COURSE #77770 — 5 CLOCK HOURS RELEASE DATE: 05/01/23 EXPIRATION DATE: 04/30/26

Counseling Patients at the End of Life

HOW TO RECEIVE CREDIT

- Read the enclosed course.
- Complete the questions at the end of the course.
- Return your completed Answer Sheet to NetCE by mail or fax, or complete online at www.NetCE.com. Your postmark or facsimile date will be used as your completion date.
- Receive your Certificate(s) of Completion by mail, fax, or email.

Faculty

Lisa Hutchison, LMHC, has more than 20 years of experience providing individual and group counseling with adults. She specifically focuses on teaching assertiveness, stress management, and boundary setting for empathic helpers. Ms. Hutchison graduated from the University of Massachusetts, Boston, with a Master's degree in education for mental health counseling.

Faculty Disclosure

Contributing faculty, Lisa Hutchison, LMHC, has disclosed no relevant financial relationship with any product manufacturer or service provider mentioned.

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Division Planners/Director Disclosure

The division planners and director have disclosed no relevant financial relationship with any product manufacturer or service provider mentioned.

Audience

This course is designed for all members of the interprofessional team responsible for supporting patients at the end of life.

Accreditations & Approvals

As a Jointly Accredited Organization, NetCE is approved to offer social work continuing education by the Association of Social Work Boards (ASWB) Approved Continuing Education (ACE) program. Organizations, not individual courses, are approved under this program. Regulatory boards are the final authority on courses accepted for continuing education credit.

American Psychological Association

Continuing Education (CE) credits for psychologists are provided through the co-sponsorship of the American Psychological Association (APA) Office of Continuing Education in Psychology (CEP). The APA CEP Office maintains responsibility for the content of the programs.

NetCE has been approved by NBCC as an Approved Continuing Education Provider, ACEP No. 6361. Programs that do not qualify for NBCC credit are clearly identified. NetCE is solely responsible for all aspects of the programs.

This course, Counseling Patients at the End of Life, Approval #20230925-4, provided by NetCE, is approved for continuing education by the New Jersey Social Work Continuing Education Approval Collaborative, which is administered by NASW-NJ. CE Approval Collaborative Approval Period: September 1, 2022 through August 31, 2024. New Jersey social workers will receive 5 Clinical CE credits for participating in this course.

NetCE is recognized by the New York State Education Department's State Board for Social Work as an approved provider of continuing education for licensed social workers #SW-0033.

This course is considered self-study, as defined by the New York State Board for Social Work. Materials that are included in this course may include interventions and modalities that are beyond the authorized practice of licensed master social work and licensed clinical social work in New York. As a licensed professional, you are responsible for reviewing the scope of practice, including activities that are defined in law as beyond the boundaries of practice for an LMSW and LCSW. A licensee who

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practices beyond the authorized scope of practice could be charged with unprofessional conduct under the Education Law and Regents Rules.

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This course is considered self-study by the New York State Board of Mental Health Counseling.

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Designations of Credit

Social workers completing this intermediate-to-advanced course receive 5 Clinical continuing education credits.

NetCE designates this continuing education activity for 5 CE credits.

NetCE designates this continuing education activity for 2 NBCC clock hours.

NetCE designates this continuing education activity for 5 continuing education hours for addiction professionals.

Individual State Behavioral Health Approvals

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About the Sponsor

The purpose of NetCE is to provide challenging curricula to assist healthcare professionals to raise their levels of expertise while fulfilling their continuing education requirements, thereby improving the quality of healthcare.

Our contributing faculty members have taken care to ensure that the information and recommendations are accurate and compatible with the standards generally accepted at the time of publication. The publisher disclaims any liability, loss or damage incurred as a consequence, directly or indirectly, of the use and application of any of the contents. Participants are cautioned about the potential risk of using limited knowledge when integrating new techniques into practice.

Disclosure Statement

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Course Objective

The purpose of this course is to provide physicians, nurses, physician assistants, and allied health professionals with the knowledge and strategies necessary to best assist patients to seek and receive optimal end-of-life care.

Learning Objectives

Upon completion of this course, you should be able to:

1. Define palliative and end-of-life care.
2. Outline the role of health and mental health professionals in end-of-life counseling.
3. Identify psychological concerns present at the end of life.
4. Discuss key components of end-of-life conversations.
5. Analyze mental health interventions that can be incorporated into end-of-life care and bereavement.
6. Describe practical, ethical, and legal issues that can arise in the provision of end-of-life care.
7. Examine the impact of culture and culturally competent care on end-of-life decisions and support.

INTRODUCTION

End-of-life decisions can be complex and challenging. Health and mental health professionals can help with their expertise, whether it is for the person facing death, their family, surrogate decision makers, or caregiver. It is vital for health and mental health professionals to learn when and how to include end-of-life discussions into their sessions, assist with decision making and planning, and learn the differences between palliative and end-of-life care.

DEFINING END-OF-LIFE CARE

The terms palliative care and end-of-life care often are used interchangeably, but there are some differences. The goal of palliative care is to improve the quality of life of patients and their families when faced with life-threatening illness. This is achieved through the prevention and relief of suffering and treatment of pain and other physical, psychosocial, and spiritual problems [1]. Palliative care includes measures used to achieve comfort for the patient. Palliative care can be provided at any stage of a serious illness, including as early as the time of diagnosis. Unlike patients receiving end-of-life care, those receiving palliative care may still be pursuing curative treatment [2].

End-of-life care (which may include palliative care) is generally defined as care that is provided to seriously ill patients who have a prognosis of six months or less. It is care intended for the last few weeks or months of a patient's life. End-of-life care can be provided in a variety of settings, including the patient's home, nursing homes or assisted living facilities, or inpatient hospice facilities [2]. End-of-life care is a multidisciplinary team approach toward "whole person care." It is intended for people with advanced, progressive, incurable, or life-limiting illness to enable them to live as well as possible before they die [3]. This course will focus on end-of-life care.

THE ROLE OF HEALTH AND MENTAL HEALTH PROFESSIONALS IN END-OF-LIFE COUNSELING

The transition of care from eliminating or mitigating illness to preparing for death can be difficult for patients, families, and caregivers, and it can be equally difficult for healthcare professionals, who are expected to meet the physical and emotional needs of dying patients and their families [4]. By understanding the experiences of the dying patient, health and mental health professionals can best support the unique needs of each patient and the patient's loved ones as well as self and other members of the patient's healthcare team [4; 5; 6; 7]. Mental health professionals are uniquely positioned to address the cognitive, mental, and emotional needs that arise during this period of life-limiting illness [8; 9]. They work to normalize emotions during a difficult time; provide spiritual support; educate about normal physical, emotional, and social changes; and assist in managing practical problems. They also may develop relationships with survivors to provide a continuity of care following the patient's death. Health and mental health professionals work in a variety of settings that address end-of-life care, including health agencies, hospitals, hospice and home care settings, nursing homes, and courts [10].

Both end-of-life and palliative counseling are services provided by clinicians who work with the terminally ill. End-of-life counseling helps patients struggling with death or families struggling with the death of a loved one and may be provided by counselors, therapists, social workers, psychologists, critical care nurses, physicians, hospice workers, and others trained in working with emotions related to death, dying, grief, and bereavement [8].

Health and mental health providers provide services to diverse individuals in a variety of settings, including end-of-life settings, as part of an interprofessional team. In the end-of-life setting, clinicians help dying patients prepare for death with education and supportive therapeutic interventions that address the patient's physical, emotional, social, spiritual, and practical needs [10]. They also help patients and their families navigate the many challenges associated with dying, including end-of-life planning; managing stresses associated with life-limiting illness; assessing patients to develop interventions and treatment planning; advocating for patients' treatment plans; overcoming crisis situations; and connecting them with other support services [11; 12]. Life-limiting illness is mentally taxing and can exacerbate or incite symptoms of anxiety, depression, and trauma and make manifest complex presentations of cognitive decline. Providers can help differentiate between trauma symptoms, mental illness, or medical decline. Reducing mental health symptoms can help patients engage more meaningfully, including in the participation of end-of-life decisions [9]. A cohesive, standardized approach to end-of-life care addresses issues related to the patient, family, caregivers, and the team of healthcare professionals involved in providing care [12].

