Nontraditional Treatment

As both health and communication deteriorate, some terminally ill patients turn away from traditional

medical care. Many such patients fall victim to dubious remedies offered outside the formal health care system. Frantic family members, friends who are trying to be helpful, and patients themselves may scour fringe publications for seemingly effective remedies or cures; they may invest thousands of dollars in their generally unsuccessful search.

What prompts people to take these often uncomfortable, inconvenient, costly, and worthless measures? Some patients are so frantic at the prospect of death that they will use up both their own savings and those of the family in the hope of a miracle cure. In other cases, turning to nontraditional medicine may be a symptom of a deteriorating relationship with the health care system and the desire for more humanistic care. This is not to suggest that a solid patient-practitioner relationship can prevent every patient from turning to quackery. However, when the patient is well informed and feels cared for by others, he or she is less likely to look for alternative remedies.

■ ARE THERE STAGES IN ADJUSTMENT TO DYING?

Do people pass through a predictable series of **stages of dying**?

Kübler-Ross's Five-Stage Theory

Elisabeth Kübler-Ross, a pioneer in the study of death and dying, suggested that people pass through five stages as they adjust to the prospect of death: denial, anger, bargaining, depression, and acceptance. Although research shows that people who are dying do not necessarily pass through each of these stages in the exact order, all of these reactions are commonly experienced.

Denial Denial is thought to be a person's initial reaction on learning of the diagnosis of terminal illness. Denial is a defense mechanism by which people avoid the implications of an illness. They may act as if the illness were not severe, it will shortly go away, and it will have few long-term implications. In extreme cases, the patient may even deny that he or she has the illness, despite having been given clear information about the diagnosis (Ditto, Munro, et al., 2003). Denial, then, is the subconscious blocking out of the full realization of the reality and implications of the disorder.

Denial early on in adjustment to life-threatening illness is both normal and useful because it can protect the patient from the full realization of impending death (Lazarus, 1983). Usually it lasts only a few days. When it lasts longer, it may require psychological intervention.

Anger A second reaction to the prospect of dying is anger. The angry patient is asking, “Why me? Considering all the other people who could have gotten the illness, all the people who had the same symptoms but got a favorable diagnosis, and all the people who are older, dumber, more bad-tempered, less useful, or just plain evil, why should I be the one who is dying?” Kübler-Ross quotes one of her dying patients:

I suppose most anybody in my position would look at somebody else and say, “Well, why couldn’t it have been him?” and this has crossed my mind several times. An old man whom I have known ever since I was a little kid came down the street. He was eighty-two years old, and he is of no earthly use as far as we mortals can tell. He’s rheumatic, he’s a cripple, he’s dirty, just not the type of person you would like to be. And the thought hit me strongly, now why couldn’t it have been old George instead of me? (quoted in Kübler-Ross, 1969, p. 50)

The angry patient may show resentment toward anyone who is healthy, such as hospital staff, family members, or friends. Angry patients who cannot express their anger directly by being irritable may do so indirectly by becoming embittered. Bitter patients show resentment through death jokes, cracks about their deteriorating appearance and capacities, or pointed remarks about all the exciting things that they will not be able to do because those events will happen after their death.

Anger is one of the harder responses for family and friends to deal with. They may feel they are being blamed by the patient for being well. The family may need to work together with a therapist to understand that the patient is not really angry with them but at fate; they need to see that this anger will be directed at anyone who is nearby, especially people with whom the patient feels no obligation to be polite and well behaved. Unfortunately, family members often fall into this category.

Bargaining Bargaining is the third stage of Kübler-Ross’s formulation. At this point, the patient abandons

anger in favor of a different strategy: trading good behavior for good health. Bargaining may take the form of a pact with God, in which the patient agrees to engage in good works or at least to abandon selfish ways in exchange for better health or more time. A sudden rush of charitable activity or uncharacteristically pleasant behavior may be a sign that the patient is trying to strike such a bargain.

Depression Depression, the fourth stage in Kübler-Ross’s model, may be viewed as coming to terms with lack of control. The patient acknowledges that little can now be done to stay the course of illness. This realization may be coincident with a worsening of symptoms, tangible evidence that the illness is not going to be cured. At this stage, patients may feel nauseated, breathless, and tired. They may find it hard to eat, to control elimination, to focus attention, and to escape pain or discomfort.

