LEARNING OUTCOME AND OBJECTIVES: Upon completion of this continuing education course, you will have increased your knowledge of end-of-life care. Specific learning objectives to address potential learning gaps include:

- Discuss the need for end-of-life care in the United States.
- Differentiate between palliative care and hospice care.
- Explain legal and ethical principles in end-of-life care.
- Discuss the essential elements of effective communication with patient and family.
- List pain management interventions for the dying patient.
- Identify the psychological and support needs of the patient and family.
- Describe the special end-of-life care needs of children, veterans, and terminal patients with cancer, dementia, and HIV/AIDS.
- Describe care of the patient during the last hours of life.
- Explain the steps in postmortem care.

THE NEED FOR END-OF-LIFE CARE

The Burden of Chronic Illness

Seventy percent of all deaths among Americans are from chronic diseases. Chronic diseases are those that last one or more years, require continuous medical treatment, and limit activities of daily living. Among adults ages 65 and older, 81% have multiple chronic conditions. The most common chronic diseases include heart disease, cancer, lung disease, diabetes, cardiovascular accident, Alzheimer’s disease, and chronic kidney disease. The most common causes for chronic
disease include smoking (including secondhand smoke), alcohol in excess, poor nutritional intake, and lack of physical activity (Burtoff et al., 2017).

Ninety percent of all healthcare funding ($3.3 trillion) pays for the treatment of chronic medical and mental illnesses (CDC, 2019a). On average, Americans with chronic illness will also need help with routine activities of daily living for two or more of their final years of life.

**Increasing Population of Older Adults**

The graying of the Baby Boom generation (born 1946 to 1964) threatens to intensify this burden of chronic illness. The first Baby Boomers turned 65 in 2010, and the last will turn 65 in 2030. In 2015, 15.1% of the United States population was older than 65. By 2050 it will be 22.5% (Agingstats.gov, 2019). Research has also shown that Baby Boomers are living longer than people roughly 20 years older but that they are not healthier. While they are less likely to smoke, have emphysema, or have heart disease, they are more likely to be obese and/or have diabetes and/or hypertension than the previous generation due to the link between advanced age and obesity as risk factors for diabetes and hypertension.

Approximately 50% of older Americans have at least one emergency department (ED) visit in the last month of life. Three quarters of these ED admissions are hospitalized, and the majority of those hospitalized patients die without being discharged from the hospital. Care in the last year of life accounts for 25% of all Medicare costs (Custer, 2019).

**Healthcare Shortage**

Together, the burdens of chronic illness and cancer point to an exponential escalation in the demand for palliative care over the next several decades. Experts are concerned that there will be too few physicians and nurses certified in palliative care to meet the needs of this aging cohort.

Boomers make up a significant part of the healthcare workforce as well. Nearly 40% of nurses will retire by 2030 and will be seeking more healthcare themselves. Nurses in their 50s will be the largest segment of the nursing population. When these health professionals who are Baby Boomers retire, the existing nursing shortage will worsen (Brooks, 2016).

**Lack of Knowledge about End-of-Life Care**

In general, Americans are reluctant to talk about death or to express their wishes about end-of-life care. Less than one third of Americans express in writing their wishes about how they want to be cared for at the end of life. Fewer still have not thought about end-of-life care at all, while some have thought about it but not told anyone what they want. Avoiding the subject of death has created woeful ignorance about end-of-life issues, resulting in less than optimum care and diminished quality of life for the dying and their families.

While about 70% of people in many industrialized countries would prefer to be cared for and die at home, 50% actually die in hospitals. Conversely, 70% of family members prefer that their loved ones be treated in a hospital at the end of life, compared to 3% of the patients. Often, the
family members are in a position to make end-of-life decisions that are not in agreement with the patients when there is no formal advance directive in place (Procter et al., 2019).

Dying in hospitals not only increases the cost of care but often subjects patients to uncomfortable and unnecessary procedures. For example, increasing numbers of elderly patients are being admitted to intensive care units (ICUs), where they require ventilator assistance, tracheotomies, aggressive treatment for sepsis, suctioning, catheterization, more frequent monitoring and interventions, and an upsurge in diagnostic tests.

Introduction of palliative care in place of aggressive interventions done in the ICU may shorten a patient’s hospital length of stay in the ICU by transferring the patient to the medical/surgical unit or by helping the patient and family to receive palliative care at home (Khandelwal et al., 2017). Similarly, the Medicare hospice benefit, instituted in 1983, guarantees comprehensive, high-quality care at little or no cost to terminally ill Medicare beneficiaries and their families. Hospice is paid for by Medicare funds in 99% of all such cases (Custer, 2019).

PALLIATIVE CARE AND HOSPICE

Both palliative care and hospice in the United States originally focused on the care of cancer patients, but now both encompass care of patients with other severe illnesses such as kidney disease or heart disease.

What Is Palliative Care?

Palliative care is a recognized subspecialty by the American Board of Medical Specialties. The word *palliative* comes from the Latin word *palliare*, which means “to cloak” or “to disguise.” The purpose of palliative care is to reduce the symptoms of a medical condition in order to provide the patient with comfort (Merriam-Webster Dictionary, 2019).

Palliative care has also been defined as follows:

> Palliative or supportive care is an alternative to frequent hospitalizations for symptom management in chronic conditions. It is defined as improving quality of life through prevention and relief of distressing symptoms by addressing physical, psychosocial, and spiritual issues while affirming life. Palliative care can and should be used with other treatment modalities early in the chronic disease process and death as normal processes (McClendon et al., 2015).

Palliative care and hospice care are not the same (see box “Palliative Care vs. Hospice Care” below). Palliative care is not limited to end-of-life care. As people are living longer with formerly fatal illnesses, palliative care may be used to give patients comfort in conjunction with more aggressive, lifesaving measures. It includes:
• Relieving symptoms that negatively affect a patient’s quality of life, such as pain, anxiety, dyspnea, confusion, hunger, thirst, nausea and vomiting, diarrhea, agitation, and sleep disturbances

• Alternative nursing comfort measures that do not require a physician’s order, such as massage, repositioning, heat, ice, a peaceful environment, distraction, guided imagery, and good hygiene

In patients with life-limiting illnesses, palliative care can be used to provide comfort, reduce hospital stays, and reduce the use of healthcare resources. Palliative care is provided in a number of settings such as physician practices, hospitals, cancer centers, dialysis units, homes, hospices, and long-term care facilities (NCP/NCHCP, 2018; Sole et al., 2017).

Palliative care’s focus on communication in addition to pain and symptom management occurs long before the end of life. Primary care providers explore their patients’ values, cultures, and goals in deciding how aggressive to be in treating diseases such as cancer and caring for the patient during treatment. Palliative care workers provide social and spiritual support for both the patient and the family in a team-based approach to care delivery.

Palliative care for those with life-limiting illness ideally begins at the time of diagnosis. Unfortunately, however, referrals to palliative care tend to occur late in the trajectory of illness. This may be related to the misperception of palliative care as “giving up.” Some patients, families, and healthcare professionals may believe that trading aggressive treatment of potentially fatal conditions for improved quality of life will shorten survival and decrease the patient’s lifespan. However, in recent studies into the effects of early palliative care, one showed a 19.5% increase in patients’ lifespan over those patients not receiving palliative care and another detected a 31% increase. Such results replicate previous studies that found early palliative care both improving quality of life and extending life (Hamano et al., 2016).

An assessment of the patient and family’s needs for palliative care and support is an important part of planning the best care for the end of life.

**SUPPORTIVE CARE**

As an alternative to the term *palliative care*, the National Cancer Institute defines *supportive care* as care given to improve the quality of life of patients with a serious or life-threatening disease. The goal of supportive care is to prevent or treat as early as possible the physical symptoms of the disease; treatment side effects; and psychological, social, and spiritual problems related to the disease or its treatment (NCI, 2016a). Supportive, or palliative, care also includes an assessment of the patient’s goals for care. Deciding when to stop treatment can be difficult and should involve the patient, family, and the healthcare team. However, ending treatment does not mean ending care.
### ACCESS TO PALLIATIVE CARE “REPORT CARD”

<table>
<thead>
<tr>
<th>Grade</th>
<th>Hospitals with Palliative Care Programs (percentage by state)</th>
</tr>
</thead>
</table>
| “A” Top performers | Montana, 100%  
                       | New Hampshire, 100%  
                       | Vermont, 100%  
                       | Washington, 92.7%  
                       | Nevada, 91.7%  
                       | New Jersey, 91.2%  
                       | Oregon, 88.9%  
                       | Rhode Island, 88.9%  
                       | South Dakota, 88.9%  
                       | Massachusetts, 87.8%  
                       | Wisconsin, 87.7%  
                       | Maryland, 87.5%  
                       | Nebraska, 87.5%  
                       | Utah, 84.6%  
                       | Connecticut, 84%  
                       | Ohio, 82.8%  
                       | Minnesota, 81.6% |
| “B” On their way | Maine, 78.6%  
                       | New York, 78.1%  
                       | Virginia, 76.9%  
                       | Colorado, 75.7%  
                       | Delaware, 75%  
                       | California, 74%  
                       | Illinois, 72.1%  
                       | District of Columbia, 71.4%  
                       | Hawaii, 70%  
                       | Arizona, 68.4%  
                       | Pennsylvania, 68.3%  
                       | Indiana, 67.7%  
                       | Idaho, 66.7%  
                       | Iowa, 66.7%  
                       | Michigan, 66.7%  
                       | Missouri, 66.7%  
                       | North Dakota, 66.7%  
                       | North Carolina, 65.3% |
| “C” States in the middle | Florida, 58.1%  
                       | South Carolina, 58.1%  
                       | Tennessee, 56%  
                       | Louisiana, 55.8%  
                       | West Virginia, 55.6%  
                       | Georgia, 55.2%  
                       | Kentucky, 53.1% |
What Is Hospice Care?

Hospice is considered the gold standard for end-of-life care. The central paradigm of hospice is that each person is entitled to a high quality of life using a holistic approach and that families are entitled to the support necessary to allow that to happen (Ashley & Fasolino, 2016; Sole et al., 2017).

In part, hospice care provides a delivery system for the palliative care services described above. However, hospice requires determination from a physician that an individual’s life expectancy is less than six months. (Or if the patient lives beyond six months, they may remain in hospice unless they choose to no longer participate.)

Hospice care is based on an interdisciplinary team approach that includes physicians, nurses, spiritual counselors, social workers, home health aides, bereavement counselors, trained volunteers, and speech, physical, and occupational therapists, if needed. The team develops an individualized care plan with family caregivers as shared decision makers to meet each patient’s needs for pain management and symptom control. When the patient is cared for at home, hospice staff is on-call 24 hours a day, 7 days a week (Washington et al., 2016; Zinn, 2016).

The services delivered by a hospice multidisciplinary team include:

- Managing the patient’s pain and symptoms
- Assisting the patient and family with the emotional, psychosocial, and spiritual aspects of dying
- Providing needed drugs, medical supplies, and equipment
- Instructing the family on how to care for the patient
- Delivering special services like speech and physical therapy when needed
- Making short-term inpatient care available when pain or symptoms become too difficult to treat at home or the caregiver needs respite
- Providing bereavement care and counseling to surviving family and friends (NHPCO, 2018)
Many people mistakenly think the term *hospice* refers to a place. Although there are some residential hospice facilities, most hospice care takes place in the patient’s home or the home of a loved one, and less frequently in hospitals and nursing homes.

Hospice is also not just for people with cancer. In fact, the majority of hospice deaths in 2017 were among people with a noncancer diagnosis: circulatory/heart (17.6%), dementia (15.6%), respiratory (11.0%), stroke (9.4%), and chronic kidney disease (2.3%) (NHPCO, 2018).

Participating in hospice care allows dying patients more time to spend with family and loved ones rather than focusing on medical care (NCHS, 2019). It is far less expensive than other types of end-of-life care (e.g., aggressive chemotherapy, intensive care), and hospice patients are more often able to die at home (NHPCO, 2018).

**HOSPICE FACTS AND FIGURES**

- The number of Medicare-certified hospice programs has grown to approximately 4,515. Hospice care is increasingly available in long-term care facilities and hospitals.

- Hospice care is available in all 50 states, the District of Columbia, Puerto Rico, Guam, and the U.S. Virgin Islands.

- More people are choosing hospice care; in 2017, 1.49 million people in the United States received services from hospice, representing a 4.5% increase from the previous year.

- Over 48% of hospice patient deaths occurred in the home, 31.8% in a nursing or long-term care facility, 11.2% in a hospice inpatient facility, 7% in an acute care hospital, and 1.7% elsewhere.

- Hospice services are covered under the federal Medicare health insurance program and, in 46 states, by the joint federal-state Medicaid program. The Medicare hospice benefit covered 88% of hospice patients in 2017.

- Military personnel and their dependents are covered for hospice care. All U.S. veterans have hospice benefits through the Veterans Administration. (NHPCO, 2018; DVA, 2016)

Despite some encouraging changes, other significant challenges remain. Hospice services are still not as widely used as they could be. Fewer than half of patients eligible for hospice choose that option. Approximately one fourth (27.8%) of dying patients have hospice care for only a week or less, which is far less than the 60 days considered necessary for people to gain maximum benefit (NHPCO, 2018).
**PALLIATIVE CARE VS. HOSPICE CARE**

The terms *palliative care* and *hospice care* are often confused or mistakenly used interchangeably, but they have different meanings. Both palliative and hospice care aim to improve a patient’s quality of life and comfort by preventing and relieving symptoms. However, palliative care can be provided at any stage of illness and concurrent with curative treatments, whereas hospice care is provided only at the end of life when curative treatments have been stopped.

For instance, a patient with curable cancer may receive palliative care to address pain, stress, and other symptoms alongside their curative treatments of radiation therapy. And a patient whose end-stage cancer is no longer responding to treatment may receive hospice care once they have received a terminal diagnosis and ended all curative treatments for the remaining weeks or months of life.

**“Open-Access” Care**

Programs called *open-access hospice, bridge hospice, concurrent care,* or *outpatient palliative care* offer terminal patients both disease-modifying and comfort-focused hospice care in their home, nursing home, or assisted-living facility. Patients also have access to an interdisciplinary team of experts to address psychosocial and special care needs. The hope is that these new programs will encourage more patients and their families to enter hospice earlier and avoid the costly final weeks of hospitalization that so many Americans experience at the end of life (Hargadon et al., 2017; NHPCO, 2018).

Open-access programs are available to those without the ability to pay and are usually available through larger hospice facilities. Smaller agencies, various visiting nurse associations, or home health agencies may provide a program of palliative care for terminal patients and their families that is not restricted by the expectation of death within six months or the requirement to forego life-prolonging treatments.

The Medicare hospice benefit (MHB) is the main method of payment for hospice care, with over 85% of hospice patients covered this way. Since the MHB per diem payment structure does not allow some costly palliative treatments, open-access programs can “bridge” the period between hospitalization and aggressive treatment and hospice care at the end of life. One quarter of hospices have open-access care (Hargadon et al., 2017).

**HOSPICE CARE AND CURATIVE TREATMENTS**

Medicare beneficiaries are required to forgo curative care such as chemotherapy and radiation therapy in order to receive hospice services, although the patient may discontinue hospice services and return to more aggressive treatment at any time. This requirement is one reason some people avoid hospice until the last days or weeks of life and continue with aggressive, expensive treatment, which may make little or no difference in survival time and may diminish the quality of life in the process.
Through the Medicare Care Choices Model, established in 2016 and revised in 2017, participating hospices offer hospice-like support services to patients who are also receiving curative treatments. Participation is limited to patients with advanced cancers, COPD, congestive heart failure, or HIV/AIDS. The duration of the model is three to five years. The Centers for Medicare and Medicaid Services will evaluate whether this model improves the quality of life, increases patient satisfaction, and reduces Medicare expenditures. (ACS, 2016; CMS, 2016)

Paying for Hospice Care

Medicare, Medicaid (in most states), the Department of Veterans Affairs, most private insurance plans, HMOs, and other managed care organizations pay for hospice care. Community contributions, memorial donations, and gifts allow many hospices to give free services to patients who cannot afford payment. Some programs charge patients according to their ability to pay on a sliding scale (ACS, 2016).

According to the Patient Protection and Affordable Care Act of 2010, the majority of patients in hospice care are covered by Medicare. To qualify for the first 180 days of hospice care, the patient’s physician and the hospice medical director (also a physician) must see the patient and certify that the patient has less than six months to live if the disease runs its normal course. The hospice doctor or nurse practitioner must recertify the patient in a face-to-face visit before each benefit period after that. Medicare offers a one-time-only hospice consultation with a hospice medical director or hospice doctor to discuss care options (ACS, 2016).

Hospice agencies receive per diem payments that vary according to the site where services are received and any other insurance coverage the patient may have. In 2019, the payment for routine home hospice care was $196.50/day for the first 60 days of care and $154.41/day after that. Payments are used to manage all care related to a patient. The benefits continue, provided that physicians certify that the patient continues to meet the eligibility requirements (after the initial six months). Medicare enforces an aggregate cap for agencies, effectively limiting the total amount they can receive per patient. The 2019 cap was $29,205.44 for the whole year (CGS, 2019).

Hospice services covered by Medicare are listed below. In addition, many private healthcare plans and Medicaid cover hospice services.