PSYCHOLOGICAL CONCERNS FOR PATIENTS AT THE END OF LIFE

Psychological suffering is a universal experience for patients at the end of life. It exists on a continuum and has many sources, including grief over anticipated loss or worry about unresolved issues. It is important to assess and differentiate the major types of distress in the dying patient and among their families to effectively treat these sources of suffering.

LIFE-CYCLE ISSUES/RELATIONSHIPS

Psychological responses to the news of a life-limiting illness will vary according to the patient's developmental stage. The young adult, about to become independent, might struggle with being thrust back into dependence upon parents or other adult figures. Parents of young children with life-limiting illness often are consumed with what and how much to tell their ill child, the impact of the child's illness on other siblings, and how to cope with the loss of the child's future. Worries about a spouse or partner are a common concern for older adults. They may feel cheated out of the expected rewards of a life of hard work. Worries about family members are a major issue for most patients at the end of life [13]. One study found that 92% to 97% of patients rated as extremely or very important "feeling appreciated by my family," "saying goodbye to people closest to me," "expressing my feelings to family," and "knowing that my family will be all right without me" [14]. Caregivers of patients with terminal illness also experience significant strains (e.g., adverse impact on work and finances) [15]. Awareness of these life-cycle and relationship issues can help the clinician listen for and inquire about concerns and emotions, normalize patient responses, and explore areas of distress [13].

MEANING AND IDENTITY

Illness comes with practical and emotional challenges that are unique to each patient. The clinician who understands what the illness means to the patient can identify specific concerns, address fears, provide reassurance, and help the patient make plans. Providing patients with the opportunity to share what their illness means can be therapeutic in and of itself [13]. Some patients state that finding meaning in illness is derived from the belief that their life has a purpose that extends beyond self. Others find that meaning enhances their ability to cope with their illness. Still others experience a loss of meaning when faced with life-limiting illness. The patient's ability to find and maintain a sense that life has purpose and meaning is associated with the ability to tolerate physical symptoms of the illness and protect against depression and a desire for hastened death [13]. Meaning and hope are closely allied in patients at the end of life, and hopes for the future reflect the patient's priorities.

Maintaining a sense of self is a high priority among patients with life-limiting illness, yet serious illness has a profound impact on patient self-identity. The physical and psychological losses (e.g., loss of feeling whole, loss of independence, loss of control) present major challenges to the patient's emotional health. Control and independence often are combined in the literature to mean the patient's dignity, or the "quality or state of being worthy, honored, or esteemed" [13]. Preservation of this dignity should be a primary concern of end-of-life care practitioners.

COPING AND STRESS

Confronting a life-limiting illness causes patients to make psychological adjustments to preserve equilibrium. Coping responses can include seeking information about the illness, staying busy to avoid thinking about the illness, resigning one's self to the illness, examining alternatives, and talking about feelings. Effective coping occurs when the patient is able to use active problem-solving strategies. Yet, as illnesses progress, patients' ability to perform cognitive tasks can decline. Some patients cope by defending against or denying the reality of their illness to fend off acute emotional distress. The dynamic tension between coping and defending/denying causes most patients to use a combination of these responses [13]. While denial is a powerful mechanism that helps preserve psychological equilibrium, it can have many negative effects, including refusal to accept death; lost trust in the healthcare team; focus on unrealistic treatment goals; and failure to make legal, financial, and healthcare arrangements [13]. Life-limiting illness represents a major adaptational challenge to patients' learned coping mechanisms. Psychosocial stressors enhance the likelihood that a patient will become depressed. Practical stressors (e.g., relationships, work, finances, legal matters) also can impact patients' ability to cope with their illness. Economic circumstances have been found to be a major stressor for patients and their families, often resulting in a decline in family economic well-being [13]. In one study, 20% of family members of seriously ill adult patients had to make a major life change (including quitting work) to care for their loved one; up to 31% of families lost all or most of their savings while caring for their ill loved one [14].

Post-Traumatic Stress Disorder

Post-traumatic stress disorder (PTSD) may first emerge, re-emerge, or worsen as individuals approach the end of life and may complicate the dying process. Unfortunately, lack of awareness of the occurrence and/or manifestation of PTSD at the end of life can result in it being unaddressed in these patients. Even if PTSD is properly diagnosed, traditional evidence-based, trauma-focused treatments may not be feasible or advisable for patients at the end of life, as they often lack the physical and mental stamina to participate in traditional psychotherapy [16]. Many therapies for PTSD require a longer window of treatment than a typical hospice period. Providers can tailor treatment for short-term interventions or use approaches such as the Stepwise Psychosocial Palliative Care (SPPC) model. The SPPC model is a multidimensional approach, integrating environmental, problem-solving, and other psychosocial interventions with patient advocacy in a patient-centered, time-sensitive manner. It incorporates techniques drawn from evidence-based approaches to PTSD, deploying them in a stage-wise manner appropriate for patients at the end of life [17]. Debriefing interventions have been widely used to treat PTSD and the psychological sequelae of traumatic events, and these approaches can be appropriate in the end of life. Further, antidepressant, antianxiety, and antipsychotic agents may be used to manage intense symptoms. Support groups and psychoeducational approaches are also common approaches, but evidence of their effectiveness in this setting is lacking [13].

ANTICIPATORY GRIEF

Anticipatory grief is the experience of grieving the loss of a patient or loved one in advance of their death [18]. It is a response to impending loss of life, identity, function, hopes, and future plans and is associated with anxiety, depression, hopelessness, and strained communication [19]. Other intense emotions, such as fear and panic, can appear as a result of unexplained symptoms and uncertainties regarding treatment [20]. One study evaluated anticipatory grief in 57 family members of patients with terminal illness receiving palliative care services [18]. Elevated anticipatory grief was found in families characterized by relational dependency, lower education, and poor grief-specific support. These families also experienced discomfort with closeness and intimacy, neuroticism, spiritual crisis, and an inability to make sense of the loss [18]. Patients, families, caregivers, and clinicians all can experience anticipatory grief. Several factors (e.g., spiritual beliefs, quality of relationships, attitudes of close others or colleagues/peers) can influence the anticipatory grief toward either positive or negative outcomes [21].

As a core component of psychological flexibility, acceptance is beneficial in situations in which individuals have little or no control over circumstances, such as when faced with a life-limiting illness. Acceptance becomes an active process wherein the patient acknowledges and opens up to their situation in order to make the most of their remaining time. Although acceptance shares a strong relationship with anticipatory grief, depression, and anxiety, it is independent of anxious and depressive symptomatology and more likely to predict the level of anticipatory grief than anxiety or depression. A higher degree of acceptance is associated with lower anticipatory grief in patients in palliative care [19]. When anticipatory grief is an expression of past or current trauma, it may develop into complicated grief if left untreated. A thorough assessment is warranted to determine if the grief is current or connected to unresolved trauma. Consider treating the initial trauma before the anticipatory grief. At the end of life, if time does not allow for intensive treatment, look to reduce individual trauma symptoms or grief.

ANXIETY AND FEAR

Death is an ever-present reality despite increasingly technologically advanced health systems, longer survivals, and novel curative treatments for life-threatening conditions [22]. Fear of the unknown has been described as the propensity to experience fear caused by the perceived absence of information at any level of consciousness or point of processing [23]. Fear of death and dying is common. In one study, a majority (70%) of participants reported some, a little, or no fear of death and dying; 30% reported more severe fears [24]. A common fear in Western society is that the process of dying will be painful and prolonged and will reduce the quality of life. Other fears associated with death include [25]:

- Fear of separation from loved ones, home, and job
- Fear of becoming a burden to others
- Fear of losing control
- Fear for dependents
- Fear of pain or other worsening symptoms
- Fear of being unable to complete life tasks or responsibilities
- Fear for the fears of others (reflected fear)
- Fear of being dead

It is important that clinicians allow patients a full expression of these fears, without judgment. Patients with anxiety often cannot take in information and may ask the same questions over and over again. They may seek detailed information or not ask reasonable questions. They may be suspicious of the physician's recommendations or not ask questions because of regression or high levels of fear. They may over-react to symptoms or treatments or behave inexpressively and stoically. Their behavior may seem inconsistent and impulsive [13]. An ongoing assessment of anxiety symptoms and anxiety's various presentations is critical to maintaining the patient's mental health. Equally important is that the clinician recognize that anxiety in end-of-life care also may be the result of a pre-existing anxiety disorder or other undertreated symptoms, especially pain. A multidrug treatment regimen in the palliative care setting also can contribute to anxiety [13].