Kübler-Ross refers to the stage of depression as a time for “anticipatory grief,” when patients mourn the prospect of their own deaths. This grieving process may occur in two stages, as the patient first comes to terms with the loss of past valued activities and friends and then begins to anticipate the future loss of activities and relationships. Depression, though far from pleasant, can be functional in that patients begin to prepare for the future. Depression can nonetheless require treatment, so that symptoms of depression can be distinguished from symptoms of physical deterioration.

Acceptance The final stage in Kübler-Ross’s theory is acceptance. At this point, the patient may be too weak to be angry and too accustomed to the idea of dying to be depressed. Instead, a tired, peaceful, though not necessarily pleasant calm may descend. Some patients use this time to make preparations, deciding how to divide up their remaining possessions and saying goodbye to old friends and family members.

Evaluation of Kübler-Ross’s Theory

How good an account of the process of dying is Kübler-Ross’s stage theory? As a description of the reactions of dying patients, her work was invaluable. She has chronicled nearly the full array of reactions to death, as those who work with the dying will be quick to acknowledge. Her work is also of inestimable value in pointing out the counseling needs of the dying. Finally, along with other researchers, she broke

through the silence and taboos surrounding death, making it an object of both scientific study and sensitive concern. Nonetheless, it bears mention, again, that patients do not typically go through five stages in a predetermined order, but rather may experience these stages in a various intermittent order.

Kübler-Ross's stage theory also does not fully acknowledge the importance of anxiety, which, next to depression, is one of the most common responses. What patients fear most is not being able to control pain; they may welcome or even seek death to avoid it (Hinton, 1967). Other symptoms, such as difficulty breathing or uncontrollable vomiting, likewise produce anxiety, which may exacerbate the patient's already deteriorating physical and mental condition.

■ PSYCHOLOGICAL ISSUES AND THE TERMINALLY ILL

Approximately one-third Americans who die each year die in hospitals (Centers for Disease Control and Prevention, 2015, November).

Medical Staff and the Terminally Ill Patient

Unfortunately, death in the institutional environment can be depersonalized and fragmented. Wards may be understaffed, with the staff unable to provide the kind of emotional support a patient needs. Hospital regulations may restrict the number of visitors or the length of time that they can stay, thereby reducing the availability of support from family and friends. Pain is one of the chief symptoms in terminal illness, and in the busy hospital setting, the ability of patients to get the amount of pain medication they need may be compromised. Moreover, as we saw in Chapter 10, prejudices against drug treatments for pain still exist, and so terminal patients run the risk of being undermedicated for their pain (Turk & Feldman, 1992a, 1992b). Death in an institution can be a long, lonely, mechanized, painful, and dehumanizing experience.

The Significance of Hospital Staff to the Patient Physical dependence on hospital staff is great because the patient may need help for even the smallest activity, such as turning over in bed. Patients



Medical staff can be very significant to a dying patient because they see the patient on a regular basis, provide realistic information, and are privy to the patient's last personal thoughts and wishes.

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are entirely dependent on medical staff for amelioration of their pain. And staff may be the only people to see a dying patient on a regular basis if he or she has no friends or family who visit regularly.

Moreover, staff may be the only people who know the patient's actual physical state; hence, they are the patient's only source of realistic information. The patient may welcome communication with staff because he or she can be fully candid with them. Finally, staff are important because they are privy to one of the patient's most personal and private acts, the act of dying.

Risks of Terminal Care for Staff **Terminal care** is hard on hospital staff. It is the least interesting physical care because it is often **palliative care**—that is, care designed to make the patient feel comfortable—rather than **curative care**—that is, care designed to cure the patient's disease. Terminal care involves a lot of unpleasant custodial work, such as feeding, changing, and bathing the patient, and sometimes symptoms go undertreated. The staff may burn out from watching patient after patient die, despite their best efforts.

Staff may be tempted to withdraw into a crisply efficient manner rather than a warm and supportive one so as to minimize their personal pain. Physicians, in particular, want to reserve their time for patients who can most profit from it and, consequently, may spend little time with a terminally ill patient. Unfortunately, terminally ill patients may interpret such behavior as abandonment and take it very hard. Accordingly, a continued role for the physician in the patient's terminal care in the form of brief but frequent visits is desirable.

Achieving an Appropriate Death Psychiatrist Avery Weisman (1972, 1977), a distinguished clinician who worked with dying patients for many years, outlined a useful set of goals for medical staff in their work with the dying:

- *Informed consent*—Patients should be told the nature of their condition and treatment and, to some extent, be involved in their own treatment.
- *Safe conduct*—The physician and other staff should act as helpful guides for the patient through this new and frightening stage of life.
- *Significant survival*—The physician and other medical staff should help the patient use his or her remaining time as well as possible.