HOSPICE SERVICES COVERED BY MEDICARE

Medicare covers these hospice services and pays nearly all of their costs:

- Physician services
- Nursing care
- Medical equipment (such as wheelchairs or walkers)
• Medical supplies (such as bandages and catheters)
• Drugs for symptom control and pain relief (patients may need to pay a small copayment)
• Short-term care in the hospital
• Short-term respite care (patients may need to pay a small copayment)
• Home health aide and homemaker services
• Physical and occupational therapy
• Speech therapy
• Social worker services
• Dietary counseling
• Bereavement services for patients and families (up to 13 months after a patient’s death)
• Any other covered Medicare services needed to manage pain and other symptoms, as recommended by the hospice team

All Medicare-certified hospices are required to employ physicians and nurses with special expertise in pain management and symptom relief. Nonpain symptoms include (but are not limited to) constipation, dyspnea, nausea and vomiting, dry eyes, and dry mouth. Bereavement and spiritual counselors are also available to help the dying and their families explore their needs and preferences as they come to terms with death.

Disparities in Palliative and Hospice Care

Variation in sociodemographic factors, clinical factors, physicians’ beliefs, and the availability of services all contribute to the wide variation of hospice services received by end-of-life patients. Areas of higher socioeconomics with regard to healthcare spending proved to have physicians who professed to be less knowledgeable about and less comfortable with introducing hospice to their patient’s treatment plans. Physician’s beliefs about hospice care may be determined, in part, by their previous experience with hospice and hospice workers. Hospice is a less costly means of treatment for terminally ill patients, which may also explain its prevalence as a method of treatment (Keating et al., 2018).

GEOGRAPHIC DISPARITIES

Access to palliative care and hospice programs varies from state to state and between rural and urban populations. States with more concentrated population centers have a greater number of clinical settings other than patient’s homes in which hospice care can be provided (Keating et al., 2018).

A nationwide survey of the 4,515 Medicare-certified hospice programs in the United States revealed wide geographic variation in the prevalence of these programs (NHPCO, 2018).
Medicare patients in rural areas are much less likely than those in metropolitan areas to use hospice care. Discrepancies also exist in the provision of palliative care (see also “Access to Palliative Care Report Card” earlier in this course).

RACIAL/ETHNIC DISPARITIES

Disparities between white and nonwhite populations exist across the spectrum of healthcare, including end-of-life care. Most patients express a wish to die at home in the event of a terminal illness and not to receive life-prolonging drugs or mechanical ventilation. However, black families were less likely than whites to receive information about what to expect during end-of-life care. Black patients were more likely than white patients to be admitted to the emergency department, to be admitted to the hospital, and to prefer spending their last days in the hospital (Anonymous, 2018; Birenbaum, 2018).

National statistics found the majority of Medicare hospice patients to be Caucasian (82.5%), followed by African American (8.2%), Hispanic (6.4%), Asian (1.7%), and Native American (0.4%) patients (NHPCO, 2018). White patients are also much more likely than African American patients to have admissions to hospice in counties with more physician specialists and more hospital beds (Johnson et al., 2019).

Other disparities in end-of-life care include lack of adequate pain care in minority patients and poor management of pain by healthcare practitioners. Hispanics and non-Hispanic blacks are more likely to report more pain sites, worse pain intensity, and higher levels of pain. They were also more likely to have concurrent depression and pain self-efficacy than white hospice patients (Birenbaum, 2018; Murtaugh et al., 2016).

Other factors contributing to disparities include lack of knowledge about end-of-life care options, mistrust of the healthcare system, and poor communication between clinicians and patients. Hospice care may be perceived as a luxury in some communities, even though Medicare and Medicaid benefits require little out-of-pocket expenditure.

Language differences can lead to misunderstanding and misinformation that affect medical decision-making. For example, *hospice* may translate to *hospicio* in Spanish, meaning “orphanage” or “place for poor people or poorhouse” (Reverso Dictionary, 2016). In a study among non-Cuban Hispanics, proficiency with the English language increased use of hospice services by 3.1 times (Park et al., 2016).

Recent studies show minority cultures, such as Latinx (a newer term combining Latino and Latina) and African Americans, use hospice services to a lesser degree than white patients. African American patients may suspect that since hospice care is less costly than more aggressive care, it is being offered for the financial gain of the hospital. They may also feel that hospice care is being offered to deprive them of the more acute care they deserve. African American, Hispanic, and other racial minorities may also believe that the absence of lifesaving treatments is forbidden by their particular religion (Birenbaum, 2018).
Black and Latinx people are more likely to consider religion/spirituality more important than whites and less likely to use hospice or palliative care services. Latinx patients are also more likely to rely on family-based decisions at the end of life than to make autonomous choices. Some Asian/Pacific Islanders are also less likely than whites to use hospice or palliative care services than white patients and families (Boucher, 2016).

LEGAL AND ETHICAL FACTORS IN END-OF-LIFE CARE

The Right to Die

The right-to-die movement in America is gaining public support, indicating widespread dissatisfaction with the quality of end-of-life care. The right-to-die concept includes assisted suicide (also called physician aid in dying [PAD]) and voluntary active euthanasia. In assisted suicide, the healthcare practitioner, usually a physician, provides the means to end life—such as a prescription for a lethal amount of drugs, the drugs themselves, or other measures—by a patient or a person who has knowledge of the patient’s intention.

According to the American Nurses Association Code of Ethics (last updated in 2015), Provision 1.4, however, nurses “may not act with the sole intent of ending a patient's life” even though such action may be motivated by compassion, respect for patient autonomy, and quality of life considerations (ANA, 2019).

Both nurses and physicians are confronted with requests for assistance in dying. However, as of 2019, this practice is legal in only nine jurisdictions.

- In 1997, Oregon became the first state to pass right-to-die laws.
- Washington (2008) and Montana (2009) soon followed. While the law in Montana does not allow a specific PAD or right-to-die procedure, it states that assistance does not violate any current state laws.
- In 2013, the Vermont legislature passed a right-to-die law by a 75–65 vote. The guidelines for practice are very stringent.
- In 2016, California became the fifth state to pass a right-to-die law, allowing terminally ill patients the right to end their own lives by using a lethal dose of medications ordered by a physician and self-administered. Two physicians must attest to the patient as being terminal within six months and mentally capable of making the decision. The California law passed after much debate, advertising on both sides, and input from healthcare providers, parents of terminally ill children, and religious leaders.
- The five other jurisdictions that have adopted physician-assisted suicide (PAS) or right-to-die laws include: Colorado (2016), Hawaii (2018), Washington DC (2018), Maine (2019), and New Jersey (2019).

(Charlotte Lozier Institute, 2019)
Healthcare practitioners acknowledge that there is an underground practice of assisted suicide in the United States. Some maintain that the principle of double effect is used to justify what is really assisted suicide. The principle of double effect states that the potential to hasten imminent death is acceptable if it is the unintended consequence of the primary intention to provide comfort and relieve suffering. For example, a terminal patient with severe difficulty breathing may be given large doses of narcotic to relieve suffering. As the breathing is eased by the narcotic, there may be a second effect that stops breathing altogether (Wholihan & Olsen, 2017).

**Palliative Sedation Therapy**

Palliative sedation therapy (PST) is considered a last-ditch option in end-of-life care to relieve terminal suffering. The suffering may be physical, psychological, or existential (a loss or interruption of meaning, purpose, or hope in life). PST may be used to treat intractable pain and suffering when other measures such as a physician-assisted death is not an option. Narcotic pain medications mixed with sedation for comfort and anti-anxiety medications may have the sometimes unintentional result of terminally sedating the patient (O’Rourke & Navarro-Leahy, 2016).

Palliative sedation therapy is controversial. Some opponents have incorrectly equated it with euthanasia. Euthanasia and PST are different in intention (relief of intolerable suffering in PST, killing the patient in euthanasia), in procedure (use of a sedative for symptom control in PST, use of a lethal agent in euthanasia), and in outcome (alleviation of suffering in PST, immediate death in euthanasia) (Dwyer & McCarthy, 2016).

As pain escalates and becomes more difficult to control, it may be necessary to consider palliative sedation. Palliative sedation is an appropriate method to consider when symptoms are refractory (not adequately controlled with conventional treatment options). Poorly controlled pain, agitation, refractory dyspnea, vomiting, and extreme psychological or existential suffering about impending death are the primary reasons for using palliative sedation (Azoulay et al., 2016).

**EUROPEAN ASSOCIATION OF PALLIATIVE CARE 10-ITEM FRAMEWORK FOR GUIDELINES IN PALLIATIVE SEDATION**

1. Recommend preemptive discussion of potential role of sedation in end-of-life care and contingency planning.

2. Describe the indications in which sedation may or should be considered.

3. Describe the necessary evaluation and consultation procedures.

4. Specify consent requirements.

5. Indicate the need to discuss the decision-making process with the patient’s family.

6. Present direction for selection of the sedation method.
7. Present direction for dose titration, patient monitoring, and care.

8. Guidance for decisions regarding hydration and nutrition and concomitant medications.

9. The care and informational needs of the patient’s family.

10. Care for the medical professionals.
    (O’Rourke & Navarro-Leahy, 2016)

The role of the nurse in palliative sedation includes the administration of medications, recognizing and notifying healthcare practitioners of refractory symptoms, providing psychosocial support and education to the patient and family, and identifying culturally specific needs related to dying and death. Nurses have a responsibility to provide symptom relief and prevent suffering in dying patients (ANA, 2019). It is important to palliative nurses that consent by the patient or family be given before administering potentially lethal doses of sedation to the terminally ill (Dwyer & McCarthy, 2016).

**TYPES OF PST**

Two types of palliative sedation may be used in end-of-life care: proportionate palliative sedation (PPS) and palliative sedation to unconsciousness (PSU). In PPS, medications such as benzodiazepines are increased gradually together with other symptom-relieving measures until suffering is relieved during both waking and sleeping hours. In a study of 179 patients who died during 2012, PPS was used among 21.2%. The medications used by the study participants were the benzodiazepine midazolam (Versed), haloperidol (Haldol) for delirium and agitation, and concurrent morphine to relieve pain. Indications included agitation (71%), pain (36.8%), and dyspnea (21%). Survival following PPS was longest with higher sedative doses, an observation that may help dispel fears concerning the use of PPS to hasten death (Azoulay et al., 2016).

In PSU, unconsciousness is the intended goal of sedation rather than a side effect. Medications are increased rapidly over minutes and hours to achieve unconsciousness and left at that level until death occurs. PSU is usually administered when the imminently dying patient finds severe physical symptoms intolerable despite state-of-the-art palliative care.

However, controversy surrounds the use of PSU to treat psychological, existential (a loss or interruption of meaning, purpose, or hope in life), or spiritual suffering. Some consider these to be outside the realm of a physician’s expertise, and others consider them within the knowledge, tools, and expertise of the interdisciplinary team.

Health professionals must understand the difference between the practice of PPS and PSU and the ethical issues surrounding their use. Nurses understand that the timing and appropriateness of palliative sedation is crucial to the patient or family’s comprehension and consent. Patients and families need to understand these last-resort options and make decisions about such end-of-life care before the need arises (Dwyer & McCarthy, 2016).
Healthcare practitioners also need to recognize that the patient always has the right to stop unwanted medical treatments or procedures while they are in progress—as was the case prior to consenting. These procedures may include CPR, mechanical ventilation, and artificial nutrition and hydration.

**CASE**

Doris is in the terminal phase of stage IV pancreatic cancer and experiencing severe abdominal pain much of the time. She has been under hospice care and requires proportionate palliative sedation (PPS) to achieve any degree of relief from the pain. It is Doris’s expressed wish that she not be left in intractable pain, and she has named her daughter Sheila in her advance directive to make medical decisions if she is unable. Sheila has been estranged from her mother for seven years but is now at her side most of the time.

The PPS has left Doris comfortable, rousable, but barely coherent. When her mother is unable to answer questions, Sheila asks that the PPS be reduced, stating her mother would want to be able to communicate with family. When the PPS is withdrawn, Doris becomes more lucid but complains of severe abdominal pain and asks for more pain medication. This results in periods of unresponsiveness, causing Sheila to again instruct the nurses to decrease the medication.

Donna is the charge nurse on Doris’s unit and has 20-plus years of experience in oncology. She arranges a conference for the following day with the family, including Sheila, the palliative care nurse, the primary physician, and Donna herself. Sheila is encouraged to express her fears of losing her mother and her hope to have time to communicate with her first. The group discusses the severe level of pain caused by pancreatic cancer and Doris’s wish that she not experience intractable pain. A compromise is reached that takes both Doris’s and Sheila’s wishes into consideration.

**Removing or Deactivating Cardiovascular Implants**

Implanted cardioverter/defibrillators (ICD) are used to correct life-threatening dysrhythmias. An actively dying patient may develop ventricular tachycardia due to hypoxia or electrolyte imbalances. One third of patients with ICDs will experience a shock in the last 24 hours of life unless the device is removed or deactivated. The shocks can potentially cause pain, distress, and anxiety and may prolong the dying process (Mooney et al., 2019).

A consensus statement from the Heart Rhythm Society (2010) suggests that patients nearing the end of life (or their healthcare proxy) have the right to decide whether to have these pacemakers or other cardiovascular implants removed or deactivated. The statement was developed in collaboration with several organizations, including the American College of Cardiology and the American Heart Association. It explicitly states that removing or deactivating an implanted cardiovascular device near the end of life “is not physician-assisted suicide or euthanasia.” However, it also states that physicians or other caregivers cannot be compelled to carry out a procedure that conflicts with their ethical values. In such cases, the physician cannot abandon the patient but rather should refer patients to a colleague willing to carry out the task. This consensus statement was reaffirmed in 2018 and will be formally reassessed in 2023 (HRS, 2019).
Advance Directives (ADs)

Advance medical directives are documents containing patients’ oral and written expressions of their preferences about future medical care if they should become unable to speak for themselves. Federal law (the Patient Self-Determination Act) requires hospitals to inform patients that they have the right to complete an advance directive.

Such documents usually address the patient’s wishes regarding:

- CPR (cardiopulmonary resuscitation)
- Ventilator use
- Artificial nutrition (tube feeding) and artificial hydration (intravenous [IV] fluids)
- Comfort care

Less than one third (30%) of Americans have advance directives. ADs usually name the person chosen to make healthcare decisions for an individual when they are no longer to make them for themselves. Older patients with chronic disease(s) are especially encouraged to have advance care planning in place (CDC, 2018).

The use of ADs varies according to race/ethnicity. According to the American Psychiatric Association, Asian and white patients are more likely to have ADs than patients with other racial/ethnic backgrounds. Many others feel that ADs are not necessary because family and physicians should already know what their wishes are (McDarby, 2019).

When a surrogate is making end-of-life decisions for a patient, the surrogate will be expressing the wishes of the patient that they have previously discussed. Particularly in the case of chronic illness in which a slow physical or mental decline takes place, advance directives provide the opportunity to ensure that a person’s own preferences will be followed. Copies of the advance directive may be given to family, care providers, one’s hospital, an attorney, or others. The plan should be reviewed periodically to provide for necessary updates (CDC, 2018).

A video can also be made explaining the patient’s precise wishes, although this is not a legally compelling document.

Healthcare professionals have an obligation to work with patients and their families to reach decisions that balance autonomy and beneficence. However, healthcare professionals are legally constrained from witnessing an AD if they are an employee of the organization in which the patient’s wishes will be enacted.

Advance directives are regulated by state law and therefore differ from state to state.

LIVING WILL AND MEDICAL POWER OF ATTORNEY

In most states, an advance directive can be either a living will or a medical power of attorney, also called a durable power of attorney for healthcare, a healthcare proxy, or declaration or...
appointment of a healthcare agent. Living wills and medical or durable powers of attorney predate ADs but may still be in use among older patients, and healthcare workers should be able to distinguish among the various forms.

A living will is a document written while alive to dictate preferences for healthcare decisions. It addresses personal preferences regarding the above-mentioned life-sustaining measures and under what circumstances the patient would prefer those measures be performed or withheld.

A medical or durable power of attorney (DPOA) names one or more people who may make decisions for the person who is unable to make their own wishes known. Referred to as a healthcare proxy (representative, agent, or surrogate), this person(s) is named on the advance directive form. It is essential that a very specific conversation take place between the patient and the person named in the DPOA to ensure that there is clear understanding about the patient’s final wishes (NIA, 2018).

PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)

Several states have adopted an advance directive form developed in Oregon and known as POLST, which stands for Physician Orders for Life-Sustaining Treatment (POLST, 2016). This simple form, to be completed and signed by both patient and a physician or nurse practitioner, specifies the patient’s preferences concerning measures such as antibiotics, artificial nutrition (including tube feeding) and hydration, CPR, comfort measures, and mechanical ventilation/respiration.

The form is printed on brightly colored paper and stays with the patient during transfers from one care setting to another. Patients at home keep the POLST form on the refrigerator, where emergency responders can find it. Long-term care facilities retain POLST forms in residents’ charts. (See “Resources” at the end of this course for information about POLST programs in each state.)

DO-NOT-ATTEMPT-RESUSCITATION (DNAR) ORDERS

Do-not-attempt-resuscitation orders (formerly known as do-not-resuscitate [DNR] orders) have been renamed to emphasize the minimal likelihood of successful cardiopulmonary resuscitation (CPR). Additionally, a specific order to refrain from intubation is referred to as “do not intubate” (DNI).

Patients and families need to understand not only the unlikely success of resuscitation but also the risks involved, which include fractured ribs, damaged internal organs, and neurologic impairment. Although the patient (or family) must ultimately decide about whether to attempt CPR, healthcare professionals need to explain that withholding CPR does not equate with letting someone die. Rather, a DNAR order should be considered an “allow natural death” (AND) order (Curesearch, 2016).

The primary care provider should discuss the possibility of a DNAR order as soon as it is reasonable and while the patient is still able to make decisions. A delay in putting a DNAR order in place may result in treatment unwanted by the patient and in distress for the healthcare team.
The DNAR order should be readily available in the event of an emergency to ensure that the patient’s wishes will be honored. It should be posted prominently, either on the head or foot of the bed, or if the patient is at home, on the refrigerator. In the facility where the patient is admitted or resides, specifics of the order should also be carefully documented in the patient’s chart.