Thanatophobia

Thanatophobia is an extreme fear of death or of the dying process [26]. Fear of death as a disease entity behaves much like initial anxiety due to trauma that leads to PTSD [27]. Evidence suggests that thanatophobia is highest in patients who do not have high self-esteem, religious beliefs, good health, a sense of fulfillment in life, intimacy, or "a fighting spirit" [27]. While anxiety, depressive symptoms, and beliefs about what will happen after death can contribute to a patient's fear, death anxiety does not always follow after a diagnosis of life-limiting illness [27]. It appears to be a basic fear at the core of a range of mental disorders, including hypochondriasis, panic disorder, and anxiety and depressive disorders [28]. Antecedents of death anxiety include stressful environments and the experience of unpredictable circumstances, diagnosis of a life-threatening illness or the experience of a life-threatening event, and experiences with death and dying. Consequences of death anxiety include both adaptive and maladaptive presentations. When encountering death anxiety in a patient, assess for PTSD and the various anxiety disorders to determine whether it is anxiety-based or associated with an underlying trauma [22].

Death anxiety is a central feature of health anxiety and may play a significant role in other anxiety disorders [29]. Exposure to death-related themes has been found useful for the treatment of death anxiety [29]. A 2015 study that assessed death anxiety among patients with life-limiting cancer found that life stage, particularly having dependent children, and individual factors, such as lower self-esteem, increased patients' vulnerability to death anxiety [30]. Depressive symptoms also have been reported in health professionals who work with dying patients [31]. A 2011 study sought to assess the impact of death and dying on the personal lives of clinicians involved in end-of-life care [32]. Early life experiences and clinical exposure to death and dying helped the clinicians to live in the present, cultivate spirituality, and reflect on their own mortality and the continuity of life. Despite reporting accounts of death's ugliness, participants consistently described the end of life as a meaningful life stage [32]. Yet, not all clinicians find that working with patients at the end of life decreases their death-related anxiety, and many will require support and guidance. Burnout and death anxiety can be emotionally devastating, resulting in impaired performance that makes the goal of quality patient care almost impossible to accomplish [33]. All providers of end-of-life care should be reminded that they are not alone and that they can rely on other members of the healthcare team [34].

Education about death also may be helpful. In a 2015 study of 86 human services professionals, participation in a course on death, dying, and bereavement was shown to significantly reduce clinicians' fear of death and death anxiety [35]. In a study that included 42 nurses enrolled in death education programs, some affirmative impacts on the death distress of participants was observed [31]. Younger nurses consistently reported a stronger fear of death and more negative attitudes towards end-of-life patient care, indicating that workplace education might be beneficial [36]. One study investigated whether a brief induction of gratitude could reduce death anxiety [37]. Participants (mean age: 62.7 years) were randomly assigned into one of three conditions (gratitude, hassle, and neutral) and asked to write about a variety of life events before responding to measures of death anxiety. Participants in the gratitude condition reported lower death anxiety than those in the hassle and neutral conditions; no difference was observed between hassle and neutral conditions [37]. Even a temporary relief of death anxiety may help facilitate the making of important end-of-life decisions [37].

PHYSICAL DEPRESSIVE SYMPTOMS VERSUS REPLACEMENT PSYCHOLOGICAL SYMPTOMS

Physical Symptoms	Replacement Psychological Symptoms
Change in appetite	Tearfulness, depressed appearance
Sleep disturbance	Social withdrawal, decreased talkativeness
Fatigue	Brooding, self-pity, pessimism
Diminished ability to think or concentrate	Lack of reactivity, blunting

Source: [43] *Table 1*

PAIN

Pain management is an integral part of palliative care. Pain management in end-of-life care presents unique opportunities in the patient-physician relationship [38]. In some instances, pain can be reduced when the patient has a sense of control and knows what to expect. Patients report feeling empowered by participating in treatment decisions with their physicians [39]. Pain management in children presents special challenges. A multidisciplinary team with an open attitude to differences, listening skills, availability, flexibility, creativity, resourcefulness, and empathy can help the child and his or her family live with the least pain possible [40]. For both adult and pediatric patients at the end life, planning for what could happen is often key. Honest, dynamic discussions about treatment goals and possible options and their respective side effects allows patients and their families to make choices that best fit their wishes [40]. Treating pain at the end of life means caring for all possible manifestations, including physical symptoms as well as psychological symptoms and reduced well-being. This can be achieved by integrating pharmacotherapy with psycho-socio-spiritual interventions [41].

DEPRESSION

Evidence of hopelessness, helplessness, worthlessness, guilt, and suicidal ideation are better indicators of depression in the context of life-limiting illness than neurovegetative symptoms [42]. Yet, diagnosing and treating depression in patients with life-limiting illness remains challenging for several reasons. Typical symptoms of depression (e.g., impaired concentration, anergia, sleep disturbances) also are common symptoms of advanced mental illness, and side effects from medications commonly used at the end of life can mimic depressive symptoms. Delirium occurs in up to 90% of patients at the end of life. A mistaken diagnosis of depression in a patient with hypoactive delirium can lead to a prescription for an antidepressant or psychostimulant, which can exacerbate the delirium. To further complicate assessment, patients frequently do not report or may disguise symptoms of depression at the end of life [43]. It can also be difficult to determine if pharmacotherapy or reflective listening would be the appropriate intervention for the specific patient.

An assessment of available screening tools and rating scales for depressive symptoms in palliative care found that the tool with the highest sensitivity, specificity, and positive predictive value was the question: "Are you feeling down, depressed, or hopeless most of the time over the last two weeks?" [43]. One structured approach was found to help clinicians differentiate major depressive disorder from common physical symptoms of the patient's illness. With this approach, physical criteria for a diagnosis of major depressive disorder are replaced by psychological symptoms (***Table 1***) [43].

Some patients fear that being diagnosed with depression will cause their medical providers to stigmatize them or treat their physical symptoms less aggressively. It may then be necessary to address these issues before the patient will be willing to accept treatment for depression [42]. Left untreated, depression in seriously ill patients can be associated with increased physical symptoms, suicidal thoughts, worsened quality of life, and emotional distress. It also can impair the patient's interaction with family and erode patient autonomy [43]. Although patients with terminal illness often have suicidal thoughts, they are usually fleeting. Sustained suicidal ideation should prompt a comprehensive evaluation [42].

SUICIDALITY

Suicide is a response to two stimuli (i.e., pain and despair) that often overlap. The pain can be physical or psychological, but in either aspect, it consumes the person to the point of seeking release. Despair is the result of believing that there is no longer any hope of having a good life [44]. Uncertainty about how death will unfold and whether they will be able to cope can be intensely stressful for patients. For some, suicide may seem preferable to a protracted period of anxiety, uncertainty about the process of dying, and fear of substantial physical suffering [29]. Diagnosis of severe physical illness (e.g., chronic obstructive pulmonary disease, low-survival cancer, degenerative neurological conditions) is associated with higher suicide risk [162].

A Wish to Die

Despite research efforts to deepen understanding of why some patients with terminal illness express a wish to die, there is consensus that there is more to learn about the factors that influence such a wish [45]. A case study review of patients with terminal cancer diagnoses in palliative care sought to understand possible motivations and explanations of patients who express or experience a wish to die [45]. Intentions, motivations, and social interactions were key to understanding and analyzing a patient's wish-to-die statements. The study focused on motivations, which address the question (from the patient's perspective) of why a wish to die is present. Motivations appear to consist of three layers: reasons (the causal factors), meanings (explanatory factors), and functions (effects of the wish) [45]. Patients' motivations were not able to be explained by a single reason, and, for most, their wish to die had broader significance that reflected their personal values and moral understandings—that is, the "meaning" of their wish to die [45]. Patients reported nine types of meanings, with some appearing more frequently than others. The meanings were shaped by patients' personal experiences, cultural background, and relationships. Patients expressed that a wish to die can be a wish to [45]:

- Allow a life-ending process to take its course
- Let death put an end to severe suffering
- End a situation that is seen as an unreasonable demand
- Spare others from the burden of oneself
- Preserve self-determination in the last moments of life
- End a life that is now without value
- Move on to another reality
- Be an example to others
- Not have to wait until death arrives

Health and mental health professionals cannot properly address a patient's wish to die if the meanings of the wish remain unexplored. Meanings are loaded with moral beliefs that need to be understood and respected in communication, disease management, and care of patients and their families [45].