- *Anticipatory grief*—Both the patient and his or her family members should be aided in working through their anticipatory sense of loss and depression.
- *Timely and appropriate death*—The patient should be allowed to die when and how he or she wants to, as much as possible. The patient should be allowed to achieve death with dignity.

These guidelines, established many years ago, still provide the goals and means for terminal care. Unfortunately, a “good death” is still not available to all. A survey of the survivors of 1,500 people who had died revealed that dying patients often had not received enough medication to ease their pain and had not experienced enough emotional support. Lack of open communication and lack of respect from medical staff are two other common complaints (Teno, Fisher, Hamel, Coppola, & Dawson, 2002).

Counseling with the Terminally III

Many dying patients need the chance to talk a counselor. Therapy is typically short-term and the nature and timing of the visits typically depend on the desires and energy level of the patient. Moreover, in working with the dying, patients typically set the agenda.

Therapy with the dying is different from typical psychotherapy in several respects. First, for obvious reasons, it is likely to be short term. The format of therapy with the dying also varies from that of traditional psychotherapy. The nature and timing of visits must depend on the inclination and energy level of the patient, rather than on a fixed schedule of appointments. The agenda should be set at least partly by the patient. And if an issue arises that the patient clearly does not wish to discuss, this wish should be respected.

Terminally ill patients may also need help in resolving unfinished business. Uncompleted activities may prey on the mind, and preparations may need to be made for survivors, especially dependent children. Through careful counseling, a therapist may help the patient come to terms with the need for these arrangements, as well as with the need to recognize that some things will remain undone.

Some **thanatologists**—that is, those who study death and dying—have suggested that behavioral and cognitive-behavioral therapies can be constructively employed with dying patients (Sobel, 1981). For example, progressive muscle relaxation can ameliorate

discomfort and instill a renewed sense of control. Positive self-talk, such as focusing on one's life achievements, can undermine the depression that often accompanies dying. Family therapy can also be an appropriate way to deal with issues raised by terminal illness, to help the family and patient recognize and plan for the future.

The Management of Terminal Illness in Children

Working with terminally ill children is perhaps the most stressful of all terminal care. As a result, family members, friends, and even medical staff may be reluctant to talk openly with a dying child about his or her situation.

Nonetheless, terminally ill children often know more about their situation than they are given credit for (Spinetta, 1982). Children use cues from their treatments and from the people around them to infer what their condition must be. As their own physical condition deteriorates, they develop a conception of their own death and the realization that it may not be far off, as this exchange shows:

TOM: Jennifer died last night. I have the same thing. Don't I?

NURSE: But they are going to give you different medicines.

TOM: What happens when they run out?
(Bluebond-Langner, 1977, p. 55)

It may be difficult to know what to tell a child. Unlike adults, children may not express their knowledge, concerns, or questions directly. They may communicate the knowledge that they will die only indirectly, as by wanting to have Christmas early so that they will be around for it. Or they may suddenly stop talking about their future plans.

One child, who when first diagnosed said he wanted to be a doctor, became quite angry with his doctor when she tried to get him to submit to a procedure by explaining the procedure and telling him, "I thought you would understand, Sandy. You told me once you wanted to be a doctor." He screamed back at her, "I'm not going to be anything," and then threw an empty syringe at her. She said, "OK, Sandy." The nurse standing nearby said, "What are you going to be?" "A ghost," said Sandy, and turned over (Bluebond-Langner, 1977, p. 59).

Counseling with a terminally ill child may be required and typically follows some of the same guidelines as is true with dying adults, but therapists can take cues about what to discuss from the child, talking only about those issues the child is ready to discuss. Parents, too, may need counseling to help them cope with the impending death. They may blame themselves for the child's illness or feel that there is more they could have done. The needs of other children may be passed over in the process of dealing with the dying child's situation. A counselor working with the family can help restore balance.

Parents of dying children experience an enormous stress burden to the degree that they sometimes have the symptoms of post-traumatic stress disorder. The emotional distress of parents with dying children may require supportive mental health services and meetings with the physician to help the patients make sense of and derive meaning from the child's terminal illness, especially during the first few months after the child's diagnosis (Dunn et al., 2012) and death (Meert et al., 2015).