If the patient’s preferences are not known at the time of a cardiopulmonary arrest, then resuscitation must be initiated. The resuscitation may then be stopped if it is learned that it is not keeping with the patient’s wishes (AMA, 2019).

**MECHANICAL VENTILATION (MV)**

Mechanical ventilation is achieved by the introduction of an endotracheal or tracheostomy tube into the patient’s trachea. This provides an artificial airway through which air under pressure and oxygen can be used to simulate breathing. If the cause of a patient’s inability to breath adequately is temporary, such as pneumonia, use of MV can prolong life long enough for the needed treatment, such as antibiotics, to be provided.

Decisions about mechanical ventilation may be spelled out in a patient’s advance directive. Some patients choose to forgo MV, believing that it merely prolongs the dying process. Others choose to have MV when they can no longer breathe on their own (NIA, 2018). Choosing MV may reflect the erroneous belief that this life-sustaining treatment can improve the patient’s prognosis.

Depending on the physician, choosing MV may affect the physician’s certification of the patient as terminal and, therefore, the patient’s eligibility for hospice benefits. Use of MV requires that the patient lie in bed or sit in a chair with restricted movement. If an endotracheal tube is used, the patient will not be able to speak or swallow. Mechanical ventilation also increases the risk of pneumonia because it prevents patients from coughing effectively and allows fluid to build up in the lungs.

Once MV is started, the decision to withdraw it may present a legal and ethical controversy for the physician and the family. In some cases, withdrawal of this life support may require a court order.

**ARTIFICIAL NUTRITION AND HYDRATION (ANH)**

Patients who receive hospice care have food and drink as they wish or need. Some individuals make their own choice, often as part of an advance directive, to stop or limit eating or drinking at a certain point in their dying process. When oral nutrition is no longer safe for a patient, ANH using enteral feeding tubes is sometimes used to deliver nutrition.

Decisions about whether to have ANH involve weighing the potential benefit with the burden to the patient. The American Nurses Association (ANA) position statement supports a patient’s (or surrogate’s) right to weigh the risks, benefits, and burdens of ANH after a full discussion with the healthcare team (ANA, 2017). The ANA position statement thereby supports the ANA beliefs about autonomy, relief of suffering, and patients receiving expert care at the end of life.
Little evidence supports the use or disuse of hydration as a comfort measure in end of life. The reason for this lack of evidence is that it is not ethically possible to conduct a controlled, randomized clinical trial in which one group of patients near the end of life receives hydration and a second group has hydration withheld (Heuberger & Wong, 2019).

Although ANH may extend the patient’s life a few days or weeks, there is considerable physical and emotional trauma in inserting a nasogastric tube or undergoing surgery to place a gastrostomy (feeding) tube. There is also the increased risk of infection, increased risk of aspiration, erosion of nasal tissue, and increased diarrhea, all of which would prolong suffering (NIA, 2018).

The potential burdens of ANH depend on the route of administration and may include sepsis (with total parenteral nutrition), aspiration (especially with tube feedings), diarrhea (also with tube feedings), pressure sores and skin breakdown, and complications due to fluid overload. Demented or confused patients receiving ANH may need to be physically restrained to prevent them from removing a gastrostomy tube, nasogastric tube, or central intravenous line. Pain, epistaxis (with a nasal feeding tube), pharyngitis, esophagitis, and airway obstruction may also occur. Many health professionals feel that hospice care with cessation of feeding and fluids is a more humane alternative to ANH (Heuberger & Wong, 2019).

There is widespread use of feeding tubes at the end of life, particularly in patients with Alzheimer’s disease or other cognitive impairment, even though there is not sufficient evidence to prove enteral tube feeding is beneficial in patients with advanced dementia. (See also “The Patient Who Has Dementia” later in this course.)

Research suggests that people who choose not to have ANH do not suffer due to hunger or thirst. Without ANH, in fact, patients are less likely to experience bloating or to develop pleural effusions (fluid around the lungs), which can cause shortness of breath, or fluid in the throat, which requires suctioning. Studies also indicate that forgoing artificial hydration increases the body’s production of endorphins (natural pain-relieving hormones), making the patient more comfortable and less likely to experience pain. The only side effect of dehydration at the end of life is dry mouth, which can be relieved by good mouth care or ice chips.

Clinicians can help families understand that forgoing ANH is not “killing” or “starving” the patient. Communication among the nurses and physician writing orders and taking care of the patient, and those making decisions about care, should guide the decisions made regarding AHN. One of the important considerations is the patient’s religious or spiritual beliefs. Communication with family or surrogates with these fears can help assuage worries that the patient is “starving to death.” It is significant for them to know that inability to eat and drink is a natural part of dying (Heuberger & Wong, 2019).

**CASE**

Kathy, a hospice nurse, was questioned by the family of an elderly patient on hospice care in the nursing home where she worked. When the discussion turned to a decision about providing artificial nutrition and hydration for their loved one, a few of the family members
expressed concern that withholding nourishment and liquids would cause unnecessary suffering by “starving her to death.”

Kathy gently explained to family that studies have shown no benefit in giving tube feedings or intravenous therapy to dying patients and that these measures could, in fact, cause additional pain and other burdens, such as aspiration or diarrhea, on their loved one. Kathy assured the family that the nursing staff would continue to keep the patient comfortable, give her pain medication when needed, and provide mouth care and moisten her mouth with ice chips to keep it from feeling dry.

EFFECTIVE COMMUNICATION WITH PATIENTS AND FAMILIES

Although talking about illness and death can be difficult for both health professionals and patients, studies show that most patients want to have this discussion. Sharing bad news while maintaining hope is a delicate balance that takes practice to achieve. The patient is encouraged to discuss these matters with the people closest to him/her, especially with any person who is named as a healthcare proxy in an advance directive.

The definition of “family” may include more than those people with a common heritage, but those with whom the patient has a very close relationship. It may incorporate unmarried life partners, family friends, roommates, and close friends (Sole et al., 2017).

Many people who do not fear death do fear the process of dying, the prospect of pain and suffering, and being a burden to their families. Research shows that the top priorities for a loved one with terminal illness are:

- To be sure that the patient’s wishes are honored
- Choice among the types of services the patient can receive
- Pain control tailored to the patient’s wishes
- Emotional support for the patient and family
  (NHPCO, 2016a)

The healthcare professional must demonstrate nonjudgmental acceptance of the patient and family’s composition, values, and personal feelings. This includes supporting the patient’s and the family’s hopes for prolonging life as well as their hopes for peace and dignity throughout illness, dying, and death. Effective management of pain and other symptoms as well as emotional and psychological support of the patient and family are always possible (NIA, 2018).

Effective communication by hospice nurses and all of the members of the multidisciplinary team enhances symptom management for the patient, reduces family caregiver burnout and distress, and potentially improves bereavement adjustment.
STRATEGIES FOR PROMOTING FAMILY-CENTERED END-OF-LIFE CARE

- Get to know the family.
- Assess the family's understanding of the patient's condition.
- Keep the family informed.
- Provide clear, honest information to the family.
- Maintain consistency of care providers.
- Coordinate early family meetings.
- Facilitate the decision-making process.
- Assist the family through shared decision-making.
- Guide the family through the end-of-life process.
- Prepare the family for what to expect during the dying process.

(Wiegand et al., 2013)

When and How to Talk about Death

The avoidance of something invests the feared object with a great deal of energy. Facing that fear causes the energy to dissipate and removes the ability of fear to control one’s actions or feelings (Erickson, 2019).

Preparation for impending death is therefore one of the most crucial experiences that a person can have. In addition to selecting a healthcare proxy, making decisions about lifesaving or extraordinary measures, and financial planning, a person must face their own feelings about death. The conversations with family, loved ones, the healthcare proxy, clergy, and healthcare professionals must be open and honest about the patient’s wishes. This may also lead to discussions about beliefs and values around death.

Coming to the end of life includes tying up loose ends, saying goodbye, and giving thanks, whether or not a patient is religious. Loose ends usually include financial arrangements, typically in the form of a will or a trust. Saying goodbye includes those closest to the patient, favorite activities or locations, and possessions. Giving thanks may include working with a spiritual advisor or simply reflecting on one’s life. If they are able, patients at the end of life often spend time contemplating significant events and turning points in their lives (Erickson, 2019).

Opening Up the Conversation

Many patients need permission or an invitation to express their values and preferences about end-of-life care. One way to broach the subject is with an open-ended question such as, “When you think about getting very sick, what worries you the most?” “How important is your religion to you?” “You sound very frustrated with your family.” “I am really worried that you aren’t getting enough sleep.”
Some questions or statements are directed to the caregiver: “You need to make the effort to take a break every day” or “I was very close with my mother, too.”

Another way to open the conversation is to say: “Many patients with this condition tell me they think about dying. They have questions about this. How about you?” “What do you think would help?” “How do you think you can tell your kids about this?” Making empathic statements gives the patient an opportunity to express needs and concerns and shows the healthcare practitioner’s concern for the patient. Feeling that one’s doctor or nurse truly cares evokes trust, confidence, and hope in the patient.

Raising the topic of advance directives can also help to open the discussion of what the patient wants, needs, expects, and fears during this final phase of life. The following questions may be helpful:

- If you were to get so sick that you could not talk to me directly, whom should I talk with to help me make decisions about your care?
- Does this person know about this responsibility?
- Does he or she know what you want?
- What would you want?
- Have you written down what you want?

The physician is most likely to initiate the conversation, but nurses and other healthcare practitioners should also be prepared to discuss these issues as needs and circumstances change.

Actively listening to the patient is equally if not more important than talking to the patient. Questions that will elicit key information about the patient’s perspective include:

- What do you hope for as you live with this condition?
- What do you fear?
- It is usually hard to know when death is close. If you were to die soon, what would be left undone in your life?
- How are things going for you and your family?

Both patient and family need timely, clear information about prognosis. It is difficult, and often impossible, for clinicians to answer questions about “how long,” but it is possible to describe the probable course of a particular illness in understandable terms. This helps patients do what is most important to them, such as making a will, seeing family and friends, and telling loved ones. Clinicians tend to be overly optimistic when discussing prognosis, which can delay referral to hospice and cause unnecessary pain and suffering for the patient and family.

Explicitly discussing death helps the patient express fears and concerns about the dying process and allows the clinician to address them directly. For example, the patient may say, “I don’t want
to die hooked up to machines” or “I don’t want any heroics.” This is an opportunity to allay that concern, for instance, by talking about hospice care and to ascertain whether the patient has an advance directive in place or would like information about one (Ellington et al., 2012).

**FAMILY CONFERENCES FOR PATIENTS DYING IN THE ICU**

End-of-life family conferences are an important part of ICU practice in many hospitals because they help relieve stress and anxiety for those with loved ones dying in the ICU. Families are intricately involved in the end-of-life decision-making process for a family member with a serious illness who is in the ICU setting. However, families are not always as involved and as informed as they would like to be.

Ideally, these conferences are held in a quiet room once the family has been given sufficient time to gather. They allow for discussion of the patient’s situation and an opportunity for the family to ask questions, express concerns, and confront painful emotions with the help of caring, compassionate professionals. Included in these discussions will be the attending physician, the nurse most familiar with the patient, and possibly a member of the clergy.

Guidelines for these conferences are based on the VALUE mnemonic:

<table>
<thead>
<tr>
<th>VALUE</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>V</td>
<td>Value what the family members say</td>
</tr>
<tr>
<td>A</td>
<td>Acknowledge their emotions</td>
</tr>
<tr>
<td>L</td>
<td>Listen</td>
</tr>
<tr>
<td>U</td>
<td>Understand the patient as a person through asking questions</td>
</tr>
<tr>
<td>E</td>
<td>Elicit questions from family members</td>
</tr>
</tbody>
</table>

(Wiegand et al., 2013)

**Cultural Sensitivity**

Culture is often defined as the set of attitudes, beliefs, and values that people and societies pass down between generations. Cultural competency requires that healthcare professionals understand cultural differences in order to be effective and respectful in their delivery of care. This involves acquiring specific knowledge about the beliefs and practices of different cultures as related to healthcare and end of life. Thus, it is important that clinicians ask open-ended questions rather than make assumptions based on appearances. Cultural sensitivity also includes the avoidance of stereotyping.

**DIVERSE PREFERENCES**

Cultural beliefs about healthcare, especially end-of-life issues, are as diverse as the different cultures that seek healthcare. Some examples of this diversity are discussed below.
African Americans value personal autonomy and often mistrust the healthcare system because of observations of disparate treatment of their community in the delivery of care. A desire for aggressive interventions results in a low percentage of terminal African Americans agreeing to hospice care. African Americans may fear that acceptance of palliative or hospice care will prevent them from receiving the care they desire, and prior difficulties with access to healthcare may color their acceptance of less aggressive care. Due to strong spiritual beliefs, African American families may prefer to have a Bible in the hospital room of their dying loved one. The presence of clergy and nonrelated fellow church members may also be especially appreciated (Collins et al., 2018; McDarby, 2019).

Because hospice care is considerably less expensive than care that would occur in an acute care hospital, particularly in the ICU, nonwhite patients and families may question solutions that may have the appearance of not including the best care possible. Again, this may be based on prior difficulties with access to care.

When a loved one is dying in the hospital, Latinx patients and families express preferences for care usually through a male spokesperson. Often the request is made that a priest or chaplain be present when healthcare professionals are discussing end-of-life issues. It is felt that there is a burden placed on the family to understand much of the healthcare procedures and that the paperwork handed out to aid in comprehension is not helpful. Latinx patients and family often communicate that having caregivers of a similar race/ethnicity is more comfortable (McCleskey & Cain, 2019).

Latinx families who are strongly Catholic often request that the patient’s rosary beads be placed in the dying patient’s hands or, at least, taped to the frame of the bed. The patient and family feel comforted if a priest can be present to perform the Sacraments of the Sick (no longer called Last Rites) for the patient. Language can be a significant challenge working with members of this particular patient population who do not speak English unless the healthcare professional speaks some Spanish. Older Latinx patients are less likely to have advance directives and prefer comfort care at the end of life.

Rhee and Yang (2019) conducted a quantitative study by extracting data from the 2015 Asian American Quality of Life survey. The sample included 499 subjects with varied Asian backgrounds and who were at least 60 years of age. The following results of the study are considered factors in older Asians’ use of ADs (advance directives):

- Asians use family-centered decision-making.
- The family may choose not to disclose a terminal diagnosis to the patient because of the taboo that discussing death may cause death.
- Language is a factor that may block access to AD use across all Asian subcategories.
- Study subjects with less time in the United States were less likely to have ADs.
- Those with increased education, financial status, and better health insurance were more likely to have ADs.
• The older the study subject, the less likely they were to have ADs.

• Gender and marital status did not significantly affect use of ADs.

Among the study subjects, the following Asian groups showed these statistics for active use of ADs:

• Chinese, 24.7%
• Asian Indian, 31.2%
• Korean, 8.2%
• Vietnamese, 21.2%
• Other Asian, 25%
  (Rhee & Jang, 2019)

Healthcare practices are very different in the Southeast Asian Hmong community when compared to Western medicine. A traditional Hmong belief is that illness is caused by spirits and soul loss. The decision to seek Western medicine vs. a traditional shaman may therefore depend on whether the illness is believed to be spiritual in nature. The fundamental conviction about death in this culture is that it is a journey from the physical to the spiritual world.

Elaborate religious ceremonies are undertaken during dying, including an altar built by the eldest son. The family must be involved in all decision-making. Withholding lifesaving procedures is considered disrespectful. The preferred scenario would be for the patient to die at home, as this is believed to bring good fortune to those in the household (Bjelica & Nauser, 2018).

“BENEFICENCE” VS. “TRUTH-TELLING”

Whereas the mainstream U.S. model of end-of-life care values autonomy and “truth-telling,” healthcare models in other cultures place a greater value on beneficence, which includes protecting the patient from bad news about serious illness. In these cultures, disclosure of serious illness may be considered disrespectful, impolite, or even harmful to the patient.

Learning about the patient’s and family’s cultural values can begin with a simple statement followed by an open-ended question: “Some people want to know about their illness and others do not. Some would prefer that I talk with a family member. How do you feel about it?” This gives the patient the option to refuse or accept information about diagnosis or prognosis and to designate a family member to act as a surrogate.

Researchers suggest three strategies for addressing the “secrecy” dilemma and other cultural differences in end-of-life care:

• Community education to increase the knowledge about palliative and hospice care
• Use of case assessment tools to determine communication preferences and the family’s role in decision-making
• Providing culturally sensitive end-of-life navigation

In Latinx communities, *promotores* may prove helpful in implementing the above education and communication strategies. *Promotores* are community members who promote health in their own communities and help alleviate access-to-care barriers. As members of minority and underserved populations, they are in a unique position to build on strengths and to address unmet health needs in their communities (Rhett-Mariscal, 2016).

**MANAGEMENT OF PAIN AND OTHER SYMPTOMS**

Many people who have come to terms with their own mortality still fear the possibility of a painful death. Almost all pain can be controlled to some extent with the wide range of available treatments. When properly treated, most patients gain significant relief from pain.

Pain is frequently multidimensional, with psychosocial and spiritual components. Other symptoms, distress, or psychosocial or spiritual concerns can interact with and exacerbate physical pain or impact the effectiveness of pain treatment (Lewis et al., 2017). Pain not only hurts, but it is also physically and emotionally debilitating. Severe chronic pain can cause depression, anxiety, fear, diminished appetite, impaired sleep, irritability, inability to focus, and sometimes thoughts of suicide. When pain is relieved, many of these symptoms disappear. The patient then can focus on other important end-of-life issues, such as unfinished business with family and friends or spiritual or religious concerns.