END-OF-LIFE CONVERSATIONS

Dr. Elisabeth Kübler-Ross is credited as one of the first clinicians to formalize recommendations for working with patients with life-limiting illness. Her book, *On Death and Dying*, identified a gap in our understanding of how both patients and clinicians cope with death [46]. She wrote that it could be helpful if people could talk about death and dying as an intrinsic part of life [47]. In writing specifically about psychotherapy with the terminally ill, Dr. Kübler-Ross stated: "It is evident that the terminally ill patient has very special needs which can be fulfilled if we take time to sit and listen and find out what they are" [47].

Patients who receive the news that they do not have long to live will experience strong emotions accompanied by questions, which can be viewed as opportunities for clinicians to provide answers and open a broader discussion about the end of life. Such questions (and answers) may include [48]:

- *How long have I got?*

  Giving patients a sense of how much time is left allows them to focus on what is important to them. Answers to this question should be clear and as accurate as possible, while acknowledging that exact timeframes are impossible to know.

- *Will palliative care help?*

  When palliative care is appropriate, it supports patients and their families/caregivers by helping them to manage their physical, mental/emotional, spiritual, and practical needs. For patients at the end of life, palliative care is almost always appropriate.

- *What is a "good death?"*

  The answer to this question varies depending on each patient's attitudes, cultural background, spiritual beliefs, and medical treatments. Patients' wishes regarding where they prefer to die (e.g., at home, in hospital) also should be discussed.

- *How will I know that the end is near?*

  The answer depends on the patient and the patient's illness, but events that commonly occur during the dying process include reduced appetite, gradual withdrawal from the outside world, and sleeping more.

Data derived from a national survey of physicians, nurses, social workers, chaplains, hospice volunteers, seriously ill patients, and recently bereaved family members indicate an overwhelming preference for an opportunity to discuss and prepare for the end of life [39]. And while a majority (92%) of Americans say it is important to discuss their wishes for end-of-life care, only 32% have had such a conversation [49]. A majority of patients also prefer that a healthcare provider initiate end-of-life discussions [50]. It is important to note that these discussions do not have to wait for the end of the patient's life. The American Psychological Association has identified four time periods when health and mental health professionals can contribute to end-of-life care [51]:

- Before illness strikes
- After illness is diagnosed and treatments begin
- During advanced illness and the dying process
- After the death of the patient, with bereaved survivors

The end-of-life conversation can be divided into four simple steps [50]:

- Initiate the discussion:
  - Establish a supportive relationship with the patient and the patient's family.
  - Help the patient to appoint a surrogate decision maker.
  - Elicit general thoughts about end-of-life preferences through the use of probing questions.
- Clarify the prognosis:
  - Be direct yet caring.
  - Be truthful but sustain spirit.
  - Use simple, everyday language.
- Identify end-of-life goals:
  - Facilitate open discussion about desired medical care and remaining life goals.
  - Recognize that, as death nears, most patients share similar goals (e.g., maximizing time with family and friends, avoiding hospitalization and unnecessary procedures, maintaining functionality, minimizing pain).
- Develop a treatment plan:
  - Provide guidance in understanding medical options.
  - Make recommendations regarding appropriate treatment.
  - Clarify resuscitation orders.
  - Initiate timely palliative care, when appropriate.

Optimal end-of-life care begins with an honest discussion between clinicians and patients about disease progression and prognosis [52]. Patients and families are sensitive to verbal and nonverbal cues during these discussions. It is therefore incumbent on the healthcare team to train themselves in active listening skills, correct body language, and appropriate empathic responses in order to convey information in a clear, concise, and empathic manner [3]. Physicians also must balance their desire to honor patient wishes and autonomy against the concern of inflicting psychological harm. A 2008 study sought to determine whether end-of-life discussions were associated with fewer aggressive interventions and earlier hospice referrals [53]. The study enrolled advanced cancer patients and their informal caregivers (332 dyads) and followed them up to the time of death, a median of 4.4 months later. Quality of life and psychiatric illness was assessed in bereaved caregivers a median of 6.5 months later. Thirty-seven percent of patients reported having end-of-life discussions at baseline. These discussions were associated with lower rates of ventilation, resuscitation, intensive care unit (ICU) admission, and earlier hospice enrollment. Overall, end-of-life discussions were associated with less aggressive medical care near death, better patient quality of life, and earlier hospice referrals [53].

PATIENT WISHES

What do patients consider important in the process of preparing for the end of their lives? How do their perspectives differ from the values of family members or healthcare providers [39]? A 2015 study was conducted to define what matters most about end-of-life care [54]. Providers and administrators from 14 specialized palliative care teams were interviewed and their responses were analyzed to derive themes depicting the universal essence of end-of-life care. The most predominate theme, mentioned by almost one-half of the respondents, was that the "patient's wishes are fulfilled" [54]. Honoring patient wishes involves identifying what a patient wants through open communication and end-of-life care planning, providing education about options, providing realistic expectations, and allowing patients to have control over decision making [54]. Clinicians can regularly promote communication and education about end-of-life care issues by taking the initiative and discussing each patient's goals for end-of-life care. These goals may change over time and with illness and should be regularly re-evaluated and restated [55]. The patient's cultural and/or religious background can influence end-of-life decisions regarding comfort care and patient management, who can be present at the time of death, who will make healthcare decisions, and where the patient wants to die [56]. Encourage patients to elaborate on their wishes with prompts such as [56]:

- "In my religion, we . . ." This will help patients describe religious traditions to be observed at death.
- "Where we come from . . ." This will help patients share important customs to be observed at death.
- "In our family, when someone is dying, we prefer . . ." This will help patients describe what they hope will happen at death.

BARRIERS TO END-OF-LIFE CONVERSATIONS

Barriers to end-of-life discussions can seriously interfere with the quality of remaining life for patients with terminal illness. Barriers have been identified as originating with patients/families, with healthcare professionals, and within the structure of the healthcare system [57].

Patient-Related Barriers

Patients often avoid discussing end-of-life care with their clinicians and may conceal the full extent of what and how they are feeling, given the scope of end-of-life decisions. Family members and significant others also can complicate end-of-life conversations when they either cannot or will not discuss and accept the advanced nature of the patient's disease or the patient's preferences concerning end-of-life care, or when they overestimate the chance of cure, placing unreasonable demands upon the clinician [57].

GUIDELINES FOR BREAKING BAD NEWS
Formulate a plan. Mentally rehearse the steps of the conversation.
Schedule a time for the discussion to allow all important family members and medical staff to be present.
Meet in a quiet and private setting.
Make arrangements for a professional translator if English is not the first language of the patient/family. Meet with the professional translator before the discussion to discuss expectations.
Preface bad news with a phrase to prepare the patient or family, such as "I wish the results were different, but…"
Communicate clearly and minimize use of technical language.
Let the patient's and family's reactions guide the flow of the conversation. Allow silence.
Be empathetic and acknowledge the patient's/family's emotions.
Determine the family's level of understanding of the illness/situation to assess misconceptions, aspects of news that will be surprising, and their unique information needs.
Determine if the patient or any family members are "numbers people" so they can be provided the type of information with which they feel most comfortable.
Schedule a future meeting to discuss the bad news and options (e.g., in an hour, the next day, the next week).

Source: [159; 160; 161] *Table 2*

Clinician-Related Barriers

Clinicians might avoid end-of-life discussions with their patients because they are reluctant to cause pain or be the bearers of bad news. They may lack the necessary communication training and skills, particularly in the delivery of bad news. They may focus solely on clinical parameters or have medical-legal concerns. Clinicians may fear confrontation and/or disagreement with the patient's family, particularly if they feel ill-prepared for such discussions. They may have a lack of confidence in their own judgment of their patient's true condition [57; 58]. Structured and content-based interventions are needed to ensure that critical aspects of the patient's physical, psychological, and spiritual experience are not excluded from care. For healthcare professionals who are delivering bad news, guidelines for the conversation can help give structure and enhance the confidence of the clinician (***Table 2***).