■ ALTERNATIVES TO HOSPITAL CARE FOR THE TERMINALLY ILL

Hospital care for the terminally ill is palliative, emotionally wrenching, and demanding of personalized attention in ways that often go beyond the resources of the hospital. Consequently, hospice care in one's own home or in a hospice facility is increasingly an option for dying people.

Hospice Care

The idea behind **hospice care** is the acceptance of death, emphasizing the relief of suffering rather than the cure of illness. Hospice care is designed to provide palliative care and emotional support to dying patients and their family members. About 1.65 million people received services from hospices in 2014, making hospice care a significant contributor to the delivery of services to advancing in terminally ill patients (National Hospice and Palliative Care Organization, 2015, September).

In medieval Europe, a **hospice** was a place that provided care and comfort for travelers. In keeping with this original goal, hospice care is both a philosophy concerning a way of dying and a system of care for the terminally ill. Typically, painful or invasive



Hospice care, an alternative to hospital and home care for the terminally ill, is designed to provide personalized palliative treatment without the strains that home care can produce.

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therapies are discontinued. Instead, care is aimed toward managing symptoms, such as reducing pain and controlling nausea.

Most important, the patient's psychological comfort is stressed. Patients are encouraged to personalize their living areas as much as possible by bringing in their own familiar things. Thus, in institutional hospice care, each room may look very different, reflecting the personality and interests of its occupant. Patients also typically wear their own clothes and determine their own activities.

Hospice care is oriented toward improving a patient's social support system. Restrictions on visits from family or friends are removed as much as possible. Staff are especially trained to interact with patients in a warm, emotionally caring way. Usually, counselors are available for individual, group, or family intervention.

Home Care

Recent years have seen renewed interest in **home care** for dying patients. Home care appears to be the care of choice for most terminally ill patients (National Hospice and Palliative Care Organization, 2015, September), and for many patients, it may be the only economically feasible care. The psychological

advantages of home care are that the patient is surrounded by personal items and by family rather than medical staff. Some degree of control can be maintained over such activities as what to eat or what to wear.

Although home care is often easier on the patient psychologically, it can be very stressful for the family. Even if the family can afford around-the-clock nursing, often at least one family member's energies must be devoted to the patient on an almost full-time basis. The designated caregiver must often stop working and also face the additional stress of constant contact with the prospect of death. The caregiver may be torn between wanting to keep the patient alive and wanting the patient's and their own suffering to end.

■ PROBLEMS OF SURVIVORS

The death of a family member may be the most upsetting and dreaded event in a person's life. For many people, the death of a loved one is a more terrifying prospect than their own death or illness. Even when a death is anticipated and, on some level, actually wished for, it may be very hard for survivors to cope.

Each culture has its own way of coming to terms with death. Although in some cultures death is feared, in others it is seen as a normal part of life. Each culture, accordingly, has developed death-related ceremonies that reflect these cultural beliefs.

In traditional Japanese culture, death is regarded as a process of traveling from one world to another. When someone dies, that person goes to a purer country, and the function of death rituals is to help the spirit make the journey. A series of rites and ceremonies takes place, aided by a minister, to achieve this end. The funeral events begin with a bedside service, in which the minister consoles the family. The next service is the *Yukan*, the bathing of the dead. An appreciation service follows the funeral, with food for all who have traveled long distances to attend. When the mourning period is over, a final party is given for friends and relatives as a way of bringing the mourners back into the community (Kübler-Ross, 1975).

In Hinduism, which is the main religion of India, death is not viewed as separate from life or as an ending. Rather, it is considered a continuous, integral part of life. Because Hindus believe in reincarnation, they believe that birth is followed by death and death by rebirth; every moment one is born and dies again. Thus, death is like any transition in life. The Hindus teach that one should meet death with tranquillity and meditation. Death is regarded as the chief fact of life and a sign that all earthly desires are in vain. Only when an individual neither longs for nor fears death is that person capable of transcending both life and death and achieving *nirvana*—merging into unity with the

Absolute. In so doing, the individual is freed from the fear of death, and death comes to be seen as a companion to life (Kübler-Ross, 1975).