The patient’s preferences should define the goal of pain management. Some patients will choose to be completely pain-free, even if it means sedation. Others will choose only to control pain enough so that they can continue to function with alertness. If pain becomes severe at any time, but particularly in the last days or hours of life, it should be treated around the clock (Lewis et al., 2017).

**Patients have a right to relief from pain.** The Joint Commission requires that hospitals and other healthcare facilities regularly assess, monitor, manage, and document pain and response to treatments in all patients. Those facilities that fail to do so risk losing accreditation. Until all health professionals learn the principles of pain management explicit to palliative care, however, patients will continue to suffer needlessly.

Inadequate education of health professionals in pain management is only one reason why patients suffer. Another is general mistrust about the use of narcotic analgesics and worry about addiction or overdosing on these medications. Patients may also consider requests for pain medication as “giving up” or “giving in” to their disease. Clinicians can correct these myths and misinformation and reassure patients that managing their pain is fundamental to improving their quality of life.

Although addiction is not a concern when treating dying patients, tolerance to and a chemical dependence on opioids may develop over time. If tolerance to particular drugs occurs, it will be necessary to increase the dosage or change medications to gain relief. If dependence develops
and the patient needs to be taken off the drug, it should be done gradually in order to avoid withdrawal symptoms.

Assessing Pain

Effective pain management begins with assessment of the patient’s pain. Because pain is a subjective experience, it is important to ask the patient to describe the pain in terms of location, intensity, and character. There are a number of pain assessment tools available; healthcare practitioners should consult their agency/facility protocols.

A thorough pain assessment includes:

- Onset
- Mechanism of injury or etiology of pain, if identifiable
- Location/distribution
- Duration
- Course or temporal pattern
- Character and quality of the pain
- Aggravating/provoking factors
- Alleviating factors
- Associated symptoms
- Severity/intensity
- Impact on function, sleep, mood
- Barriers to pain assessment
  (Kirshner, 2018; Lewis et al., 2017)

Pain perception varies from person to person, depending on age, culture, emotional status, past experiences with pain, and the source and meaning of the pain. Some cultures dictate stoicism when experiencing pain, which may cause people not to admit pain or request medication. Men are more likely to “tough it out” because of cultural and gender attitudes.

Older adults may have a higher pain threshold than younger people or children due to normal age-related changes in neurophysiology. Because of their higher pain threshold, however, older patients are at risk for undertreatment of pain. They may have multiple chronic diseases and sources of pain as well as complex medication regimens that increase the risk of drug-drug and drug-disease interactions.

Visual, hearing, motor, and cognitive impairments as well as language differences can impede communication about patients’ pain. Anxiety and depression can exacerbate the pain experience,
as can fatigue and sleeplessness. Untreated pain can then cause further sleeplessness, which leads to more fatigue, setting up a cycle of suffering.

Knowing the source of pain can be a relief in itself, particularly if the patient has imagined a worst-case scenario and the source of the pain turns out to be a minor, correctable condition. The meaning of pain also affects the patient’s perception of it.

Pain should be reassessed at least as often as the vital signs are taken and management efficacy reassessed when patients are transferred from home to any new healthcare facility (Lewis et al., 2017).

**Pain Medications**

Medications can make a drastic difference in the lives of those suffering with pain, and they comprise an important aspect to end-of-life care in many instances. (A detailed description of pain medications is beyond the scope of this course, but the following provides basic information.)

The World Health Organization (WHO) has developed a three-step analgesic “ladder” for cancer pain relief in adults, and this approach can also be used in palliative and end-of-life pain management. If pain occurs, there should be prompt oral administration of drugs in the following order:

1. Nonopioids (aspirin and acetaminophen)
2. Then, as necessary, mild opioids (codeine)
3. Then strong opioids such as morphine, until the patient is free of pain

To calm fears and anxiety, additional drugs (adjuvants) should be used. To maintain freedom from pain, drugs should be given “by the clock” (i.e., every 3–6 hours) rather than “on demand.”

This three-step approach of administering the right drug in the right dose at the right time is inexpensive and 80%–90% effective (WHO, 2019).
DRUG ADMINISTRATION

Many opioids are available in sustained-release form as tablets and granules. Fentanyl is also available in a skin patch that will last up to 72 hours. However, sustained-release formulations should not be used for “rescue” dosing because they will not work quickly enough to relieve intense pain. In January 2010, the FDA approved morphine sulfate oral solution for the relief of moderate-to-severe acute and chronic pain in opioid-tolerant patients. Each 5 mL contains 10 mg or 20 mg of morphine sulfate (Daily Med, 2016).

When a patient is unable to swallow an oral medication, less invasive routes (rectal, sublingual, or transdermal) should be offered first. Parenteral methods should be used only when simpler, less-demanding, and less-costly methods are inappropriate, ineffective, or unacceptable to the patient. Intravenous (IV) or subcutaneous doses should be chosen over intramuscular (IM) injections, as they are less painful and absorb at a comparable rate. In general, assessing the patient’s response to several different oral opioids is advisable before abandoning the oral route in favor of anesthetic, neurosurgical, or other invasive approaches (Lewis et al., 2017).

Oral transmucosal fentanyl citrate is used for the relief of breakthrough pain. The lipid solubility of fentanyl allows rapid onset of pain relief. Fentanyl can also be given in the form of an intranasal spray, topical skin patch, or a buccal tablet for patients who are unable to swallow pills.

End-of-life patients may experience agitation. Lorazepam (Ativan) is an anxiolytic/sedative that may be taken as an injection, intravenously, orally, or sublingually (McCuistion et al., 2018).
PROPER SAFEGUARDING OF NARCOTICS

Many end-of-life patients receiving palliative care or hospice at home possess large amounts of narcotics and other controlled substances to alleviate pain and control anxiety. While these are essential to keep the patient comfortable, abuse and disposal of such medications may pose problems. Improper disposal of these substances by flushing down the toilet or into sinks may introduce them into the groundwater, drinking water supplies, or eventually the tissue of aquatic organisms.

Instead, unused drugs may be given to collectors who are registered with the Drug Enforcement Administration. Authorized collection sites may be retail pharmacies, hospitals, clinic pharmacies, and law enforcement locations. Some may offer mail-back programs or collection receptacles (“drop-boxes”).

Equally important is the need to safeguard against the use of controlled substances in the home by anyone other than the patient for whom the medications were ordered, including children and pets (FDA, 2019).

CASE

Isabella is a 76-year-old widow with an inoperable astrocytoma in the parietal lobe of her brain. She has undergone palliative radiation treatments in the hospital and has been discharged to home to be cared for by her 54-year-old daughter, Eileen, and a home health aide who comes every other day. Her physician has determined that she likely has less than six months to live and has designated that she is to be cared for as a home hospice patient.

Although her tumor has shrunk in size since the radiation therapy, Isabella still complains of severe headaches, up to 7 or 8 on the 0–10 pain scale. Her doctor has ordered ibuprofen with fentanyl patches for the pain. Isabella and Eileen are instructed to keep a log indicating when patches are applied and removed and how disposal of used patches is managed. Isabella is forgetful and occasionally neglects to remove the previous patch when she puts on the new one, every 72 hours. When this happens, she becomes confused, agitated, and even more forgetful. Also, she does not consistently maintain the log.

Eileen’s 28-year-old son, Paul, has a history of substance abuse and has been in rehab twice for narcotic addiction. Lately he has been taking his grandmother’s fentanyl patches when he visits his mother, telling himself they’re not good for Isabella. The home health aide notes that the count is off and notifies Eileen. She also notifies her agency supervisor. After reviewing all the circumstances (Isabella’s forgetfulness, the incomplete log, the presence in the house of a person with a known history of substance abuse), the supervisor instructs Eileen to lock up the supply of patches, remove and apply them to Isabella herself in order to prevent overdosing, and lock up the used patches as well.
ADDRESSING SIDE EFFECTS

The use of opioids affords effective pain relief to most patients. Like all drugs, however, they have side effects, some of which can be uncomfortable or even painful in themselves. They include drowsiness, nausea and vomiting, dyspnea, dry mouth, and constipation. Some side effects ameliorate after a few days, and most can be prevented or treated successfully.

Drowsiness

Drowsiness frequently occurs at the beginning of opioid therapy, not only from drug action on the brain but also because the patient has been sleep-deprived due to unrelieved pain. Once normal sleep patterns resume, the drowsiness generally lessens.

Nausea and Vomiting

Nausea and vomiting can usually be controlled once the source of the problem is identified. For patients who cannot tolerate morphine or NSAIDs, substitution of a different opioid or a sustained-release formulation may relieve the symptoms. Vomiting related to chemotherapy can be treated with serotonin receptor antagonists such as ondansetron, granisetron, or dolasetron.

If nausea and vomiting are related to disturbances of the labyrinth—such as motion sickness, vertigo, or migraine—use of antihistamines and anticholinergics (meclizine, dimenhydrinate, or transdermal scopolamine) may offer relief.

In some patients, nausea and vomiting can be triggered by smells, sights, or sounds; this is referred to as psychogenic or anticipatory vomiting. For these patients, benzodiazepines (anti-anxiety drugs such as lorazepam and buspar of the azapirone chemical class) may provide relief. Benzodiazepines can interfere with short-term memory, especially in older patients, or cause confusion in those already cognitively impaired.

Vomiting may also be related to increased intracranial pressure (e.g., from central nervous system tumors). These patients may benefit from a combination of corticosteroids and serotonin receptor antagonists.

Constipation may trigger nausea and vomiting in patients with advanced disease. Stimulant laxatives such as senna derivatives can promote gut emptying and offer relief.

Dyspnea

Dyspnea (shortness of breath, difficult breathing) is common among dying patients, who may report a feeling of tightness in the chest or a feeling of suffocation. Dyspnea may be an initial effect of opioid therapy or may result from other causes, including pneumonia, pulmonary embolism, pleural effusion, bronchospasm, tracheal obstruction, neuromuscular disease, restricted movement of the chest or abdominal walls, cardiac
ischemia, congestive heart failure, superior vena cava syndrome, or severe anemia. Treatment is determined by the diagnosis.

Three basic approaches are used to treat dyspnea in the dying patient: oxygen, opioids, and anti-anxiety medications. Nonpharmacologic methods such as meditation or guided imagery may also be effective. Although most patients are not hypoxic, supplemental oxygen may be helpful unless the cannula or face mask cannot be tolerated. Fresh outdoor air or a breeze from a fan may also afford relief. Low-dose immediate-release morphine, in either oral or buccal formulations, also can be effective.

**Constipation**

Preventive measures against constipation should begin at the same time as opioid therapy. Normal bowel function varies from person to person, so it is essential to establish what the patient considers normal and whether he or she is having any difficulty with bowel movements. Preventive or treatment measures can then be tailored accordingly. Untreated constipation can cause bloating, abdominal pain, nausea and vomiting, overflow incontinence, fecal impaction, or bowel obstruction.

First-line therapy for constipation includes stool softeners and stimulant laxatives such as prune juice or senna derivatives. If these prove insufficient to maintain or restore normal bowel function, osmotic laxatives such as magnesium salts, sorbitol, or lactulose may be added.

A lubricant stimulant such as mineral oil may be used if the patient is able to swallow. However, mineral oil should not be given to patients who have difficulty swallowing because aspirating mineral oil can cause pneumonia. Mixing the oil with orange juice or root beer makes it more palatable. It should be given when the patient’s stomach is empty to avoid interference with fat-soluble vitamins.

If the patient is ambulatory, increased activity can help promote bowel function. Simple measures such as increased fluid intake, more dietary fiber (if tolerated), a regular toileting schedule, privacy, and if the patient is bedfast, use of a bedside commode rather than a bedpan can be helpful. Peristalsis is generally strongest after eating, especially in the early morning.

**Dry Mouth**

Pain medications and many other pharmaceuticals (e.g., antidepressants, anticholinergics) can dry the lips and oral mucous membranes, leading to cracking, ulceration, and bleeding. Patients on oxygen therapy and those who have chosen to forgo artificial hydration and nutrition may also experience dry mouth. When increasing fluid intake is not an option, lubricants such as liquid vitamin E or petroleum jelly applied to the lips can help prevent cracking. Mouth swabs moistened with water or alcohol-free mouthwash can be used to relieve discomfort and to clean teeth, gums, and tongue.
Limit or avoid use of any products containing alcohol, which can further dry the mouth (McCuistion et al., 2018).

**Nonpharmacologic Pain-Relief Measures**

Not all pain relief comes through medications. Other methods, some of them simple, may increase patient comfort and well-being as they augment the effects of drugs. For example, massage or application of heat or cold may help relieve musculoskeletal pain. Repositioning the patient can sometimes relieve pain. Physical therapy may also be beneficial.

Adjuvant therapies for intractable pain include radiation therapy (to shrink tumors or relieve bone pain), radiofrequency ablation for bone pain, surgery to debulk a tumor, nerve blocks, or intrathecal pumps to deliver large doses of opioids without systemic sedative effects.

Complementary therapies such as acupuncture, guided imagery, biofeedback, hypnosis, progressive muscle relaxation (e.g., listening to audiotapes of relaxation techniques), meditation, distraction, and music therapy can also be helpful, not only in relieving pain but also in relieving emotional and psychological distress. Psychotherapy, particularly for patients suffering from depression, can have a positive effect on patients’ perception of pain and response to pain medications. Support groups and pastoral counseling may also be helpful to some patients by reducing psychological distress (Lewis et al., 2017).

**Treating Other End-of-Life Symptoms**

**DELIRIUM**

Delirium is a condition marked by changes in clinical and mental status and has been understood as prevalent and dangerous, particularly among elderly or frail patients. It is the most common neuropsychiatric disorder at the end of life. It is defined as a disorder of global cerebral dysfunction characterized by disordered awareness, attention, and cognition.

Disturbances in sleep-wake cycles and psychomotor activity, delusions or hallucinations, insomnia, and emotional lability may all occur. The agitation, moaning, and grimacing of delirium may be misinterpreted as signs of pain. The person may also exhibit mood swings, disorientation to time and place, and uncharacteristic speech. The most significant elements of delirium are inattention and broad fluctuations of symptoms. These are not major components of any other psychiatric illness of late life (Hosker & Bennett, 2016).

Delirium can create distress for both patient and caregivers, interfering with patient comfort and meaningful interaction with family members.

Many episodes of delirium can be effectively treated and, in some cases, prevented. Delayed treatment may result in terminal restlessness. Risk factors for delirium include cognitive impairment, sleep deprivation, medications such as narcotics or anti-anxiety drugs, hypoxia, fever, brain tumors or swelling, immobility, visual impairment, hearing impairment, and dehydration. Early identification and interventions to address these risk factors can significantly
reduce the number and duration of episodes of delirium in older patients (Hosker & Bennett, 2016). For example, the patient who normally wears glasses and/or a hearing aid may become confused without these appliances.

The principle of treatment of delirium is to determine and treat the reversible causes of delirium and to mitigate other causes. Determining one cause may be difficult and delay treatment. Delirium may be related to use of medications such as opioids. Changing to a slightly less potent opioid may be effective. Neuroleptic medications (antipsychotics) such as haloperidol are recommended to reduce agitation in patients with hyperactive delirium; however, they may cause drug-induced Parkinsonism and motor restlessness. Evaluating the clinical need for opiates, anticholinergics, benzodiazepines, and dopaminergics is critical to identify whether any CNS active medications can be discontinued (Hosker & Bennett, 2016).

FEVER

Some patients experience a significant fever, which may be evidence of an infection or the body’s response to chemotherapy or radiation therapy. At the very end of life, no effort is made to discover the source of the fever, as it will not be treated, and obtaining cultures may be painful for the patient. However, a fever is expected to cause the patient discomfort. Acetaminophen may be ordered for the patient as an antipyretic. If the patient is unable to swallow pills, the acetaminophen may be given via suppository.

DRY EYES

Patients in a comatose or obtunded state may not fully close their eyes, allowing the uncomfortable possibility of dried corneas. Artificial tears (polyvinyl alcohol 1.4%) may be ordered to be administered every hour around the clock to lubricate the eyes, particularly when the eyes are not fully closed.

CASE

Mr. Willoughby is an 83-year-old hospice patient admitted to the hospital since his family is no longer able to care for him at home. He is unresponsive to all stimuli and unable to swallow. His respirations are 10 to 12 per minute; no other vital signs are being taken. The physician’s orders are as follows:

- DNAR
- Comfort care
- Turn every 2 hours
- Mouth care every 4 hours
- Lip balm every 8 hours
- Family may visit at all hours
Ordered medications include:

- Roxanol (immediate release oral morphine sulfate solution) 20 mg/ml concentration, with a dosage of 0.5–1 ml every hour sublingually as needed for signs of pain
- Dulcolax suppository per rectum every day for constipation
- Artificial tears, 1 drop each eye every hour
- Tylenol suppository, 650 mg per rectum every 4 hours PRN for fever or “hot skin”
- Ativan, 1 mg SL every 4 hours PRN agitation

Luanne, his nurse, explains to the family that comfort care status doesn’t mean Mr. Willoughby will not be cared for. She explains that every usual nursing care activity in the hospital, such as collecting vital signs, is considered in terms of the discomfort it may cause the patient and the possible benefits that may be derived. Luanne explains the reasons for each of the physician’s orders and how they help keep the patient comfortable.

Family members express their wish to help and are encouraged to participate in Mr. Willoughby’s care. Luanne demonstrates how to turn the patient and support him with pillows. She tells them that gentle massage to the extremities and frequent application of lip balm to the patient’s mouth will help to keep him comfortable. However, family members are not allowed to administer medications in the hospital, not even over-the-counter remedies.