Organizational Barriers

Barriers to end-of-life conversations also originate within the healthcare system. First, end-of-life discussions are not always considered part of routine care; clinicians are not always given the time and structure for discussing end-of-life issues. Next, coordination of these conversations, which becomes more necessary as the patient's illness progresses, may not be included as part of routine care. When patient care is provided by multiple clinicians across multiple sites, there is no clear directive about which clinician should be responsible for initiating and documenting end-of-life conversations. Last, decreased contact time and fewer long-term patient/clinician relationships inhibit end-of-life discussions [57].

No single clinician can successfully undertake all aspects of this challenge. End-of-life planning should be one component of a series of ongoing conversations that together can assist patients with advanced illness to approach death in accord with their own values and wishes. These necessary discussions can draw on the expertise of several disciplines, and the creation of a new professional role specializing in this area might be considered [57].

MENTAL HEALTH INTERVENTIONS FOR END-OF-LIFE CARE

Shortly after Kübler-Ross began to publish her work, group psychotherapists began developing systematic interventions for patients who were dying. This included Irvin Yalom in the 1980s, who was heavily influenced by existential philosophy. Yalom's work formed the basis for what became supportive expressive group psychotherapy (SEGT). SEGT was originally developed to help patients with metastatic breast cancer face and adjust to their existential concerns (e.g., death, meaninglessness), express and manage disease-related emotions, and enhance relationships with family and healthcare providers. SEGT challenged the thinking that group therapy for patients with terminal illness would be demoralizing [47; 59]. Over the next several decades, research in end-of-life care, patients' end-of-life needs, and the role of mental health professionals in these settings increased [47].

In the late 20th century, physician-assisted death (also referred to as medical aid in dying, physician aid in dying, physician-assisted suicide, or euthanasia) became a topic of interest as researchers sought to understand why some patients with life-limiting illness might want to hasten death [47]. Pain, depression, and physical symptoms were at first thought to be the primary motives behind the desire to hasten death, but literature in the 1990s and 2000s emphasized the psychological and existential correlates (i.e., depression, hopelessness, spiritual well-being) of physician-assisted death. This shift in emphasis led to the development of a number of psychotherapeutic interventions that focused on the psychological and spiritual needs of patients [47].

DIGNITY MODEL/DIGNITY THERAPY

Dignity therapy was one of the first interventions developed for use in end-of-life care [60]. This modality aims to relieve psycho-emotional and existential distress to improve the experiences of patients with life-limiting illness. It offers patients the opportunity to reflect on what is important to them and on what they might want to communicate to loved ones [61]. In dignity therapy, patients are invited to reflect on and later discuss what aspects of their life they most want recorded and remembered—often referred to as their "legacy" [62]. The sessions are audiotaped and guided by a framework of questions (provided in advance) that facilitate disclosure of the patient's thoughts, feelings, and memories. The interview is then transcribed and printed for the patient's review and editing, as desired. Once finalized, the document is given to the patient, who may (or may not) share with friends and family, as desired. In addition to providing a tangible legacy for the patient, dignity therapy helps enhance the patient's sense of meaning and purpose, thus contributing to a preservation of the patient's dignity [47].

A 2011 study revealed that the items most commonly included in legacy documents were autobiographical information, lessons learned in life, defining roles (e.g., vocations, hobbies), accomplishments, character traits, unfinished business, overcoming challenges, and guidance for others [63]. Dignity therapy has been shown to positively affect patients' sense of generativity, meaning, and acceptance near the end of life. Positive impacts on families and caregivers of dignity therapy participants provide additional support for the clinical utility of this intervention [64]. However, dignity therapy is not for every patient with terminal illness. Despite the demonstrated beneficial effects, its ability to mitigate outright distress (e.g., depression, desire for death or suicidality) has yet to be proven [65]. Acknowledged limitations of dignity therapy include having adequate time, space, and means to engage in this intervention. Dignity therapy also cannot be used with patients who are nonverbal or unconscious or with those who have severe cognitive limitations [66]. Further studies are needed to determine whether patients with specific types of terminal illnesses (e.g., oncologic, cardiac, renal, pulmonary, neurologic) or in specific age cohorts (e.g., pediatric, adult, geriatric) benefit more or less significantly in certain domains (e.g., measures of spiritual distress, autonomy, death anxiety) [66].

Life Review

Dignity therapy incorporates the concept of life review, which is the systematic and structured process of recalling past events and memories in an effort to find meaning and achieve resolution of one's life. It is conducted over four sessions in which patients chronologically review their childhood, adolescence, adulthood, and present situation. A health or mental health professional takes notes, but no other end product is produced [67]. Life review can be useful for patients of any age at the end of life [68]. Life review is typically structured around life themes (e.g., being a parent/grandparent, first job, life's work, important turning points) [69]. The process can be either reminiscent or evaluative. It also can teach or inform others and pass on knowledge and experience to a new generation. Life review conducted for therapeutic purposes can help patients cope with loss, guilt, conflict, or defeat and find meaning in their accomplishments [69]. In Western culture, life review may subsequently be shared with family or friends. For patients of other cultures, life review may be more communal and may involve rituals that are an important part of the dying process [34]. Few studies have evaluated therapeutic life review interventions, but preliminary results are promising [67].

Narrative Approach

Narrative practice is built on the assumption that people live multistoried lives. This perspective allows patients to shift from one life story to another to give meaning to their lives and shape their identities. A narrative approach frees the care team from the role of "expert" to the role of "helper" who facilitates patients' creation of personal stories of agency at times of life-limiting illness [70]. Narrative therapy is a practical psychotherapeutic process in which the professional and patient collaborate to deconstruct cultural and personal narratives that negatively affect the patient's sense of resources, efficacy, and identity. Together, clinician and patient discover and enrich positive, empowering, and helpful stories that originate in the patient's previous experiences [71]. Narrative therapy is patient-centered and goal-directed. Goals are to help patients improve their sense of self, separate problematic experiences away from their identity, and see themselves outside problems they may be facing. Narrative interventions can help patients and their families create new meaning of the patient's illness and end-of-life experiences [72].

TERROR MANAGEMENT THEORY

The concept of terror management theory was developed in 1986 and was based upon the work of Ernest Becker, a cultural anthropologist who had written about death and anxiety [73; 74]. Terror management theory is the concept that people feel threatened by a deep and terrifying fear of living an insignificant life that is destined to be erased by death. People cope with the awareness of their mortality in different ways. Some will adopt a worldview that allows them to find meaning, purpose, and enduring significance; others simply avoid thinking about death altogether and instead devote themselves to leaving behind a legacy that will make them "immortal" [74; 75]. While the fear of death can promote insecurity and bias or prejudice (based upon one's worldview), terror management theory helps people use their awareness of death to consciously choose to take positive steps to find meaning in their lives [74]. The awareness of mortality can motivate people to prioritize growth-oriented goals, live according to positive standards and beliefs, and foster the development of peaceful, charitable communities [76].

COGNITIVE-BEHAVIORAL THERAPY

The focus of traditional cognitive-behavioral therapy (CBT) is changing maladaptive thought patterns or perceptions that lead to mood disorders, such as anxiety and depression. But changing maladaptive thoughts to more realistic or positive ones does not always meet the needs of patients with life-limiting illness. These patients have very real fears about suffering and uncontrolled pain and other noxious symptoms, and their fears and thoughts are neither maladaptive nor unreasonable [77]. CBT adapted to end-of-life care can help patients identify "all-or-nothing" thinking and help them recognize that core parts of themselves remain unchanged [78].

Studies demonstrate that palliative care professionals have effectively applied CBT techniques to reduce mild-to-moderate anxiety or depression at the end of life and increase the patient's focus on the quality of remaining life [77; 79; 80]. For example, researchers incorporated elements of acceptance and commitment therapy (ACT) and dialectical behavior therapy (DBT). With ACT, patients learn to stop avoiding, denying, and struggling with their emotions. They instead learn to accept their emotions (and the source), accept their private circumstances, and not allow the circumstances to prevent them from moving forward in ways that serve their chosen values [81; 82]. DBT includes a strong educational component designed to provide patients with the skills to manage intense emotions [83].