What would people from another culture think about attitudes toward death in the United States if they were to witness our death practices? First, they would see that many deaths take place in the hospital without the presence of close relatives. Once death has occurred, the corpse is promptly removed without the help of the bereaved, who see it, if at all, only after morticians have made it acceptable for viewing. In some cases, the corpse is cremated shortly after death and is never again seen by the family. A paid organizer, often a director of a funeral home, takes over much of the direction of the viewing and burial rituals, deciding matters of protocol and the timing of services. In most subcultures within the United States, a time is set aside when the bereaved family accepts condolences from visiting sympathizers. A brief memorial service is then held, after which the bereaved and their friends may travel to the cemetery, where the corpse or ashes are buried. Typically, there are strong social pressures on the friends and relatives of the deceased to show little sign of emotion. The family is expected to establish this pattern, and other visitors are expected to follow suit. A friend or relative who is out of control emotionally will usually withdraw from the death ceremony or will be urged to do so by others. Following the ceremony, there may be a brief get-together at the home of the bereaved, after which the mourners return home (Huntington & Metcalf, 1979).

The weeks just before the patient's death are often a period of frenzied activity. Visits to the hospital increase, preliminary legal or funeral preparations may be made, last-minute therapies may be initiated, or the patient may be moved to another facility. Family members are kept busy by the sheer amount of work that must be done. After the patient dies, there are activities related to the death and settling the estate (Box 12.4 describes some of the ways in which culture vary in reactions to death and the formalities that follow). Then, very abruptly, the activities cease. Visitors return home, the patient has been cremated or buried, and the survivor is left alone.

The Survivor

The aftermath of a death creates demands of its own. The typical survivor is a widow in her 60s or older, who may have physical problems of her own. If she has lived in a traditional marriage, she may find herself with tasks, such as preparing her income tax return and making household repairs, which she has never had to do before. Survivors may be left with few resources to turn to.

Grief, which is the psychological response to bereavement, is a feeling of hollowness, often marked by preoccupation with the image of the deceased person, expressions of hostility toward others, and guilt over the death. Bereaved people often show a restlessness

and an inability to concentrate on activities, and they may experience yearning for their loved one, as well as anger or depression, especially during the first 6 months (Maciejewski, Zhang, Block, & Prigerson, 2007). Health problems are common as well (Vahtera et al., 2006).

It may be difficult for outsiders to appreciate the degree of a survivor's grief. They may feel, especially if the death was a long time coming, that the survivor should be ready for it and thus show signs of recovery shortly after the death. Widows say that often, within a few weeks of their spouse's death, friends are urging them to pull out of their melancholy and get on with life. In some cases, the topic of remarriage is brought up within weeks after the death. However, normal grieving may go on for months, and many widows and widowers are still deeply troubled by their spouse's death several years later (Stroebe & Stroebe, 1987).

Whether it is adaptive to grieve or not to grieve has been debated. In contrast to psychologists' usual caution that the avoidance of negative emotions can be problematic, some evidence suggests that emotional avoidance (Bonanno, Keltner, Holen, & Horowitz, 1995) and positive appraisals (Stein, Folkman, Trabasso, & Richards, 1997) actually lead to better adjustment in the wake of a death. Bereaved adults who ruminate on the death are less likely to get good social support, they have higher levels of stress, and they are more likely to be depressed (Nolen-Hoeksema, McBride, & Larson, 1997). By contrast, extraverts seem to be good at marshaling their social support and on the whole, extraverted and conscientious people seem to get through the bereavement period with less depression than people without these qualities (Pai & Carr, 2010).

The grief response may be more aggravated in men, in caregivers, and in those whose loss was sudden and unexpected (Aneshensel, Botticello, & Yamamoto-Mitani, 2004; Stroebe & Stroebe, 1987). Nonetheless, the majority of widows and widowers are resilient in response to their loss (Vahtera et al., 2006), especially if the partner's death had been expected and they have had the opportunity to accept its inevitability (Wilcox et al., 2003; Bonanno et al., 2002). Among women who are depressed in widowhood, financial strain appears to be the biggest burden. For men, the strains associated with household management can lead to distress (Umberson, Wortman, & Kessler, 1992). Grief may be especially pronounced in mothers of children who

have died (Li, Laursen, Precht, Olsen, & Mortensen, 2005), and it may be complicated by depression (Wijngaards-Meij et al., 2005).

As we will see in Chapter 14, the experience of bereavement can lead to adverse changes in immunologic functioning, increasing the risk of disease and even death. Increases in alcohol and drug abuse and inability to work are common problems for survivors (Aiken & Marx, 1982). Programs designed to provide counseling to the bereaved can offset these adverse reactions (Aiken & Marx, 1982).