PSYCHOSOCIAL SUPPORT ISSUES

Coming to terms with one’s own mortality is different for each individual and is related to the way he or she handles other life challenges. Compassionate care and support from health professionals and loved ones are essential during this crisis. Adjusting to palliative care involves shifting the patient’s and family’s expectations from curing to healing. Even when cure is no longer possible, healing is.

In the landmark work Choices in Healing, Lerner (1996) defines healing as “an inner process through which a person becomes whole,” a process of transforming one’s life in a variety of ways in the face of death. This shift in expectations can help maintain hope, seen as crucial in overall adaptation to crisis. For example, the patient who has confidence that pain and suffering can be controlled will have hope for future quality of life. Patients who believe they are loved and cared for will have hope in their relationships.

Common End-of-Life Emotions

The person diagnosed with a terminal illness experiences a host of emotions, including those famously described by Dr. Elisabeth Kübler-Ross in her classic 1969 book On Death and Dying. Her model includes the five stages of denial, anger, bargaining, depression, and eventual
acceptance. An individual may move back and forth among the stages and may repeat one or more stages.

These and other emotions described below are all normal reactions and deserve equal emphasis with physical care at the end of life. Effective coping with these reactions can improve the quality of life remaining and help the patient resolve important issues with family and friends.

DENIAL

According to Dr. Kübler-Ross, denial of a terminal diagnosis occurs when an individual is unable to believe the eventual outcome of death. This may take the form of disbelief in diagnostic test results, questioning whether an error has been made, or maligning the person who has made the diagnosis. Denial usually gives way gradually to an understanding that the diagnosis is, in fact, an accurate one, although denial may evolve to other stages in the process before acceptance of the diagnosis occurs, if at all (Bronstad, 2016).

ANGER

Anger is common during terminal illness. Patients may express anger at the illness, the side effects of medications and other treatments (or the failure of same), disruption in life plans, changes in social roles and lifestyle, and the prospect of death. Validating a patient’s anger as a normal reaction to terminal illness can open a discussion of how to deal with the anger and make the most of their remaining time.

BARGAINING

Bargaining in response to a terminal illness means that an individual promises to change or enact certain behaviors for continued life. The bargaining may be proposed with one’s physician, the bearer of bad news, or even God. The idea is that the eventual outcome of death may be changed if the bargain is carried out (Bronstad, 2016). For example, someone with a diagnosis of terminal lung cancer may promise to quit smoking to extend life. Another person may promise to attend church.

DEPRESSION

Health professionals must distinguish between normal sadness and possible depression in each patient facing a terminal illness. Depression is commonly underdiagnosed in the general population; consequently, depression in dying patients may be a preexisting condition. Just as patients require ongoing evaluation for depression and anxiety throughout their course of treatment, so do family caregivers.

The incidence of major depression in patients with advanced cancer and terminal illness ranges up to 26%. An untreated diagnosis of depression may lead to an impaired quality of life. Severe depression may cause a shortened survival rate, increased pain, and suicide. Recognizing the symptoms in people with terminal illness and referring them for appropriate treatment can greatly improve their quality of life.
The patient who appears depressed should first be assessed for pain. Untreated or undertreated pain can cause depression and other symptoms.

**SYMPTOMS OF DEPRESSION**

- Feeling sad, anxious, or “empty” most of the day, almost every day
- Decreased interest or pleasure in almost all activities, including sex
- Decreased or increased appetite and/or weight changes
- Disturbed sleep patterns, sleeping more or less than normal
- Fatigue or agitation
- Feelings of worthlessness or excessive guilt
- Inability to concentrate or make decisions
- Recurrent thoughts of death or suicide, or suicide attempts

The following factors may suggest the need for early intervention to treat depression as part of end-of-life care:

- History of depression
- Weak support system (few or no family members, few friends, solitary work environment)
- Evidence of persistent irrational beliefs or negative thinking regarding the diagnosis
- Greater dysfunction related to the illness, such as pain, shortness of breath, appetite and sleep dysfunction, and decreased mobility (NCI, 2016b)

Patients with mild depression may be helped by supportive individual or group counseling with a mental health professional. More intense depression will likely require pharmacologic management in addition to counseling. Family and close friends of dying patients may also require counseling and temporary pharmacologic management (NCI, 2016b).

Although depression in dying patients is not markedly different from depression in other medical conditions, treatment may need to be modified because of other factors, particularly other medications. Antidepressants such as tricyclics and selective serotonin reuptake inhibitors (SSRI’s) have a delayed onset of action up to eight weeks, and patients undergoing end-of-life care may not live a sufficient length of time to benefit from the antidepressant therapy (Sullivan et al., 2017).
FEAR

The most common fears are those of death itself, pain, dying alone, and being a burden. People with strong spiritual beliefs may not fear death but still fear the possibility of pain and suffering at the end of life. Fear can heighten the expectancy of pain and lead to symptoms such as distress, sleep disturbances, anticipatory nausea, and vomiting. Fear can substantially interfere with the quality of life. Health professionals with expertise in palliative care can reassure patients that pain and suffering will be relieved and that patients will not die alone.

Most people also have fears and concerns about loss of dignity and control. Caregivers can provide comfort by allowing the person to express any fears and concerns about dying and by reassuring the person that they will honor advance directives. They include patients in discussions about issues that concern them. They listen to patients reminisce about their lives. They encourage friends and family members to visit and talk to the patient as well, even when they progress to unresponsiveness or sedation. They may simply keep the person company; talking, reading, or just “being there” also can be comforting.

LOSS

Life is filled with losses, some minor (lost car keys), some major (job loss), some physical and tangible (losing hair during chemotherapy), others psychological and intangible (losing social contacts). Loss may be sudden and unexpected or anticipated and predicted. The meaning or value of what is lost to the individual determines the feelings that result. Aging and the end of life involve a succession of losses, concluding with the ultimate loss: loss of self. Other losses may include:

- Loss of physical strength and abilities
- Loss of mental abilities (confusion/dementia)
- Loss of relationships
- Loss of self-esteem
- Loss of body image
- Loss of independence
- Loss of control over life plans and lifestyle

Experiencing multiple losses often leaves insufficient time to grieve those losses and creates feelings such as hopelessness, withdrawal, isolation, and anger. Physical weakness and/or pain can also diminish the ability to cope with loss.

GRIEF

Grief is a normal human response to loss, and it is universal, individual, and unpredictable. Researchers have proposed different models to describe the various stages of grief, but people do not always move through such stages sequentially or predictably. Each person progresses at their
own pace and may move forward and backward through one or more of stages, which can include:

- Shock and numbness
- Yearning and searching
- Disorganization and despair
- Some degree of reorganization

Patients’ experiences of grief are determined by their values, cultural norms, physical and emotional coping resources, current life stresses, personality, and circumstances. In uncomplicated grief, an individual is able to move through the stages and emerge from the grieving process. Complicated grief (also called chronic grief or dysfunctional grief) is an exaggeration of the normal process of grieving, often resulting from multiple losses and making it difficult for an individual to reorganize and move on.

The dying patient and the family may also experience anticipatory grief, a process of working through their intellectual, behavioral, and emotional responses to what the expected death will mean when it happens. During this process, families often try to resolve personal and family issues, offer love and support, involve the dying person in plans for a memorial service, and determine any last wishes not yet spelled out in a legal document. Adaptive grief is when the reality of death is starting to be accepted (Lewis et al., 2017).

(See also “The Family’s Bereavement” later in this course.)

Religion and Spirituality in End-of-Life Care

National and international palliative care guidelines acknowledge the importance of religion and/or spirituality in illness, particularly at the end of life, and support care that attends to the spiritual needs of patients (NCP/NCHPC, 2018). Spiritual well-being has been shown to affect the coping mechanisms and quality of life of dying patients. Strong spiritual well-being significantly reduces depression and hopelessness at the end of life. The greater the self-reported religious beliefs, the more optimistic individuals are in their perceptions of outcomes, including greater confidence in treatment efficacy (Kruizinga et al., 2017).

However, in one study, over half of physicians stated they did not feel responsible for providing religious and spiritual care for their patients. While 87% of patients reported religious or spiritual care from their physicians to be important in end-of-life care, 94% reported receiving none from their physicians, resulting in patient and family dissatisfaction with the quality of their care (Partain et al., 2017).

Therefore, it is vital that all members of the healthcare team learn culturally competent practices regarding religion and spirituality in end-of-life care and elicit the patient’s expectations and preferences for the end of their life. For instance, in order to address the patient’s religious or spiritual values, clinicians may ask, “Are you at peace?” or “Do you find comfort in religious or spiritual beliefs?” (Partain et al., 2017). Many healthcare decisions, such as whether to withdraw
or withhold life-sustaining treatment, to palliate symptoms, or to initiate terminal sedation, require consideration of a patient’s religion and beliefs.

Perceived or real, barriers to performing end-of-life rituals of religious significance can have negative and enduring repercussions that are significant when such spiritual needs go unrecognized by health professionals. Research has found that patients may believe their faith helps them cope with impending death and that practices such as prayer, both alone and with others, are meaningful. They may believe that the trajectory of their lives is the plan of a supreme creator but that they should do their best to live right. They may feel that their religion/spirituality transforms how they experience their illness and the end of life, and they often depend on support from their faith community.

Religious and spiritual beliefs and practices are highly individual, although research shows some racial/ethnic similarities. For instance, black people are more likely to consider religion/spirituality more important than whites. Some South Asian religious faiths believe that prolonging the dying process and interfering with clarity of consciousness should be avoided. Muslims believe that death marks the transition from one life to another, and that the treatment of terminal pain is permissible under the distinction of intended actions (Becze, 2013; Samanta, 2013).

**Family Caregiver Burdens**

Family caregivers, partners, and close friends make up a “shadow workforce” that bears an enormous burden during end-of-life care of a loved one. They play a major role in actual patient care and in decision-making about care provided by others. Wider informal caregiver networks also help ease the multiple burdens placed on primary caregivers. This may include other family members, church groups, neighbors, or volunteer respite workers.

Access to support services for family caregivers may improve the quality of life for the patient, but despite the multitude of available resources, family caregivers of those with chronic disease continually underutilize such services to cope with the demands of caregiving. Therefore, healthcare professionals should be aware of some common burdens of family caregiving when communicating and interacting with the family (Borges et al., 2017).

Many organizations and online resources are available for dying patients and their families that can provide information and support. It is imperative for healthcare workers to familiarize themselves with these resources and direct patients and families on how to access them. *(See also “Resources” at the end of this course.)*

**TIME AND LOGISTICS**

Caring for a spouse or other family member with serious chronic illness or disability is time-consuming and demanding. Whether caregiving takes a few hours per week or 24 hours a day, the responsibility is continuous. Coordinating medications, treatments, and social services and possibly tending to the needs of other family members can be overwhelming and exhausting, causing caregiver burnout. There are a multitude of support services available to family
caregivers that are underutilized likely because they do not self-identify as caregivers and do not recognize the need for respite care or other services. Conversely, when an individual recognizes that they are experiencing burnout, they are more apt to determine what services may help them and to practice self-care (Finkelstein et al., 2018).

PHYSICAL TASKS

The majority of family caregivers are middle-aged or older women who may not have the training or physical stamina necessary to lift, move, or turn terminally ill loved ones. Without professional help, they risk physical injury. Caregivers experience more physical injury than non-caregivers. The most common physical complaints of caregivers are pain, particularly headaches and back pain (APA, 2016). Clinicians should anticipate this risk and offer assistance with physically strenuous aspects of care.

FINANCIAL COSTS

The financial burden caused by the cost of terminal care is problematic for many patients and families at the end of life. Although the majority of costs typically relate to medical expenses, other costs may include legal services, transportation, insurance subsidies, financial planning, and funeral expenses. Even though the Medicare hospice benefit may relieve some of the financial burden of serious illness, families can still face severe economic consequences. Many caregivers must give up their paying job and lose wages and benefits or make major life changes in order to care for their loved one. In our society, a large number of caregivers are African Americans and Hispanic Americans, who generally face greater economic hardship from caregiving.

To address this, in some states, cities, and counties, family caregivers are able to apply for some payment for providing in-home supportive services (CDSS, 2019). Other possible means to help include: reducing out-of-pocket costs by applying to drug companies for assistance with the cost of prescriptions, using legal aid services, seeking debt management counseling, and applying to charitable organizations (Spencer et al., 2018).

MENTAL AND PHYSICAL HEALTH RISKS

Caregivers experience many emotions, ranging from sadness, resentment, anger, and a sense of inadequacy, to deep gratitude for being able to care for the loved one. Physical exhaustion, economic worries, disrupted routines, and seemingly endless responsibilities can lead to mental health problems such as anxiety and depression. Inadequate or interrupted sleep is also common among caregivers, as is loss of social and leisure time.

Caregiver physical deterioration may also be exacerbated by caregivers failing to take the time to have their own medical issues treated (Borges et al., 2017). Health problems related to caregiving are most pronounced among women and those with limited education and can include increased risk of cancer as well as increased mortality, particularly among older adults (APA, 2016). Increased stress in caregivers can be overwhelming and could result in abusive behavior.
toward an elderly patient. Referring the patient for respite care can offer caregivers much needed relief and time to take care of themselves.

**SUPPORT AND EDUCATION FOR CAREGIVERS**

Various programs and interventions have been developed to assist family caregivers to cope with the demands of caregiving. These support services include assistance with caregiving or related tasks and emotional or educational support that is provided to family caregivers by health professionals and community service providers. Some examples of support services include information and referral, education, support groups, counseling, crisis intervention hotlines, and problem-solving training. One such educational program is the Resources Enhancing All Caregivers Health (REACH) in the Veterans Administration (VA) (Easom et al., 2018).

The negative health effects of caregiving can be at least partially alleviated by thorough assessment of caregiver needs, leading to a care plan with support services. Respite care, caregiver support groups, and skills-training interventions can further reduce caregiver burden. Lethin and colleagues (2016) performed an exploratory, cross-sectional study regarding formal support for informal caregivers of older dementia patients. Counseling, caregiver support, caregiver education, adult day care, and in-home respite care appeared to have positive results for the caregivers.

**END-OF-LIFE CARE FOR SPECIAL POPULATIONS**

**The Patient Who Has Cancer**

There were estimated to be over 15.5 million people living with cancer in the United States in 2019, and this is expected to increase to 20.3 million by 2026. About 38.4% of the population will develop cancer during their lifetime. The current estimated cost of cancer is $197.3 billion in the United States. This is expected to increase because of the aging population and as new expensive treatments become the standard of care (NCI, 2019).

The most common cancers (in descending order) are breast cancer, lung and bronchus cancer, prostate cancer, colon and rectum cancer, skin melanoma, bladder cancer, non-Hodgkin lymphoma, kidney and renal pelvis cancer, endometrial cancer, leukemia, thyroid cancer, and pancreatic cancer (NCI, 2019).

Aggressive end-of-life care is considered to be chemotherapy within the last two weeks of life, an emergency room visit or hospital or ICU admission within 30 days of death, or admission to hospice within the last three days of life (Wang et al., 2016). Approximately 50% of terminal patients experience some form of aggressive therapy, especially repeated hospital and ED visits. Although hospice use is increasing, many cancer patients are entering hospice care just days before death.

Aggressive end-of-life care may not be in keeping with a patient’s stated preferences. Earlier enactment of palliative care and better communication with patients are considered essential to
improving end-of-life care (Wang et al., 2016). Therefore, education for healthcare practitioners about the end-of-life care options for patients and their families is needed so that providers can offer information about possible alternatives to aggressive treatment.

People with terminal cancer have the same physical and emotional needs as any dying person, not the least of which is pain management and its side effects. Not every person with terminal cancer experiences excruciating pain, but it is common. Other physical needs arise as the disease progresses, affecting all major body systems, and should be managed based on the goals of patient comfort and quality of life.

The person with advanced cancer may also be suffering the effects of chemotherapy and radiation therapy. A recent study showed that people with very late chemotherapy use, very short hospice enrollment, and repeated hospitalization were considered to have poor end-of-life experiences by oncologists. More aggressive treatment occurred less frequently for patients with health maintenance organization insurance coverage (Wang et al., 2016). Healthcare professionals need to discuss these issues with the patient and family so they may be better prepared for the time ahead. The person with advanced cancer faces special problems.

**DISRUPTION OF FUNCTION**

As cancer metastasizes to liver, lungs, bone marrow, brain, bowel, and/or adrenal glands, it disrupts the function of those organs. For example:

- Liver metastases can impair digestion and cause nausea and vomiting.
- Cancer that has metastasized to the bowel can interfere with elimination, even to the point of fecal impaction.
- Brain tumors increase intracranial pressure as they grow and can cause changes in mental status, vomiting, headache, dizziness, and seizures.
- Growth of metastatic breast, lung, or prostate cancer may compress the spinal cord and lead to irreversible paraplegia if not treated by radiation to shrink the tumor.

Decisions concerning whether and how to treat these complications should involve the patient and the family as well as clinicians.

**HEMATOLOGIC ISSUES**

Most people with cancer are at least mildly anemic, but chemotherapy and radiation therapy can exacerbate the problem. Erythropoietin (Epogen) has been used to treat the anemia; however in 2010, the Food and Drug Administration (Medline Plus, 2016) issued a safety announcement indicating that the use of Epogen and other erythropoiesis-stimulating agents (ESAs) such as Procrit and Aranesp can increase the risk of cancerous tumor growth and shorten life expectancy in patients with cancer. ESAs can also increase the risk of heart attack, heart failure, stroke, or blood clots in patients who use these drugs for other conditions.
A medication guide explaining the risks and benefits of ESAs must be provided to all patients receiving ESAs. Only hospitals and healthcare professionals who have enrolled in and completed a special training program on ESAs are permitted to prescribe and dispense ESAs to patients with cancer.