MEANING-CENTERED PSYCHOTHERAPY

Meaning-centered group psychotherapy, based on the works of Viktor Frankl, was originally conceived as a group-based intervention for individuals with advanced cancer. Frankl's theory is existential in nature and postulates that the creation of meaning is a primary force of human motivation, even during times of great suffering [69]. The group therapy helps patients identify sources of meaning as a resource to sustain meaning, spiritual well-being, and purpose in the midst of suffering [47; 69]. Meaning-centered psychotherapy was later adapted for use with individual patients [84]. The goals of meaning-centered psychotherapy are to provide support for patients to explore personal issues and feelings related to their illness; to help patients identify sources of meaning; and to help patients discover and maintain a sense of meaning in life, even as their illness progresses [47]. Randomized controlled trials conducted to date, totaling nearly 800 patients, have demonstrated support for meaning-centered psychotherapy in improving spiritual well-being and reducing psychological stress in patients at the end of life [85; 86; 87]. The extent to which the observed results can be attributed to the patient's changes in sense of meaning require further study [47]. Like dignity therapy, meaning-centered psychotherapy has fueled multiple adaptations to target unique clinical populations and settings (e.g., bereaved family members, caregivers) [88; 89; 90].

COMPASSION-BASED THERAPY

Compassion-based therapy is rooted in an evolutionary analysis of basic social and emotional systems that motivate humans to live in groups, form hierarchies, help and share through alliances, care for kin, respond to threats, and seek states of contentment/safeness [91]. Compassion-based therapy can be supportive to those facing end-of-life decision making. It is inextricably linked to the inherent values, needs, and expectations of patients, families, and healthcare providers. Compassion coupled with a collaborative framework sustains patient- and family-centered care in end-of-life practice settings [92].

Compassion-based therapy offers a novel, transdiagnostic approach for reducing psychopathology and increasing well-being. It changes the focus of therapy from individual thoughts or unconscious conflicts toward the development of affiliative and prosocial functioning [93]. One overview of compassion-based therapies found at least eight different interventions (e.g., compassion-focused therapy, mindful self-compassion, cognitively based compassion training), six of which have been evaluated in randomized controlled trials. Compassion-based interventions demonstrated reduced suffering and improved life satisfaction for patients [93]. A systematic review conducted to assess the effectiveness of compassion-based therapy analyzed 14 studies, including three randomized controlled studies [94]. Compassion-focused therapy was effective with depressive disorders and for people who are highly self-critical. Compassion-based therapy is most effective when used in conjunction with other types of treatment and therapy [94].

Being Present

One of the most important therapeutic and compassionate aspects a health professional can offer is their presence. Listening to and allowing patients to express their end-of-life experience is healing and can be more comforting than guidance. One study investigated how palliative care chaplains work with patients at the point when it has been decided to cease active treatment, the point at which patients risk losing hope and falling into despair [95]. The author identified four types of presence in the chaplain-patient relationship that were a result of the chaplain's "being with the patient." Each type of presence (i.e., evocative, accompanying, comforting, hopeful) represented a discernable development in the chaplain/patient relationship—a theory of chaplain as hopeful presence [95].

The effects of educating patients and families about the importance of being present was the goal of a descriptive study that included 19 critical care nurses [96]. The nurses were interviewed to understand their experiences and perceptions about caring for patients and families transitioning from aggressive life-saving care to palliative and end-of-life care [96]. The nurses prioritized educating the family, advocating for the patient, encouraging and supporting the family's presence, protecting families, and helping them create positive memories. The family's presence at the end of life also helped them to process the reality of their loved one's death and make peace with it [96].

OTHER INTERVENTIONS

Researchers and clinicians have developed a variety of other interventions for end-of-life care. One proposed treatment is called short-term life review (STLR). Like dignity therapy, STLR interviews the patient for the purpose of creating a legacy album, but STLR differs from dignity therapy in the substance of the interview. A single published randomized controlled trial has examined the utility of STLR, and little research has been conducted to support the STLR approach. The research that has been published has suggested increases in spiritual well-being, sense of hope, and death preparedness among patients with terminal cancer [47; 97; 98].

Managing cancer and living meaningfully (CALM) is a brief, structured intervention developed for patients with advanced and/or terminal cancer [47; 99; 100]. The focus of CALM is similar to meaning-centered psychotherapy, but it provides less emphasis on spiritual well-being and existential issues due to its longer timeframe [47]. The first large-scale randomized controlled trial of CALM reports that individuals demonstrated significantly greater improvements in depressive symptoms and overall quality of life compared to those who received usual care [101].

Mindfulness

Mindfulness is the practice of paying deliberate attention to experiences of the present moment with openness, curiosity, and a willingness to allow things to be as they are [102]. End-of-life care is, by its nature, rooted in mindfulness through [103]:

- The healthcare team providing steady presence and compassion to the dying patient
- Bringing one's full attention to clinical assessments and supportive interactions and acknowledging what arises during these interactions for patients, families, and clinicians
- Being attuned to the dying and their needs, remaining present with their suffering
- Being genuinely interested in the patient's/family's experiences
- Allowing the full expression of personal experiences, with no attempt to change or fix them
- Cultivating compassion and acknowledging our shared humanity

Spiritual Care

Spiritual care is considered a basic tenet of palliative care and a responsibility of the entire end-of-life care team. Patients who receive good spiritual care report greater quality of life, better coping, and greater well-being, hope, optimism, and reduction of despair at the end of life. Despite these benefits, patients and caregivers often refuse spiritual care when offered. One study that sought to understand this reluctance focused on the effect of education. The authors reported that an educational intervention, which included explaining the services of hospice chaplains and the evidence-based benefits of spiritual support, led to greater patient/caregiver acceptance of spiritual care [104]. End-of-life counselors, therapists, and social workers are uniquely positioned to work with patients to explore the variables that they and their families use as guiding principles when making difficult decisions [105]. This requires assessing the patient's spiritual, religious, and existential needs (i.e., spiritual needs) to provide appropriate interventions [106].

The specifics of how to conduct assessment are determined by individual healthcare organizations but usually consist first of obtaining a spiritual history of the patient and the patient's family. A variety of tools are available. The FICA acronym asks four questions about faith, importance/influence of beliefs, community involvement, and addressing issues of care [107]. The HOPE questions inquire about patients' sources of hope and meaning, whether they belong to an organized religion, their personal spirituality and practices, and what effect their spirituality may have on end-of-life care [108]. Reported barriers to spiritual assessment include clinician lack of time/experience, difficulty identifying patients who wish to discuss spiritual beliefs, and addressing concerns not regarded as the clinician's responsibility. Assessing and integrating patient spirituality into end-of-life care can build trust and rapport and strengthen the patient's relationship with the end-of-life care team [108]. Unaddressed spiritual issues may frustrate attempts to treat other symptoms and adversely impact the patient's quality of life [105].

Art and Music Therapy

Art and music therapists are becoming increasingly available to palliative care teams and are advancing the diverse and unique clinical services available to effectively meet the holistic needs of patients with serious illness [109]. Art can connect with deep psychological and physical pain, allowing the patient to find expression and relief. Studies have found that expressive arts (e.g., paint, clay, textiles, drawing) help patients more effectively deal with ambivalent emotions regarding life-death issues and communicate with their families about their feelings. It helps patients articulate their end-of-life journey beyond language [110; 111].

Art therapy also may be helpful in reducing burnout among end-of-life care providers by enhancing their emotional awareness, fostering meaning-making, and promoting reflection on death. One study found significant reductions in exhaustion and death anxiety in end-of-life care providers who participated in an art therapy program [38].

Music therapy incorporates music chosen by the patient in consultation with a qualified music therapist. The music is often chosen to arouse specific emotions that allow the patient to more easily access, recall, and interrogate memories, with the goal of understanding the role those memories play in the patient's current circumstances [38]. Music therapy also may be an effective adjuvant to pain management therapy [38].