For child survivors, the death of a sibling raises particular complications, because many children have fervently wished, at one time or another, that a sibling were dead. When the sibling actually does die, the child may feel that he or she caused it. Possibly, the surviving child did not get much attention during the sibling's illness and may feel some temporary elation when the sibling is no longer around as a source of competition (Lindsay & McCarthy, 1974). As one child remarked on learning of his sibling's death, "Good. Now I can have all his toys" (Bluebond-Langner, 1977, p. 63).

In helping a child to cope with the death of a parent or a sibling, it is best not to wait until the death has actually occurred. Rather, the child should be prepared for the death, perhaps by drawing on the death of a pet or a flower to aid understanding (Bluebond-Langner, 1977). The child's questions about death should be answered as honestly as possible, but



Grief involves a feeling of hollowness, a preoccupation with the deceased person, and guilt over death. Often, outsiders fail to appreciate the depth of a survivor's grief or the length of time it takes to get over the bereavement.

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without unwanted detail. Providing only what is asked for when the timing is right is the best course.

Death Education

Because death has been a taboo topic, many people have misconceptions about it, including the idea that the dying wish to be left alone and not talk about their situation. Because of these concerns, some courses on dying, which may include volunteer work with dying patients, have been developed on some college campuses. A potential problem with such courses is that they may attract the occasional suicidal student and provide unintended encouragement for self-destructive leanings. Accordingly, some instructors have recommended confronting such problems head-on, in the hopes that they can be forestalled.

Whether college students are the best and the only population that should receive death education is another concern. Unfortunately, organized means of educating people outside the university system are few, so college courses remain one of the more viable vehicles for death education. Yet a book about death and dying, *Tuesdays with Morrie* (Albom, 1997), was a best seller for years, a fact that underscores how much people want to understand death. Moreover, causes of death, especially diseases with high mortality, dominate the news (Adelman & Verbrugge, 2000). At present, though, the news and a few books are nearly all there is to meet such needs. Through **death education**, it may be possible to develop realistic expectations, both about what modern medicine can achieve and about the kind of care the dying want and need. ●

SUMMARY

1. Causes of death vary over the life cycle. In infancy, congenital abnormalities and sudden infant death syndrome (SIDS) account for most deaths. From ages 1 to 15, the causes shift to accidents and childhood leukemia. In adolescence and young adulthood, death is typically due to auto accidents, homicide, suicide, cancer, and AIDS. In adulthood, cancer and heart attacks are the most common causes of death. Death in old age is usually due to heart disease, stroke, cancer, or physical degeneration.
2. Concepts of death change over the life cycle. In childhood, death is conceived of first as a great sleep and later as a ghostlike figure that takes a person away. Later, death is recognized to be an irreversible biological stage. Middle age is the time when many people first begin to come to terms with their own death.
3. Advancing disease raises psychological issues, including treatment-related discomfort and decisions of whether to continue treatment. Issues concerning the patient's directive to withhold extreme life-prolonging measures, assisted suicide, and euthanasia have been topics of concern in both medicine and law.
4. Patients' self-concepts must continually adapt in response to the progression of illness, change in appearance, energy level, control over physical processes, and degree of mental alertness. The patient may withdraw from family and friends as a result. Thus, issues of communication can be a focal point for intervention.
5. Kübler-Ross's theory of dying suggests that people go through stages, progressing through denial, anger, bargaining, depression, and finally acceptance. Research shows that patients do not necessarily go through these stages in sequence but that all these states describe reactions of dying people to a degree.
6. Much of the responsibility for psychological management of terminal illness falls on medical staff. Medical staff can provide information, reassurance, and emotional support when others cannot.
7. Psychological counseling needs to be made available to terminally ill patients, because many people need a chance to develop a perspective on their lives. Developing methods for training therapists in clinical thanatology, then, is an educational priority. Family therapy may be needed to soothe the problems of the family and to help patient and family say goodbye to each other.
8. Counseling terminally ill children is especially important because both parents and children may be confused and frightened.
9. Hospice care and home care are alternatives to hospital care for the dying. Palliative and psychologically supportive care in the home or in a homelike environment can have beneficial psychological effects on dying patients and their survivors.
10. Grief is marked by a feeling of hollowness, preoccupation with an image of the deceased person, guilt over the death, expressions of hostility toward others, restlessness, and an inability to concentrate. Many people do not realize how long normal grieving takes.

KEY TERMS

curative care
 death education
 euthanasia
 grief
 home care
 hospice

hospice care
 infant mortality rate
 living will
 palliative care
 premature death
 stages of dying

sudden infant death syndrome (SIDS)
 terminal care
 thanatologists