Cancer that metastasizes to the bone marrow can cause leukopenia (decreased leukocyte count), which increases the risk of infection, and thrombocytopenia (decreased platelet count), which increases the risk of hemorrhage. For example, in liver metastases the tumor may rupture spontaneously and cause hemorrhage.

ANOREXIA-CACHEXIA

Anorexia is loss of appetite, which may be related to both physiologic and psychological factors. Cachexia is a malnutrition syndrome that includes anorexia; early satiety (feeling of fullness after only a few mouthfuls of food); weight loss; anemia; weakness; and alterations in taste and in metabolism of proteins, lipids, and carbohydrates. Cachexia results in wasting and emaciation and is one of the leading causes of death in cancer patients.

HYPERCALCEMIA

Hypercalcemia is an elevated level of serum calcium and the most common life-threatening metabolic disorder associated with cancer. Hypercalcemia can occur in nearly 10% to 20% of cancer patients at any stage of the malignancy. Some types of cancerous tumors (particularly lung and breast tumors and multiple myeloma) as well as bone metastases produce a protein that acts as excess amounts of parathyroid hormone. When serum calcium levels exceed the kidneys’ ability to excrete the excess calcium, nausea and vomiting, constipation, muscle weakness, and dysrhythmias result. Diagnosis and timely interventions can be lifesaving in the short term and may improve the patient’s compliance with primary and supportive treatments as well as improve quality of life.

Untreated hypercalcemia leads to loss of consciousness, coma, and death. Depending on the therapeutic goals determined by the patient, the family, and the responsible clinicians, this course of events may represent a preferred timing and/or mode of death when compared with a more prolonged death from advancing metastatic disease. It is important to consider this option long before the onset of hypercalcemia or other metabolic abnormalities that impair cognition so that the patient may be involved in the decision-making (Cancer.net, 2018).

PLEURAL EFFUSION

Pleural effusion is the accumulation of fluid in the pleural space, which can cause pain and difficult breathing. Thoracentesis (needle aspiration) to drain the fluid, which may be a liter or more, relieves the pain and facilitates breathing.
The Patient Who Has Dementia

The widespread misconception that hospice care is only for cancer patients has created a barrier to seeking hospice care for people with other terminal conditions. Among hospice patients, 44.7% have a diagnosis of Alzheimer’s or other dementias, sometimes in addition to other diseases (CDC, 2016). The requirements for dementia patients to be admitted to hospice are the same as for other patients: a physician’s signed opinion that the patient has less than six months to live.

Psychiatric management fits well with palliative care. Cross-training mental health with palliative care nurses improves the delivery of care and outcomes for dementia patients. Near the end of life, dementia patients may experience agitation, psychosis, depression, and delirium that may require judicious use of psychopharmacology. Patients often experience pain but may only be able to communicate this through behavioral changes such as uncharacteristic irritability or withdrawal, increased vital signs, and pained facial expressions. The palliative care approach emphasizes relieving suffering. Applying this philosophy to advanced dementia acknowledges that the patient has a limited life expectancy and is not likely to benefit from an aggressive approach to comorbid conditions (Hawkins, 2016).

Health professionals need to educate families about the benefits of hospice care for their loved one and for themselves. Decisions about end-of-life care for people with Alzheimer’s disease or other dementias should be made as soon as possible after diagnosis while the patient is able to express personal wishes and participate in decisions.

Referral to the local chapter of the Alzheimer’s Association can help families find attorneys who specialize in elder law or estate planning. This referral should not be made abruptly but as a suggestion, emphasizing that every adult, regardless of health status, should make such a plan. This helps ensure that an individual’s wishes are respected in end-of-life care and in the disposition of property after death. Otherwise, families will need to make difficult decisions without knowing the patient’s wishes. Care must be taken to ensure that those involved in elder law and estate planning are well-informed and honest.

PAIN MANAGEMENT

Chronic pain is as prevalent among people with dementia (almost half) as among older adults in general. Failure to detect pain is especially apparent among those with severe cognitive impairment. Pain in older people is mainly due to degenerative disease of the joints and spine, neuropathic pain, fractures, and cancer.

Patients with dementia may not always be able to verbally communicate their pain. Verbal and visual self-report scales; face pictures; and bedside observation of posture, guarding, facial expressions, and behavior during usual activities may indicate an increase in the pain level (Agit et al., 2018).
NUTRITION AND HYDRATION

In the late stages of dementia, patients may become unable to consume sufficient oral feedings to prevent weight loss. This may be related to poor swallowing, lack of appetite, and a choking cough after eating. Late-stage dementia patients lose significant amounts of body weight. When the patient loses the ability to swallow, he or she is considered terminal. This is a normal occurrence in the final stages of Alzheimer’s disease. Most patients with advanced dementia have a low metabolic rate due to physical inactivity. This can be confirmed by weighing the patient every four weeks. If he or she is maintaining a constant body weight, this rules out starvation and any medical indication for tube feeding (Riachi, 2016).

If the patient’s advance directive indicates that he or she does not want artificial nutrition and hydration (ANH), caregivers and health professionals must respect that decision. However, if the decision was not made earlier, the patient’s surrogate or proxy decision maker, together with the physician and other members of the healthcare team, must decide together whether to initiate tube feedings. When nurses and other healthcare practitioners are well-informed about ANH issues, they are able to guide family members who have to make decisions for their older relative with dementia.

Families of people with advanced dementia are counselled that their loved ones are unlikely to benefit from tube feeding, either in terms of survival or quality of life. Based on multiple studies in patients with advanced dementia, tube feeding has not been found to improve survival time, reduce mortality risk, or reduce the incidence of pressure ulcers (Dening, 2016).

The Patient Who Has HIV/AIDS

In 2016 in the United States, there were an estimated 1.1 people ages 13 and older with HIV infection and nearly 16,000 deaths among those with HIV infection (CDC, 2019b).

More effective treatments for HIV/AIDS and for opportunistic infections have made the disease trajectory far less predictable. This has increased the difficulty of making decisions about advance care and end-of-life issues. Although patients with HIV/AIDS agree that advance care planning is important to clarify end-of-life issues, most stated that they have not signed advance directives and that their families were not aware of their wishes.

Older adults with AIDS develop multiple medical conditions. In advanced AIDS, the patient may suffer both the late effects of the disease itself as well as treatment-related toxic effects. The combined effects include fatigue, weakness, memory loss, and continuous diarrhea, which together necessitate around-the-clock care. If family or friends are unavailable to provide care, the services of home health aides are required. These aides must be informed about whether the patient has a DNAR order in effect and whether the patient wishes to be hospitalized (Slomka et al., 2016).

The person living with advanced AIDS has some of the same psychosocial concerns as patients with any terminal illness, including financial issues, bereavement issues, and fear of death. In addition, the individual may have unique issues related to HIV/AIDS, which can include:
• Stigmatization related to HIV/AIDS
• Fear of contagion
• Fear of social isolation
• Poor quality of treatment due to refusal of care by healthcare providers
• Fear of being judged negatively
• Fear of disclosure of one’s HIV status
  (CDC, 2019b)

Many lack the traditional support systems of friends and families. Friends may be HIV-infected themselves. Others may be afraid of contagion, based on ignorance about HIV transmission or unresolved homophobia. Families may live far away, since many people with AIDS have migrated to large urban areas that are more tolerant of nontraditional lifestyles, perhaps leaving them without a support system or socially isolated when their disease progresses. Persons may lose their jobs or not be able to obtain other work.

One-on-one counseling or a grief support group can help the bereaved patient and afford an opportunity to discuss his or her own concerns and fears about the death of a friend or loved one.

Dying Children and Their Families

Learning that their child has a life-threatening illness and preparing a child for death is one of the most unnatural and difficult events in any parent’s life. Yet each year parents across the United States confront this tragedy as 50,000 children die from life-threatening conditions: extreme prematurity, severe birth defects and congenital anomalies, cancer, HIV/AIDS, progressive metabolic disorders, and other diseases and disorders. The current infant mortality rate (meaning death occurring before the first birthday, generally from conditions existing at birth) is 5.8 per 1,000 (CIA, 2019).

The remarkable resilience of children can make it difficult to predict whether treatment of life-threatening conditions will end in cure or death. More than half a million children in the United States are coping with complex chronic and life-threatening conditions. These children and their families need and deserve palliative care beginning at the time of diagnosis so that treatment is not limited to the disease process itself. This gives families more time to cope with the possibility that their child will die even as they hope for cure.

If it becomes clear that cure is no longer possible, the child may be able to receive hospice care at home rather than in the hospital. Conveying to the child that he or she will not be alone as they near the end and that parental support and love will continue even afterward can be most helpful to a dying child (LLS, 2016).

For example, Massachusetts has a Pediatric Palliative Care Network of hospices that provide free palliative care to children (under 18 years old) with potentially life-limiting illnesses and their families, not just those who have a 6-month prognosis. It offers a total approach to care—
physical, psychological, social, and spiritual. Services include pain and symptom management for the ill child, counseling and spiritual care for parents and siblings, and volunteer assistance with errands (PPCN, 2019).

**PAIN MANAGEMENT**

Physical care of the child at end of life is focused on comfort, using the least invasive procedures while protecting privacy and dignity. A child with terminal illness has the same physical needs as any seriously ill child, including pain management, regular sleep and rest, nutrition, maintenance of bowel and bladder function, respiratory function, and skin care. Additionally, several studies have shown a high degree of symptom burden in children with terminal illness in the last few weeks of life. These symptoms include pain, dyspnea, fatigue, lack of appetite, nausea and vomiting, constipation, and changes in sleep patterns (Vitas Healthcare, 2016).

Children who are dying share the same fear of pain as adults with terminal illness. Infants are believed to be even more sensitive to pain due to underdeveloped inhibitory pain tracts (Vitas Healthcare, 2016). Care providers need to talk with the family about pain management before the need becomes severe. Parents are greatly concerned that their child not suffer at the end of life.

When pain or other symptoms are not treated or are treated unsuccessfully in their dying child, parents are likely to experience long-term distress. For most children, pain control can be achieved using standard dosing with medications such as opioids and benzodiazepines (Vitas Healthcare, 2016). Families who express concerns about addiction from narcotic pain medication need to be reassured that there is no evidence to support the idea. Like adults, children may develop a tolerance to sedatives and opioid medications, so that the dosage or the choice of drugs may need to be changed.

**COMMUNICATION WITH PARENTS**

Parents of children who have life-threatening conditions want to be kept informed about their child’s condition and what to expect throughout the course of the illness. They may also want information about caring for their child at home and about how to support siblings of the ill child.

Effective, timely, understandable, and sensitive communication is essential in all aspects of children’s palliative care. Effective communication leads to improved trust among the patient, their family, and healthcare professionals. Linguistic, religious, and cultural differences may prove especially challenging in pediatric palliative care. Limitations in time and staffing as well as inadequate education can also be barriers to good communication. These issues can interfere with parents’ ability to participate fully in their child’s care and contribute to frustration, anger, and sadness for parents long after their child’s death.

Therefore, healthcare practitioners need to ensure that all parents receive clear, factual information and that the family can understand and respond to questions and emotional concerns. This fosters trust in the relationship and reduces distress and anxiety in the parents and family (Sawin et al., 2019).
END-OF-LIFE ISSUES FOR INFANTS

Advances in medicine, surgery, technology, and skilled nursing care have vastly improved the survival of premature and other high-risk infants. However, sometimes the very best care and the strongest hopes and prayers are not enough to save these fragile lives.

The child who dies before age 1 year will likely have been hospitalized for much of their life. The challenge for healthcare professionals is to make that time as comfortable and meaningful as possible for the infant and the family, supporting their need to be together, to touch each other, to create shared memories, and to prepare for the loss ahead.

Parents generally seek a nurse or physician who can provide an overview on the infant’s condition every day. This helps avoid misunderstandings from fragmentary information. Parents need to know that it is okay to ask questions and expect honest, understandable answers about what is going on. Other children in the family as well as the grandparents also need to be involved. Taking photographs of the infant with family members is important, particularly for those parents whose infant will never get to go home with them.

COMMUNICATING WITH CHILDREN

It is essential to be honest when discussing end-of-life issues with a child, but also to refrain from scaring the child (LLS, 2016). The first consideration is to determine the appropriate developmental level of the child for ideal communication. Successful communication with a child may increase cooperation, decrease anxiety, and normalize discussions. Effective communication with the dying child and the family recognizes interpersonal boundaries and is demonstrated as competent, thoughtful, and caring (Sawin et al., 2019).

It is important for the dying child and the family to talk about death with each other, although it can be difficult and painful. Parents may worry that talking about death will cause the child to lose hope and thus the will to live. But keeping the diagnosis secret denies the child’s right to express feelings, fears, and questions. Children pick up cues from parental and/or sibling behavior that something bad is going to happen, and they need to express their feelings.

There is documented evidence that all patients, even very young children, know they are dying and that they are able to recognize the exceptional distress among family and caregivers around them when death becomes close. By age 6, children begin to recognize the fact of death and what it means. By age 10, children know that death is final. References to its imminence can be quite direct and explicit, however most pediatric patients can tell when adults are having difficulty talking to them about end-of-life issues, death, and dying, and they begin to feel isolated and alienated. If an open and honest dialogue has been established from the beginning, it will be reflected in the willingness of the child or adolescent to talk about fears regarding death (LLS, 2016).

Keeping the diagnosis secret also risks having someone else reveal the information, eroding the child’s trust in the parents. Healthcare professionals can offer support and guidance to the parents by asking, “How will you tell your child the diagnosis?” and then suggesting how and
what to say based on the child’s age. Naming the illness helps explain what to expect in terms of procedures and possible outcomes. Once the child learns the diagnosis, he or she may choose not to talk about death. Parents and healthcare professionals need to respect that wish.

Communicating with children about death involves more than just words. It is important to ask the child questions about what they understand and what they are feeling. Reassurances are given that all of those feelings are acceptable, even sadness, anger, and tears (LLS, 2016). Healthcare professionals can assess the child’s body language and encourage expressive outlets for feelings, such as drawing; play with dolls, puppets, or stuffed animals; writing stories; or working with modeling clay. Children with a terminal illness also still enjoy age-appropriate play activities—games, drawing, coloring, seeing friends. School-age children who are able to attend classes can be encouraged to do so to maintain a sense of normalcy and stay connected with their peer group. Frequent absences are common, but some children want to continue their studies at home as long as possible.

Both the child and the family generally fear what the actual death will be like, particularly whether it will be painful. The child fears dying alone; the family fears not being with the child when death occurs. Having family members nearby enhances the child’s feelings of security and safety. Physical contact—touching, hugging, and holding hands—is comforting and helps the child feel more secure. When parents or siblings need to leave, it helps to tell the child when they will be back.

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(University of Maryland Baltimore, 2016)

**CASE**

Ryan is a 6-year-old boy with terminal cancer who has been undergoing chemotherapy off and on for the past three years. He is now considered end-stage and is being discharged from the Children’s Hospital pediatric hematology/oncology (Hem/Onc) unit to go home for hospice care. His oncologist, Hem/Onc nurse, and parents have explained the situation honestly and at a level he can understand, creating an open climate where he feels able to ask any questions or express any concerns.

Ryan is happy to be going home and in knowing that he will not have to come back to the hospital or undergo chemotherapy again. He understands that he will soon die and believes he will go to heaven and be able to “look down” on his family and friends. He tells his primary
nurse good-bye and thanks her. He has told his parents he is afraid of being alone when “dead comes,” and they have reassured him that someone from his family will be with him at all times. An organization called the Carousel Fund in his hometown provides funds to families with catastrophic illnesses so at least one parent can be with Ryan.

LEGAL ISSUES

The legal responsibility for decisions about a child’s treatment rests with parents. However, clinicians should encourage parents to involve the child in decisions about continuing treatment aimed either at cure or at moving to palliative care. Adolescents may have very definite ideas about the course their treatment should take.

Both the child and the family need to understand what palliative care means. For example, they need to know the risks as well as the potential benefit of CPR. Clinicians should explain that “no code” does not mean “no care” but just a different kind of care aimed at comfort and maximum enjoyment of the time they have left with their child.

FINANCIAL ISSUES

Children are not covered by the Medicare hospice benefit. Consequently, hospice care for children can impose a tremendous financial burden on families, which is one reason why so few children under age 17 are in hospice care.

Medicaid, a jointly funded federal-state health insurance program for people who need financial assistance for medical expenses, must provide home care services to people who receive federal income assistance such as Temporary Assistance to Needy Families (TANF, 2019). Medicaid coverage includes part-time nursing, home care aide services, and medical supplies and equipment. Information about coverage is available from local or state welfare offices, state health departments, state social services agencies, or the state Medicaid office.

BEREAVEMENT

Bereavement begins in the period before the child dies in the form of anticipatory grief and extends well beyond the time of death. Care of the family should extend into the bereavement period. Hospice generally offers support to bereaved family members for a year after the death of the patient. However, if the child dies in the hospital, there may not be a formal bereavement care program available.

(See also “Grief” earlier in this course and “The Family’s Bereavement” later in this course.)

Veterans

Veterans account for approximately 1,800 deaths each day in the United States (We Honor Veterans, 2019). Most veterans die either at home, in a nursing home or assisted-living facility, or in a residential hospice. Veterans may receive hospice care through the Veterans
Administration. The VA may purchase hospice services from community providers to provide care in home, hospital, or long-term care facility.