BEREAVEMENT

As stated, Kübler-Ross wrote that it could be helpful if people could talk about death and dying as an intrinsic part of life and emphasized the importance of listening as a way for practitioners to support terminally ill patients and their families when confronting the realities of impending death [46; 47]. She subsequently applied her model to the experience of loss in many contexts, including grief and other significant life changes [112]. This model identified five stages of bereavement—denial, anger, bargaining, depression, and acceptance. Though the stages are frequently interpreted strictly and hierarchically, this was not Kübler-Ross's intention. She expressed that individual patients could manifest each stage differently, if at all, and might move between stages in a nonlinear manner [112]. Her model has received criticism in recent years and many alternative models (some based on Kübler-Ross's model) have been developed [112; 113; 114; 115].

PROLONGED GRIEF DISORDER

The death of a loved one is followed by an intensely emotional and disruptive period that gradually attenuates as the death is comprehended and accepted and its consequences understood (integration). It is a highly stressful period accompanied by the need to attend to a range of things not usually on one's agenda. Most people meet the coping demands and are able to find a pathway through the sorrow, numbness, and even guilt and anger that are part of the normal grieving process. A small minority, however, do not cope effectively. For them, the feelings of loss become debilitating. They do not improve with the passing of time and can become so long-lasting and severe that recovering from the loss and resuming a normal life is impossible without assistance [116]. These people are suffering from prolonged grief disorder, a syndrome in which healing is impeded and acute grief is intense and prolonged.

Prolonged grief disorder is the newest disorder to be added to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM). The disorder was added to the DSM-5-TR in 2022 after several decades of studies that suggested "many people were experiencing persistent difficulties associated with bereavement that exceeded expected social, cultural, or religious expectations" [117]. Prolonged grief disorder often co-occurs with other mental disorders (e.g., PTSD, anxiety, depression). Sleep problems, such as poor long-term sleep, occur in an estimated 80% of people with this disorder [118].

Prolonged grief disorder is defined as "intense yearning or longing for the deceased (often with intense sorrow and emotional pain) and preoccupation with thoughts or memories of the deceased. In children and adolescents, this preoccupation may focus on the circumstances of the death" [117]. In adults, this intense grief must still be present one year after a loss to be considered prolonged grief disorder; in children, the timeframe is six months. Additionally, the individual with prolonged grief disorder may experience significant distress or problems performing daily activities at home, work, or other important areas [117]. It is important for clinicians to differentiate prolonged grief disorder from usual acute grief, as well as depression and anxiety disorders [116]. Risk factors for prolonged grief disorder include past losses, separations that can impact current losses, and a history of depressive illness [115]. Symptoms include [117]:

- Identity disruption (e.g., feeling as though part of oneself has died)
- A marked sense of disbelief about the death
- Avoidance of reminders that the person is dead
- Intense emotional pain (e.g., anger, bitterness, sorrow)
- Difficulty reintegrating (e.g., unable to engage with friends, pursue interests, plan for the future)

- Emotional numbness
- Feeling that life is meaningless
- Intense loneliness and feeling of being detached from others

An estimated 7% to 10% of bereaved adults will experience the persistent symptoms of prolonged grief disorder, and 5% to 10% of bereaved children and adolescents will experience depression, PTSD, and/or prolonged grief disorder [118; 119]. Treatments using elements of CBT have been found to be effective in reducing symptoms [117]. Complicated grief treatment incorporates components of CBT and other approaches to help patients adapt to the loss. It focuses on accepting the reality of the loss and on working toward goals and a sense of satisfaction in a world without the loved one [118]. Research has shown that CBT is effective in addressing sleep problems associated with prolonged grief disorder. CBT also has been shown to be superior in long-term effects to supportive counseling in children and adolescents experiencing symptoms of prolonged grief disorder [119; 120].

Bereavement support groups can provide a useful source of social connection and support. They can help people feel less alone, thus helping to avoid the isolation that could increase the risk for prolonged grief disorder. Despite the existence of effective treatments, people experiencing prolonged grief disorder may not seek help. One study of 86 bereaved caregivers with symptoms of prolonged grief disorder found that only 43% accessed mental health services [121].

PRACTICAL, ETHICAL, AND LEGAL CONSIDERATIONS

Planning ahead provides patients with the most control over their end-of-life care, but not all patients have the opportunity to do so. End-of-life planning for the patient will include knowing the type of care they need and want, knowing where they want to receive this care, knowing what documents (e.g., advance directives) and associated costs to include in planning, and determining who will help carry out their wishes [122].

CAREGIVING AND SURROGACY

The vast majority (80%) of care given to hospice patients is provided by informal and unpaid caregivers who are often family members. They can be responsible for everything from the management of household and finances to medical and personal care. Providing this level of care can contribute to increased stress and health problems [123]. Caregivers often report significant levels of anxiety, depression, and perceived stress as well as poorer physical health and decreased quality of life compared with non-caregivers [124]. In one study, nearly one-third (31%) of caregivers reported moderate-to-high levels of anxiety [125]. Even family members who are not caregivers experience distress and require support. Supporting the growing number of family and other unpaid caregivers is an urgent public health issue. The need for adequate support is especially pressing when older patients and the loved ones who assist them are most vulnerable, as at the end of life [126]. Health and mental health professionals can help the caregiver and/or family by preparing them for their loved one's death, treating symptoms of burnout and stress, and offering grief counseling when desired [127].

Family members may be called upon to make decisions on their loved one's behalf if incapacitation becomes an issue. Ideally, the decision-making process will reflect the patient's physiologic realities, preferences, and recognition of what, clinically, may or may not be accomplished [128; 129]. Being a surrogate decision maker is stressful for many and can have negative emotional effects that last months or years [130]. Frequent tension can occur between the desire to respect the patient's values and the fear of responsibility for a loved one's death, a desire to pursue any chance of recovery, and a need to ensure family well-being [131]. Counseling for the surrogate both during and after the decision-making process can be beneficial.

Shared decision making also has been found to be beneficial. Healthcare providers can encourage decision makers to involve other family members. They can repeat relevant information in simple language, prompt them to think about what the patient would or would not want, and frequently remind them that everything that can be done is being done [132]. Support for the surrogate should foster respect for patient preferences and values and help reduce guilt about decisions made following the patient's death [132]. An ideal surrogate will participate in collaborative decision-making with care providers. If a surrogate avoids communication or requests interventions that are clearly not considered in the patient's best interest, counseling should be provided. If counseling is unsuccessful, replacement of the surrogate should be considered [133]. Family members who reside far away and who are not designated as decision maker also can create difficulties by trying to undo, contest, undermine, or alter decisions made by local family members who have long been involved in the patient's care. These disagreements can compromise the ability of the patient's healthcare team to provide quality care. These limits of formal advance care planning have led some practitioners to assert that informal conversations with patients' significant others are most critical to end-of-life planning [134].

Current practice frequently fails to promote patient goals. This is an area for future research and improvement. In the meantime, clinicians should encourage patients to document their own goals, including treatment preferences and preferences regarding how they want decisions to be made for them during periods of decisional incapacity. This is achieved through advance care planning [135; 136].

ADVANCE CARE PLANNING

Advance care planning is widely considered an essential step toward achieving end-of-life care that is consistent with the preferences of dying patients and their families. Advance care planning typically includes a living will and a durable power of attorney for health care, which enable patients to articulate and convey their treatment preferences while they are cognitively intact [136]. Advance care planning documents also can include do not resuscitate (DNR) orders, medical/physician order for life-sustaining treatment (MOLST/POLST), and informal documents of preference or other healthcare proxies. Ideally, these documents reflect discussions among the patient's family, surrogate, and healthcare provider about the patient's preferences for health care in the context of serious illness [129]. Advance care planning is considered an essential step for achieving a "good death" in which physical pain and emotional distress are minimized and the patient's and family members' treatment preferences are respected [134]. Advance care planning is associated with greater use of palliative care among dying patients, lower medical expenditures at the end of life, and less distress among patients and patients' families.

Race and socioeconomic disparities in rates of advance care planning have been documented. Policy advances (e.g., Medicare reimbursement for doctor-patient consultations) may increase rates of planning among populations who may not have access to professionals who encourage such preparations [136]. Health and mental health professionals can assist families in the process of preparing advanced care planning documents. Being a mediator in advance care planning conversations can provide clarity for patients and family members about the patient's wishes regarding death [137].

ETHICAL/LEGAL ISSUES

Ethical concerns and legal considerations can influence counseling at the end of life. Health and mental health providers are on the frontline supporting and guiding the patient and the patient's family through the dying process.