Veterans benefits include palliative care and hospice care, but some veterans may not know about or understand these benefits. All VA facilities have a Palliative Care Consult Team (PCCT) as a resource for hospice and palliative care provided in the VA facility and coordinated in the community. Although local VA medical centers have the flexibility to address end-of-life care according to veterans’ needs, national policy and standards stipulate that each VA facility have the following resources and services:

- A designated hospice contact person who is part of an integrated network for local and national communications and information dissemination
- Provision of needed hospice services in all settings
- Inpatient hospice beds or access to them in the community
- An interdisciplinary palliative care consultation team
- Assistance with referrals to community hospices in its service area
- Tracking of hospice and palliative care services provided to veterans in all settings (NHPCO, 2016b)

Veterans dying in the VA system may have a higher degree of social isolation, lack of family support, or lower income than those outside the system. In addition, military training may have created in them an attitude of stoicism and a barrier to admitting pain or requesting pain medication. On the other hand, being in a hospice with other veterans offers a camaraderie that can be comforting.

Showing respect for a veteran and acknowledging service to the country is a first step in establishing a relationship. Simply asking, “What branch of the service were you in?” can be a key assessment question. Other factors that influence experiences at the end of a veteran’s life include age, whether enlisted or drafted, rank, and combat or POW experience. More than 1,600 hospices across the country participate in the We Honor Veterans campaign every year (We Honor Veterans, 2016).

DEATH OF THE PATIENT

The Final Hours

Care during the last hours of life, called active dying, can have profound effects on the patient, the family, and healthcare practitioners who attend the dying. Any distressing symptoms that the dying patient has been facing may become exacerbated when death is imminent. Therefore, in acute care, multidisciplinary healthcare professionals must transition from curative to comfort care. Comfort care provides symptom management for a patient who is actively dying.
Consideration is given to every aspect of care to determine whether the benefits are enough to outweigh the risks of discomfort. A plan of care is usually established by the patient or family and healthcare personnel to determine withdrawing or prevention of life-sustaining measures such as oxygen, cessation of diagnostic tests like painful blood tests, consideration of nutrition and hydration, and selection of comfort measures (Lewis et al., 2019). For example:

- Vital signs may be taken every 24 hours or not at all during comfort care. If an abnormal blood pressure is not to be treated, the risk of causing arm pain outweighs taking the measurement. Conversely, a fever can cause severe discomfort. Hot skin may be sufficient to justify giving the dying patient acetaminophen, by rectum if needed.

- Artificial tears or drops of normal saline given every 1–2 hours will prevent pain from dry corneas when the eyelids remain open.

- Frequent oral hygiene with swabs prevents the discomfort of a dry mouth.

These comfort measures can be performed by a nursing assistant, except the artificial tears, which may be considered a medication requiring administration by a nurse.

**SIGN AND SYMPTOMS WHEN DEATH IS NEAR**

Certain signs and symptoms indicate when death is near. Not every patient experiences each of these signs and symptoms, and the presence of one or more of these symptoms does not necessarily indicate that the patient is close to death. The final stage of dying may take from 24 hours to as long as 10 to 14 days.

When it is apparent that death is imminent, health professionals alert the family and confirm the goals of care. This discussion is documented in the patient’s chart, including the observation that the patient is dying.

**Pain**

Pain is typically the most feared symptom of dying. It can be aggravated by physical or emotional stressors. Care may include:

- Regularly assessing for severity, quality, location, and contributing and relieving factors
- Minimizing irritants such as moisture, pressure, and temperature extremes
- Administering pain medications around the clock (to prevent pain rather than treat it)
- Providing alternative comfort measures (e.g., massage, distraction, heat, repositioning)
- Including family and other visitors in comfort measures
Delirium

Delirium is a state of mind that includes confusion, restlessness, incoherence, anxiety, and often hallucinations. Care may include:

- Assessing for reversible causes
- Reorienting patient to person, place, and time with every encounter
- Providing a patient room that is quiet and well-lighted
- Medicating with benzodiazepines or other sedation PRN
- When working with the patient, staying physically close and speaking in a calm, reassuring voice

Anxiety/Restlessness

Anxiety and restlessness may increase as death becomes imminent, as evidenced by tachycardia, dyspnea, and diaphoresis. Care may include:

- Assessing for possible causes (e.g., spiritual distress, urinary retention, constipation)
- Avoiding use of restraints
- Using soft music, low lights, calm voice, and soft touch
- Limiting visitors at the bedside

Dysphagia

Patients near death may experience difficulty swallowing, with a high risk of aspiration. Care may include:

- Administering medications through routes other than oral (rectal, buccal, transdermal); discontinuing any medications that are not necessary
- Suctioning orally PRN
- Providing a modified diet (e.g., ice chips, thick liquids)
- Elevating the head during hand-fed meals or liquids and for at least 30 minutes after meals
- Considering the possibility of aspiration
**Weakness/Fatigue**

This may be caused by increased metabolic demands. Care may include:

- Bundling nursing activities to conserve energy
- Limiting activities to those most valued by the patient
- Providing frequent rest periods

**Dehydration**

This may be caused by decreased thirst and hunger at the end of life. Care may include:

- Assessing mucous membranes for dryness
- Providing frequent oral hygiene via swabs
- Using ice chips and sips of fluid, if able
- Applying lubricant to lips
- Reassuring family that the loss of hunger and thirst are natural and not dangerous at the end of life

**Dyspnea**

Shortness of breath may be accompanied by subjective feelings of suffocation or anxiety. Care may include:

- Elevating the head of the bed
- Having a fan blowing on the patient to move the air in the room
- Teaching the patient pursed-lip breathing
- Providing oxygen and suction PRN
- Administering medications (e.g., inhalers or expectorants)

**Myoclonus**

Myoclonus, or mild to severe twitching, may be caused by high opioid dosing. Care may include:

- Reducing opioid dose to alleviate discomfort
- Medicating with muscle relaxants (which may cause sedation)
Pressure Injuries

Pressure injuries may be worse at the end of life due to incontinence and poor nutritional intake. Care may include:

- Turning the patient every 2 hours if the patient is unable to move themself
- Keeping skin dry and clean
- Providing wound care, as appropriate
- Providing blankets for warmth, but avoiding applying heat
- Preventing pressure on the skin due to shearing

Incontinence

Constipation may be caused by immobility and opioids. Diarrhea and urinary incontinence may be caused by relaxation of muscles. Care may include:

- Administering suppositories, stool softeners, laxatives, or enemas, if ordered and appropriate
- Using absorbent pads for urinary incontinence
- Considering the application of a condom catheter for men or a wicking catheter for women
- Preventing skin irritation or pressure injuries that may result from the presence of stool or urine on the skin for prolonged periods

Anorexia/Nausea/Vomiting

This may be caused by the disease process, medications, or constipation. Care may include:

- Assessing for possible causes
- Medicating appropriately for symptoms
- Providing frequent mouth care, especially after vomiting (Lewis et al., 2017)
SIGNS OF DEATH

Signs that death has occurred include:

- Lack of respiration or pulse
- Eyes open but do not move or blink; pupils dilated
- Jaw relaxed; mouth slightly open
- Bowel and bladder contents expelled
- Patient does not respond to touch or speech
- Skin color becomes pale and waxy in appearance
- Body temperature drops
- Sound of internal fluids trickling or gurgling

When death has occurred, nurses or other clinicians express their sympathy to the family. It is enough to say, “I am sorry for your loss.”

CASE

Agnes, an elderly woman, had been discharged from the hospital to her home to spend her last days in comfortable, familiar surroundings, per her written wishes. Her grandson asked the hospice nurse, “How can we be sure that my grandmother has passed?” The nurse explained that the breathing may become slower, shallow, and loud, even sounding like gasping when death is imminent. She showed the grandson where to feel for a radial pulse in the wrist and explained that he would be unable to feel it when the heart stopped beating. The nurse told him that all of the muscles would relax and that this might appear as open eyes, a slack jaw, and incontinence of the bowel and bladder. The skin would become cool, pale, and waxy. When that happened, the grandson was instructed to call the hospice nurse.

Postmortem Care

Death must be certified in a formal process called *pronouncement* and the findings related to cause of death documented in the patient’s medical record. Pronouncement may be done by a physician, nurse practitioner, nursing supervisor, or hospice nurse, depending on state regulations and the policies of the healthcare agency/facility involved. Unless the death occurred under unusual circumstances, an autopsy (postmortem surgical examination) is not usually required.

CARE OF THE BODY

Care of the body after death is often the responsibility of nurses and nursing assistants. How the body is cared for after death is often influenced by religion and/or culture, so health professionals should be aware of any preferences or limitations and comply with them. For example, for a Muslim patient, the body is typically washed by family or friends to prepare it for the funeral.
The eyes will be closed, the arms will be positioned across the chest, and the body will face Mecca (Memory Tree, 2016).

If the family was not present at the time of death, the nurse or other responsible practitioner may make the body and the environment appear as normal as possible for the family to visit. If the patient or family has chosen cremation, or if there is no open-casket service planned, this will be the final opportunity for them to see their loved one.

All equipment and supplies are removed from the bedside and any soiled linens removed from the room. Local regulations may differ on how to deal with tubes that were in place at the time of death. Generally, the coroner must be notified, and no internal tubes can be removed until the patient is cleared by the coroner’s office as not requiring an investigation into the cause of death. Such cases are referred to as a coroner’s clearance. Conversely, a coroner’s case refers to instances when an investigation is deemed necessary, as dictated by the county’s policies.

Placing the body in a supine position with a pillow under the head and shoulders avoids discoloration of the face. Eyelids are closed (holding them closed for a few seconds helps them to remain closed). If the person wore dentures, those are inserted to give the face a more natural appearance. Placing a rolled towel under the chin will hold the mouth closed. The arms are positioned either at the sides of the body or across the abdomen. The identifying wristband is left on unless it has become too tight due to fluid retention, in which case it is replaced with a looser one.

Any soiled areas of the body are washed and absorbent pads are placed under the buttocks. A clean gown is placed on the body and the hair is brushed or combed. Any jewelry is removed, except for a wedding band, which is taped to the finger. The body is carefully covered up to the shoulders with clean bed linens. All belongings of the deceased are listed and placed in a safe storage area for the family. These measures are usually conducted by a nursing assistant in acute care and always conducted by the nursing assistant in long-term care, as directed by the nurse in charge.

Soft lighting is generally preferred, and chairs and tissues may be made available for family members. Clinicians reassure family members that they may take as much time as they need to say their last good-byes. Only when the family leaves the room should final preparations for removal of the body be initiated.

REMOVING THE BODY

After the family has viewed the body, the care provider attaches additional identification tags, one to the left great toe and one to the patient’s belongings. The entire body is then placed in a white, plastic body bag and another identification tag affixed to the outside zipper. Then the body is either picked up by the responsible mortician (undertaker) or sent to the hospital morgue, if there is one, until arrangements are made with a mortician.
Some hospitals or other agencies close the doors to all other patient rooms before transporting a body through the corridors and require the use of service elevators rather than public elevators during this transfer.

**Autopsy**

Autopsy is no longer a routine procedure in most hospitals. It is posited that one of the reasons for the gradual decline in autopsies is the ability to obtain postmortem information by noninvasive means (Sanchez, 2019). Likewise, in 1971 the Joint Commission ceased requiring a minimum number be performed for a hospital to receive accreditation, and in 1995 the National Center for Health Statistics ceased collection of autopsy statistics (Baumgartner & Anthony, 2016).

The average number of deaths in United States hospitals that result in autopsies is 4.3% and higher in teaching hospitals. The procedure contributes to medical education, aids in the characterization of newly emerging diseases, and advances the understanding of disease-related changes. In addition, autopsy can reveal errors in clinical diagnosis.

In the event that autopsy is required, health professionals determine whether the family has any religious or cultural concerns about this procedure. Families are also informed that autopsy does not disfigure the body and would not interfere with having an open-casket service.

**MEDICAL EXAMINER INQUESTS**

Medical examiner inquests are conducted to determine the manner of death, in accordance with state and local laws. For example, the Government Code of the State of California grants the medical examiner of a jurisdiction the authority to hold inquests at their discretion. The Code also states that the medical examiner “shall hold an inquest if directed to do so by the Attorney General, district attorney, sheriff, city prosecutor, city attorney, or chief of police of a city in the county of which such coroner has jurisdiction.” These inquests are to be open to the public and, at the discretion of the medical examiner, can be held with or without a jury.

As stipulated by the Code, the results of the inquest should yield: the name of the deceased; the time and place of death; the medical cause of death; and whether death was the result of natural causes, a suicide, an accident or a homicide. (A homicide is a death at the hands of another person, that is not accidental.) If the chief medical examiner determines that the manner of death is homicide, the medical examiner is required to transmit the written findings to the district attorney, the police in the jurisdiction where the body was recovered and any other police agency requesting copies of the findings.

Healthcare professionals may also wish to research regulations governing medical examiner inquests in their own jurisdiction.

(SFBoS, 2019)
Organ Donation

Organ procurement organizations (OPO) throughout the country facilitate the donor organ recovery process, which increases efficiency and organ yield, reduces costs, and minimizes organ acquisition charges. OPOs have taken on the responsibility of harvesting donor organs and matching them with potential recipients (Doyle et al., 2016).

In the United States, the growing disparity between organ availability for transplantation and the number of patients in need has challenged the donation and transplantation community. The number of organs available for transplantation has been a relatively fixed national resource over the last decade. By contrast, the national waiting list rises by thousands each year, with only a fraction of those waiting receiving lifesaving transplants. In 2017 an average of 18 patients died every day while on a waiting list for one or more transplanted organs (UNOS, 2019).

ORGANS AND TISSUES THAT CAN BE DONATED

One organ donor may save up to eight lives and save or improve an additional 50 lives through tissue donation. The most common organ transplants in 2018 were kidney (21,167), liver (8,250), heart (3,408), and lungs (2,530) (UNOS, 2019). Most organ donations come from deceased donors (although a living donor can donate as well). Tissues can also be transplanted. The following table shows which organs and tissues can be donated from deceased donors.

<table>
<thead>
<tr>
<th>ORGANS, TISSUES, AND BODY PARTS THAT CAN BE TRANSPLANTED FROM DECEASED DONORS</th>
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<tbody>
<tr>
<td><strong>Organs</strong></td>
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<td>• Heart</td>
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</table>
**Body Parts**

- Hands
- Face
- Skull
- Scalp
- Penis (first total penis and scrotum transplant performed in 2018)
- Uterus (trials have begun in U.S.)

*Corneal donors are universal, i.e., do not have to “match” recipients like organ donors must. Many people can donate corneas, except for people with infections or highly communicable diseases such as HIV or hepatitis. Corneas can be recovered several hours after death and can be stored; a corneal transplant can be performed within 3–5 days after donation.*

(Horsager-Boehrer, 2019; HRSA, n.d.-a)

**DISCUSSING ORGAN DONATION**

The public has a generally favorable attitude about organ donation for transplants; however, not every clinician broaches the subject with patients since they may be perceived as being more an advocate for the organ recipient than of their patient. Ideally, questions about organ donation are discussed with the patient in the context of advance directives. This relieves the family of making the decision during the stressful time immediately after death. Unless the patient has documented the wish to become an organ donor, the family must decide.

The Anatomical Gift Act was approved by Congress in 1968 following the first heart transplant the previous year. The 2006 United States Revised Anatomical Gift Act compels hospitals and OPOs to pursue donation in cases of brain death in designated donors to stimulate the supply of available organs (Schiefer, 2019). Federal law requires that only a “designated requestor” may approach the family about organ donation (see below).

**DONATION AFTER BRAIN DEATH**

Brain death statutes in the United States differ by state and institution. The Uniform Determination of Death Act of 1981 provides states with whole-brain criterion of death (Find Law, 2019; ULC, 2014). *(See “Resources” at the end of this course.)*

The **three essential findings** in death that are declared by neurological criteria are:

- Irreversible coma
- Absence of brain stem reflexes
- Apnea (suspension of breathing)
  (NJSN, 2014; Wijdicks et al., 2010)

When brain death has been confirmed, the hospital notifies the local organ procurement organization. If the patient is a potential donor, an OPO representative immediately goes to the hospital and searches the state’s donor registry for legal consent. If the patient is not registered
and there is no other legal consent, consent from the family will be required. When this is obtained, medical evaluation continues.

**DONATION AFTER CARDIAC DEATH**

Anyone who has brain function that has been deemed incompatible with life but who does not meet all criteria for brain death is a potential candidate for donation after cardiac death (DCD). DCD may be discussed as an option with families when they have accepted that their loved one cannot survive and have made the decision to remove that person from life support (CORE, 2018). There is a 90-minute time frame in which organs can be recovered after extubation to the pronouncement of death. If the patient does not progress to cardiac death within this time, organ donation cannot occur. Tissue donation may still be an option after death (NJSN, n.d.-b).

If the family agrees to DCD, the patient is removed from the ventilator in an operating room. When the heart stops beating, a physician declares death and organs are recovered. Note that DCD is the original method of managing organ donation, and it has increased donations by as much as 25% in some geographic locations in the United States (CORE, 2018).

**DESIGNATED REQUESTORS**

It is a federal regulation that a specially trained, designated hospital staff member, known as a designated requestor, approach the family to discuss the option of organ donation. A designated requestor may be a physician or other health professional who has completed a course approved by an OPO on how to approach potential donor families to request organ or tissue donation. Who this person is varies according to the facility.

The requestor lets the family know the patient is registered to be an organ donor and that those wishes will be carried out after death is pronounced. The family is also given clarification of the definition of brain death and informed that the patient will remain on life support after death is pronounced (CFR, 1998).

**MEDICAL EVALUATION OF POTENTIAL DONORS**

Screening of a potential donor is essential to determine whether the donor has an infection that could be transmitted to recipients through transplanted organs and/or tissues. The Organ Procurement and Transplantation Network policies (for OPOs) and FDA regulations and guidance (for tissue and eye banks) require a medical and social history interview to be conducted with the deceased donor’s next of kin or another knowledgeable person (CDC, 2019c).