Autonomy

Autonomy, as viewed from the perspective of patients at the end of life, includes two core domains: "being normal" and "taking charge" [138]. These two domains account for the circumstances and clinical realities of people with life-limiting illness and allow clinicians to better understand their needs. Autonomy is, however, not just a concern when making choices of treatment for end-of-life care but also when supporting patients in their daily lives and active preparations for dying. This support can help relieve the patient of stress and the fear of being a burden to family [138]. When a patient expresses a fear over the loss of autonomy, it is important for clinicians to determine the source of the fear. Common sources of such fear include fear of becoming physically dependent on life-supporting technology; fear of losing independence; and fear of loss of engagement in meaningful activity. Often, the patient is simply expressing a desire to preserve self-determination regarding end-of-life care and planning [45]. The healthcare team respects patients' autonomy by giving them the information needed to understand the risks and benefits of a proposed intervention, as well as the reasonable alternatives (including no intervention), so that they may make independent decisions [139].

Distributive Justice

Distributive justice is the fair, equitable, and appropriate distribution of healthcare resources. It requires impartiality in the delivery of health service. Issues of distributive justice encountered in healthcare settings include the allotment of scarce resources, care of uninsured patients, conflicts of interest based on religious or legal grounds, and public health and safety issues. Despite these constraining influences, healthcare providers have an ethical obligation to advocate for fair and appropriate treatment of patients at the end of life [140; 141].

Beneficence

The principle of beneficence is the obligation of health and mental health professionals to act in the best interest of the patient [137]. Beneficence also includes preventing and avoiding harm and defending the most useful intervention for the patient [140; 141]. Beneficence is fundamental to dilemmas about the discontinuation, withholding, or withdrawal of medical treatment [137]. When wishes about end-of-life care are not known or cannot be communicated by the patient, end-of-life decisions should be made by the healthcare team as a result of consultations with the family or healthcare proxy [137].

Nonmaleficence

Nonmaleficence is the principle of refraining from causing unnecessary harm (i.e., first, do no harm) [137]. It also refers to the moral justification behind an intervention that might cause some pain or harm; harm is justified if the benefit of the intervention is greater than the harm to the patient and the intervention is not intended to harm [137]. The emphasis in nonmaleficence is on relieving the symptoms that harm the patient [142]. Health and mental health providers can exercise nonmaleficence by having an understanding of the moral principles and ethical codes governing end-of-life care. They can prevent undue harm by being as knowledgeable as possible about impending illnesses through relationships with the interprofessional team [137].

CULTURALLY COMPETENT CARE AT THE END OF LIFE

The clinician/patient discussion about end-of-life care is often a challenge and one that can be further complicated when the patient's cultural norms differ from that of the clinician. As discussed, values of medical care emphasize autonomy and individual rights to make life choices [143]. The Patient Self Determination Act of 1990 ensured that those rights are protected. This includes the rights to treatment choices, informed consent, truth-telling, open communication with healthcare providers, and control over the individual's own life and death [143; 144]. However, these core values may be in conflict with the values of many ethnic and culturally diverse groups in the United States and may lead to health disparities, fragmented care, inadequate or inappropriate symptom management, miscommunication with the patient and family, and a difficult and poor death for the patient [143].

Enhanced cultural competency in end-of-life issues continues to be identified as a need for clinicians who provide care for patients at the end of life [143]. Healthcare providers should understand and recognize the specific influences that culture has on a patient's behavior, attitudes, preferences, and decisions about end-of-life care. It is important to note that a patient's identification as a member of a particular ethnic group or religion does not necessarily mean that the patient or patient's family adheres to beliefs associated with that ethnicity or religion [143]. Other factors (e.g., age, race, sex, ethnicity, health status, religion) also can influence how patients approach the end of life, and their cultural and religious backgrounds influence their definitions of and perceptions about what constitutes quality of life, suffering, and pain [145].

Other areas of end-of-life care that vary culturally include the method used for communicating "bad news," the locus of decision making, and attitudes toward advance directives and end-of-life care specifics [146]. In contrast to the emphasis on "truth telling" in the United States, it is not uncommon for healthcare professionals outside the United States to conceal serious diagnoses from patients, because disclosure of serious illness may be viewed as disrespectful, impolite, or even harmful to the patient. The emphasis on patient autonomy may conflict with the patient's preferences for family-based, physician-based, or shared family-physician-based decision making. Lower rates of completion of advance directives by patients of some ethnic backgrounds suggests a distrust of the healthcare system, healthcare disparities, and underutilization of health care [146; 147; 148].

An assessment should be made of how acculturated a patient and family are, their language skills, and whether an interpreter is needed [143]. The clinician should assess for [149]:

- Openness/willingness of the patient/family to discussing/accepting the diagnosis, prognosis, and death
- How decisions are made and what influences decision making (e.g., age, gender, hierarchy, quality of interfamily communication)
- What does physical pain mean and how should it be managed?
- Is there spiritual pain? Does the patient desire the help of a spiritual advisor? Does the patient/family want time and space for praying, meditation, and other rituals?
- The relevance of religious beliefs regarding the meaning of death
- How the body should be handled following death

The clinician also can take advantage of available resources, including community or religious leaders, family members, and language translators [149]. It is important to note that using professional interpreters for patients and with limited English proficiency will help ensure quality care. Convenience and cost lead many clinicians to use "ad hoc" interpreters (e.g., family members, friends, bilingual staff members) instead of professional interpreters. However, professional interpreters are preferred for several reasons. Several states have laws about who can interpret medical information for a patient, so healthcare professionals should check with their state's health officials about the use of ad hoc interpreters [150]. Even when allowed by law, the use of a patient's family member or friend as an interpreter should be avoided, as the patient may not be as forthcoming with information and the family member or friend may not remain objective [150]. Children should especially be avoided as interpreters, as their understanding of medical language is limited, and they may filter information to protect their parents or other adult family members [150]. Individuals with limited English language skills have actually indicated a preference for professional interpreters rather than family members [151].

Also important is the fact that clinical consequences are more likely with ad hoc interpreters than with professional interpreters [152]. A systematic review of the literature showed that the use of professional interpreters facilitates a broader understanding and leads to better clinical care than the use of ad hoc interpreters, and many studies have demonstrated that the lack of an interpreter for patients with limited English proficiency compromises the quality of care. The use of professional interpreters improves communication (errors and comprehension), utilization, clinical outcomes, and patient satisfaction with care [151; 153]. One review of case studies regarding professional interpretation noted that "patients with limited English proficiency in the United States have a legal right to access language services, and clinicians have legal and ethical responsibilities to communicate through qualified interpreters when caring for these patients" [154].

Culturally competent counseling for patients at the end of life begins with understanding their differing cultural, religious, and other important influential factors. It involves listening to and learning about patients' varying attitudes, preferences, and practices in order to integrate them into an appropriate plan of care [155]. Clinicians should treat all patients with dignity, respecting their rich cultural traditions and incorporating them into the plan of care. It means communicating with the patient and the patient's family in advance about how the plan of care is aligned with their beliefs, concerns, values, and preferences [145]. To deny the expression of different cultural worldviews in the context of end-of-life care would be to rob patients of the security and serenity that their cultural beliefs give them when faced with uncertainty and fear [156].

CONCLUSION

Health and mental health professionals provide services to diverse individuals in a variety of settings, including end-of-life settings, as part of an interprofessional team. In the end-of-life setting, these professionals help dying patients and their families prepare for death with education and supportive therapeutic interventions that address the patient's physical, emotional, social, spiritual, and practical needs using a patient-centered, culturally sensitive approach [10; 157]. Clinicians can regularly promote communication and education about end-of-life care issues by taking the initiative and discussing each patient's goals for end-of-life care [55]. The better informed the patient and family are, the more likely their decisions about end-of-life care will reflect their beliefs, values, and the best interests of the patient. This means having difficult conversations. All professionals should work to become comfortable with the most uncomfortable of topics. This work is not done alone. It is essential to lean on and consult colleagues and other members of the care team. End-of-life care often involves interactions between caregivers and various professionals (e.g., physicians, nurses, social workers, mental health professionals, clergy) who have distinct roles in preparing caregivers for the patient's death [158]. Aligning on key concepts and approaches to care can help to ensure that the best possible care and support are given at the end of life.

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