**Interviews** are designed to assess the donor for:

- Risk behaviors that may have exposed the donor to certain diseases
- The donor’s past medical history
- Relevant travel history (which can be important for exposure to certain pathogens)
OPTN policy requires OPOs to perform the following tests to determine if the donor has certain infections:

- Human immunodeficiency virus (HIV)
- Hepatitis B virus (HBV)
- Hepatitis C virus (HCV)
- Syphilis
- Cytomegalovirus (CMV)
- Epstein Barr virus (EBV)
- Toxoplasmosis
  (CDC, 2019c)

Once a potential donor has been evaluated and accepted, additional assessments are done for the donation of specific organs.

**THE MATCHING PROCESS**

Following medical evaluation for contraindications, the OPTN is contacted by the OPO in order to begin a search for matching recipients. The OPTN matching process includes:

- Blood type
- Body size
- Severity of patient’s medical condition
- Distance between the donor’s hospital and the patient’s hospital
- Patient’s waiting time
- Whether the patient is available
- Tissue type
  (HRSA, n.d.-b)

**ORGAN RECOVERY**

During the above process, the donor is maintained on artificial support. The condition of every organ is monitored by hospital medical and nursing staff along with the OPO coordinator, who also arranges arrival and departure times of both surgical teams. When the surgical team arrives, the donor is taken to the OR, and under sterile technique, organs and tissues are recovered and all incisions closed. The tissue and organs are then transported rapidly by commercial or contracted airplanes, helicopters, and/or ambulances to the hospital where the transplant recipient is waiting and may be prepped and ready in the OR (HRSA, n.d.-b).
THE FAMILY’S BEREAVEMENT

A family’s bereavement begins when their loved one is diagnosed with terminal illness, initiating a period of anticipatory grieving for both patient and family. After the patient dies, family members continue to grieve until they become reconciled to life without the deceased. For some, the process may take weeks or months; for others, grieving may take a year or longer. The Medicare hospice benefit includes bereavement care for the family for approximately one year after the patient’s death (NHPCO, 2018).

All healthcare practitioners may encounter bereaved persons, and they need to recognize the signs of grieving and bereavement and offer appropriate support as part of care.

(See also “Grief” earlier in this course.)

Characteristics of Grief and Mourning

How a person grieves depends on their personality, physical and emotional coping patterns, relationship with and attachment to the person who died, cultural beliefs, and the situation surrounding the loss. Grief reactions can be psychological, emotional, physical, or social. Psychological and emotional reactions can include anger, guilt, anxiety, sadness, and despair. Physical reactions can include difficulty sleeping, appetite changes, somatic complaints, or illness. Social reactions can include feelings about taking care of others in the family, the desire to see or not see family or friends, or the desire to return to work (Lewis, 2017). If the deceased was the primary earner, the family may suffer stress from significant financial loss.

Several authors have given definitions of grief that are now considered classic. For example, DeSpelder and Strickland (1987) identified five characteristics of grief:

- Somatic distress
- Preoccupation with the image of the deceased
- Guilt
- Hostile reactions
- Loss of the usual patterns of conduct

Bowlby (1961) described three phases of mourning:

1. Urge to recover the lost person
2. Disorganization and despair
3. Reorganization

These phases originated from the attachment theory of human behavior, which postulates people’s need to attach to others in order to improve survival and reduce risk of harm.
Lindemann’s classic text (1994) described three tasks of what he called “grief work.” These include:

- Freedom from ties to the deceased
- Readjustment to the environment from which the deceased is missing
- Formation of new relationships

To free oneself from the deceased, a person must change the emotional energy invested in the lost person. This does not mean the deceased was not loved or is forgotten but that the grieving person is able to turn to others for emotional satisfaction. To readjust, the grieving person may need to modify his or her roles, identity, and skills to live in the world without the deceased. To form new relationships, the person redirects the emotional energy once invested in the deceased to other people and activities.

Grief work requires significant effort, so it is not uncommon for those who grieve also to experience overwhelming fatigue.

When a loved one has experienced a prolonged dying process, some family members not only grieve the loss of that person but also suffer the loss of their role as caregivers. They may experience a sense of relief that the burden of caregiving has lifted as well as guilt for feeling relief. These are natural reactions, and health professionals should encourage their expression.

**COMPLICATED GRIEF**

Complicated grief (CG) can be experienced after the loss of a loved one and is a prolonged bereavement that interferes with one’s ability to return to the activities undertaken before the death. CG may be diagnosed as a persistent, complex bereavement disorder when it continues for more than six months. The surviving family member or caregiver may show characteristics of shock or being stunned or numb. Extreme symptoms may include extended lack of trust or caring for any other individuals, including other children, and an intense reaction to or avoidance of remembrances of the loved one (Mason & Tofthagen, 2019).

In the United States approximately 7% (10 million) of those experiencing the loss of a loved one suffer CG, and family caregivers of a dying child are the most likely to undergo this. When there is prolonged bereavement after the death of a child, family caregivers, particularly parents, may experience guilt, abandonment, loneliness, and loss of purpose or identity when caregiving ceases (Tofthagen, 2019).

**Grief among Health Professionals**

Health professionals who work with dying patients and their families may also grieve when a patient dies even though the death was expected. In the aftermath of the death of a patient, grief counseling in the form of a debriefing may be offered to the involved staff. Attending the funeral or memorial service may allow expression of the grief as well as show respect for the family and their loss.
Bereavement Resources

Bereavement options for families include grief support groups (either self-help or facilitated by professionals) and one-on-one counseling by a psychologist, psychiatrist, clinical social worker, or clergyperson. Many online support groups are also available as an adjunct to in-person therapy rather than as a substitute. If depression occurs in the context of bereavement, medication may be appropriate. No consensus exists among professionals as to the most effective intervention. There are many books and videos available, most of them specifically focused on a particular family role (parents, children, siblings, or spouse).

Hospice professionals who work with the bereaved maintain contact with the family, make home visits, and encourage family members to talk about their feelings, emphasizing that grieving is a painful process that may take years to resolve. It is important to refer to the deceased person by name and to discuss shared memories with the family. Continuing contact with the family offers them an anchor during a difficult time. A good condolence letter offers a tribute to the deceased and comfort to the survivors.

CONCLUSION

The ranks of older adults continue to swell in the United States. Many of them have one or more chronic diseases. Thus, the need for high-quality end-of-life care will only increase. The number of children needing end-of-life care have also swollen, causing overtaxed parent-caregivers to seek support in the form of bereavement care, respite care, and spiritual guidance.

Americans are beginning to accept that death is inevitable and that planning for end-of-life care is essential to ensuring that our preferences are respected when we can no longer care for ourselves. More people are drawing up advance directives, appointing a healthcare proxy/agent, choosing hospice and palliative care over aggressive treatments, or considering “assisted death.” This growing awareness around end-of-life issues would not have come about without the educational and outreach efforts of nurses, other health professionals, public health agencies, and private foundations.

Increasing numbers of dying patients have opted to select palliative care or hospice as an alternative to more aggressive medical care performed in acute care hospitals, often in ICUs. Communication with patients and families is essential to stress that these are a means to make the patient more comfortable rather than “giving up.” Palliative care is mostly noninvasive and focuses on the patient’s comfort. Hospice care is ordered when a physician determines that the patient may have less than six months to live and may be renewed after six months with another physical examination.

Since pain, dehydration, excess secretions, and other symptoms at the end of life may cause discomfort, pharmacologic and nonpharmacologic measures are necessary as a part of care, particularly in the last hours of life, when the patient is considered to be actively dying. After death, specific legal considerations and tasks are performed by physicians, nurses, and nursing assistants as part of postmortem care.
All healthcare professionals have a role in helping their patients and families understand the range of options available and the benefits of planning for end-of-life care before it is needed.

RESOURCES

American Academy of Hospice and Palliative Medicine
http://aahpm.org

Caregiver Action Network
http://caregiveraction.org

Center to Advance Palliative Care
http://www.capc.org

Children’s Hospice International
http://www.chionline.org

Hospice & Palliative Nurses Association
https://advancingexpertcare.org

National Association for Home Care and Hospice
http://www.nahc.org

National Coalition for Hospice and Palliative Care
https://www.nationalcoalitionhpc.org

National POLST Paradigm: State Programs
http://polst.org/programs-in-your-state

Pediatric Palliative Care Network
https://www.mass.gov/pediatric-palliative-care-network-ppcn

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TEST

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1. According to a study cited in this course, most people would prefer to die in:
   a. The hospital.
   b. A long-term care facility.
   c. Their own home.
   d. A hospice facility.

2. Which statement best describes a core belief of palliative care programs?
   a. Providing services preferably in a hospital-based setting
   b. Avoiding therapies that prolong a patient’s life
   c. Controlling only the symptoms of advanced cancer
   d. Providing care to relieve a patient’s pain and suffering

3. Which term is often used as an alternative to “palliative care”?
   a. Supportive care
   b. Discomfort care
   c. Pain relief care
   d. Emotional care

4. Hospice services have the primary aim of:
   a. Bringing palliative care to adult patients with advanced cancer.
   b. Providing interdisciplinary care to patients with terminal illness.
   c. Supporting patients to receive end-of-life care at inpatient facilities.
   d. Alleviating suffering by shortening a terminal patient’s survival.

5. Which is a correct statement regarding recent data on hospice care?
   a. Fewer people are choosing hospice care.
   b. The Medicare hospice benefit covers about half of hospice patients.
   c. Hospice care is available in all 50 states.
   d. Hospice benefits are not provided to veterans.
6. Which statement **best** describes the difference between palliative care and hospice care?
   a. Palliative care is typically provided for cancer patients, whereas hospice care is not.
   b. Palliative care aims to provide curative treatments, whereas hospice care aims to relieve symptoms.
   c. Palliative care is primarily provided in a home setting, whereas hospice care is primarily provided in a facility.
   d. Palliative care can be provided at any stage of illness, whereas hospice care is provided at the end of life.

7. To access the Medicare hospice benefit, a patient must agree to forgo treatments such as chemotherapy and radiation, and his or her physician must certify that the patient: 
   a. Is diagnosed with advanced cancer.
   b. Does not have a living will.
   c. Likely has six months or less to live.
   d. Will not require further hospital care.

8. Which is a **correct** statement about variations in end-of-life care among patients of different racial or ethnic backgrounds?
   a. African American patients are less likely to prefer spending their last days in the hospital compared to other racial groups.
   b. Hispanic patients mostly prefer life-prolonging drugs and mechanical ventilation.
   c. White patients are more likely than racial minority patients to receive hospice care.
   d. Proficiency in the English language does not have an impact on the use of hospice services.

9. Physician aid in dying (PAD) is legal:
   a. In all 50 states and the District of Columbia.
   b. In Canada, but not in the United States.
   c. Only in a few states.
   d. Only with the permission of the dying patient’s family.

10. The goal of proportionate palliative sedation (PPS) is:
    a. Unconsciousness.
    b. Relief of nausea and vomiting.
    c. Seizure control.
    d. Relief of intractable pain and suffering.
11. According to the Heart Rhythm Society, removing or deactivating cardiovascular implants near the end of life:
   a. Is synonymous with euthanasia.
   b. Is something that all patients have the right to decide.
   c. Must be decided by the patient’s cardiologist.
   d. Conflicts with all codes of medical ethics.

12. Under a medical or durable power of attorney (DPOA):
   a. End-of-life decisions are made by whichever adult family members are present when the patient becomes unresponsive.
   b. A healthcare proxy is named in advance to make decisions for the patient once they are no longer be able to do so.
   c. The patient’s primary care physician is empowered to decide what is best for the patient.
   d. A formal diagnosis of a serious illness must be made prior to addressing any ethical decisions that arise involving patient care.

13. Do-not-attempt-resuscitation (DNAR) orders are written:
   a. By a physician or nurse when the patient’s family fails to do so.
   b. In the patient’s chart, or else the orders can be ignored.
   c. For easy access to all healthcare practitioners in the event of an emergency.
   d. In order to permit any patient to die.

14. By forgoing artificial nutrition and hydration at the end of life, the patient:
   a. Experiences considerable physical and emotional trauma.
   b. Suffers more due to increased hunger and thirst.
   c. Is more likely to develop pleural effusions.
   d. May avoid possible risks, such as pain, aspiration, sepsis, and diarrhea.

15. All of the following are recommended guidelines for communication with families of dying patients, except:
   a. Avoid bringing up difficult or fearful topics.
   b. Acknowledge family members’ emotions.
   c. Elicit questions and listen.
   d. Value what family members say.
16. Culturally competent communication takes into account the knowledge that:
   a. It is disrespectful to withhold information from a patient, no matter their cultural background.
   b. A patient’s religious beliefs are private and best left out of discussions about healthcare.
   c. Some patients would prefer that a family member act as surrogate in discussing a diagnosis.
   d. Most minorities have a higher level of trust in physicians as authority figures.

17. Which is a true statement about pain management?
   a. Healthcare facilities are not required to manage the pain of all patients.
   b. No treatments are available for many forms of pain at the end of the life.
   c. When pain is relieved, symptoms such as depression, diminished appetite, and impaired sleep may disappear.
   d. At the end of life, it is important to protect patients from drug addiction.

18. When providing pain management for a female older adult patient, the clinician is aware that the patient:
   a. Is at high risk for overtreatment of pain.
   b. Has a lower risk for drug-drug interactions than a young adult patient.
   c. Is more likely to “tough out” her pain than a male patient.
   d. May have a higher pain threshold due to age-related neurophysiologic changes.

19. When a patient is unable to swallow oral medication, which other route of administration should be offered first?
   a. Intramuscular injection
   b. Subcutaneous injection
   c. Intravenous
   d. Sublingual

20. Which primary therapies are used to treat the shortness of breath that is common among dying patients?
   a. Nonsteroidal anti-inflammatory drugs and acupuncture
   b. Guided imagery, glucosamine, and sponge baths
   c. Oxygen, opioids, and anti-anxiety medications
   d. Inhaled corticosteroids, antibiotics, and yoga
21. The risk factors for delirium in end-of-life patients include:
   a. Sleep deprivation and visual or hearing impairments.
   b. Vomiting and constipation.
   c. Seizures and depression.
   d. Patient immobility and rheumatoid arthritis.

22. All of the following are symptoms of possible depression in a patient who is near the end of life, except:
   a. Promising to change certain unhealthy behaviors.
   a. Changes in appetite or weight.
   c. Decreased interest or pleasure in almost all activities.
   d. Inability to concentrate or make decisions.

23. A patient with a terminal illness most commonly expresses a fear of:
   a. Starvation.
   b. Disfigurement.
   c. Pain.
   d. Dying in the presence of family members.

24. The experience of grief is a universal response that is:
   a. Both individual and unpredictable.
   b. Private and best processed internally.
   c. Experienced in the same way across all cultures.
   d. Consistent and unfolds in sequential stages.

25. Which is not a common burden faced by family members caring for patients at the end of life?
   a. Failing to seek treatment for their own medical issues
   b. Giving up jobs or income to care for their loved one
   c. Risking physical injury when lifting or moving the patient
   d. Taking time to participate in caregiver support groups

26. The U.S. Food and Drug Administration has issued a safety announcement that drugs used to treat anemia in patients with cancer can cause:
   a. Risk of seizures.
   b. Mental disorders such as depression.
   c. Increased risk of cancerous tumor growth.
   d. Erectile dysfunction.
27. A patient who is receiving tube feedings in the late stages of dementia has:
   a. An improved survival time.
   b. An increased quality of life.
   c. A decreased risk of pressure ulcers.
   d. An increased risk of lung infection due to aspiration.

28. Which is a true statement about issues facing a patient who is living with advanced HIV infection?
   a. The disease trajectory has become much more predictable due to the latest treatment options.
   b. Concurrent medical conditions are not usually a concern.
   c. The patient may fear that health care providers will refuse to care for them.
   d. The patient most likely has a strong traditional support system of friends and family members.

29. Which is a true statement regarding end-of-life issues among children?
   a. Infants require less pain management since they are not as sensitive to pain as adults.
   b. Between the ages of 2 to 6, children typically come to understand death as final and irreversible.
   c. Adolescents can legally make their own end-of-life decisions.
   d. Parents have legal responsibility for decisions about a child’s treatment.

30. When counselling the parents of a dying child, the clinicians suggest that the parents:
   a. Talk with their child about what they are feeling.
   b. Keep the diagnosis from their child.
   c. Encourage their child not to go to school.
   d. Make all the end-of-life decisions for their child.

31. When caring for veterans who are dying, health professionals are aware that:
   a. Hospice care is not a provided benefit by the Department of Veterans Affairs.
   b. A veteran may be unwilling to admit being in pain.
   c. A veteran usually has strong family support.
   d. Enlisted and drafted veterans have the same experiences as one another.
32. Typically, the most feared symptom of dying is:
   a. Bowel incontinence.
   b. Dyspnea.
   c. Delirium.
   d. Pain.

33. Standard postmortem care includes:
   a. Adapting practices according to the patient’s religion and culture.
   b. Elevating the patient’s legs with pillows in order to prevent facial discoloration.
   c. Allowing the family only a brief visit with the patient’s body to avoid upset feelings.
   d. Performing an autopsy to reveal possible errors in the patient’s clinical diagnosis.

34. Which is not one of the three essential findings required to declare death by neurological criteria?
   a. Irreversible coma
   b. Absence of brain stem reflexes
   c. Apnea (suspension of breathing)
   d. No detectible heartbeat

35. Which is not one of Bowlby’s phases of mourning following the death of a loved one?
   a. Urge to recover the lost person
   b. Disorganization and despair
   c. Desire to return to work
   d. Reorganization

36. An online support group for a bereaved family member is recommended to:
   a. Discourage family sharing.
   b. Enhance in-person therapy.
   c. Predict suicidal behavior.
   d. Replace medical therapy.