Introduction to Hospice and Palliative Care

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KEYWORDS

- Palliative care • Hospice • Multidisciplinary team-based
- Primary versus specialty palliative care • Prognostication • Disease trajectory
- Communication • Advance care planning

KEY POINTS

- Palliative care improves quality of life for patients and their families facing the complexities associated with life-threatening illness through the prevention and relief of suffering.
- Palliative care is most effective early in the course of illness in conjunction with curative care to help manage physical, psychological, and social needs of patients/families.
- The primary care physician who has the trust of the patient/family and an ongoing relationship is well suited to provide primary palliative care.
- Using effective prognostication skills in the care of patients with serious illness fosters the establishment of realistic patient/family focused appropriate goals of care.
- Empathetic communication of prognosis is an essential skill required to care for patients with chronic complex illness, especially as they approach the end of life.

Our nation's population is aging, and people are living with more chronic complex illnesses. These conditions now include augmentative concerns, such as cognitive decline and frailty. The incidence of such concerns is greater than ever before. The number of Americans reaching age 65 and older is projected to more than double from 46 million today to more than 98 million by 2060. These individuals are now approximating 15% of the population, but they will be nearly 24% by the latter part of the century.[1]

Along with the growth of our aging population, the cultural and social diversity of individuals in our country continues to increase. The aforementioned adds a further dimension to the complexity needed for us to deliver patient-centered care, especially

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as these people near the end of life. The demands on our health care system to care for these individuals will put a tremendous burden on providers, and the financial impact will be staggering. Many of these patients with multiple complex illnesses are elderly and account for numerous emergency department and hospital admissions as well as high utilization of intensive care units (ICU). It is estimated that approximately 5% of our patients consume 60% of our health care spending.[2] Much of this is spent on their last year of life and often on their last hospital admission.[3] In addition, the number of individuals living with Alzheimer disease is likely to triple from the current 5 million to nearly 14 million by 2050, adding significantly to costs and caregiver burden.[1]

The Landmark SUPPORT Study that helped define Palliative Care as a specialty was published in 1996. The study highlighted several shortcomings in the delivery of end-of-life care in our country. It noted that only 47% of physicians knew when their patients preferred to avoid cardiopulmonary resuscitation. It found that 46% of do-not-resuscitate orders were written within 2 days of death. Thirty-eight percent of patients who died spent at least 10 days in an ICU. Family members reported moderate to severe pain at least half of the time for 50% of conscious patients who died in the hospital.[4] Unfortunately, in the more than 20 years since the publication of this study, there has not been significant improvement in these statistics. This study emphasizes the need for further enhancements of patient care and medical education in the field of palliative care.

There is some recent evidence that does show positive trends toward more appropriate end-of-life care. The changes especially relate to hospice and ICU utilization. Compared with data from the year 2000, Medicare patients who died in 2015 had a lower likelihood of dying in an acute care hospital. There was also a stabilization of their ICU use during their last month of life. This was accompanied by an increase and then a decline in health care transitions during the last 3 days of life. The decrease in care transitions included a decrease in hospitalizations and transfers from nursing homes.[5]

The utilization of hospice care as well as hospice length of stay has increased as well. This data provides evidence of further improvements in end-of-life care and utilization. Patients who died while receiving hospice care increased from 21.6% in 2000 to 50.4% in 2015. The number who died receiving 3 days or less of hospice care decreased from 9.8% in 2009 to 7.7% in 2015.[5]

The Institute of Medicine 2015 Report, Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life, clearly documents the state of health care in the United States and the need to increase advance care planning. It also documents the need to expand access to quality palliative care for all. The report highlights the importance of delivering person-centered, family-oriented end-of-life care. It highlights the need for clinician-patient communication, advance care planning, professional education, and development. Consistent with these areas of focus, the report addresses the need for changes in policy and payment systems to support high-quality end-of-life care, public education, and engagement.[6]

There is clear and convincing evidence that palliative care is an effective specialty of medicine. When used early and appropriately, it can assist patients and families with difficult decision making. It also can improve symptom control and lower cost. It can thus effectively improve patient and family satisfaction and possibly even prolong survival.[7,8]

The increased focus on comfort, communication, and the patient-centered team-based approach of palliative care is associated with improved outcomes. This information has been substantiated by data associated with improvements in patient quality of life and family caregiver outcomes. It fosters patient and caregiver satisfaction and improves the quality of care delivered at the end of life.[7,8] A recent meta-analysis published in 2018 reviewed the 6 major studies associated with costs and the utilization of palliative care consultation in hospitalized patients. The study clearly shows significant reductions of cost, which were most notable in patients with cancer, those with significant comorbidities, and when palliative care was initiated within 3 days of the hospital stay.[9] In 2010, studies began to show the benefits of providing palliative care alongside aggressive care. The studies began to look at life expectancy as a result of this intervention. Patients with metastatic non–small cell lung cancer who received palliative interventions along with standard care had significant improvements in both quality of life and mood. The previous individuals also received less aggressive care as they neared the end of life yet also lived longer.[10] Subsequent meta-analysis studies examining survival benefits have failed to substantiate these benefits. However, they do continue to show improved quality of life and lower symptom burden.[8]

The Kaiser Family Foundation published a report in November 2017 titled, “Serious Illness in Late Life: The Public’s Views and Experiences.” The report reviewed the state of public opinion concerning serious complex illness and end-of-life care. It highlights several facts, including the point that many elderly are aware of the complexities associated with serious illness and are worried about what may happen to them. Only a third of individuals older than the age of 65 have reported talking to their families regarding their concerns and plans about end of life. Only a third have documented their plans in a written document. Of note, very few who have a plan, have shared them with their doctor, thus leading to confusion at end of life.[11] The report once again highlights the need for further education of both the public and the medical profession. Medical professionals need to provide their patients with a better understanding of the complexities associated with chronic illness and the importance of advance care planning and effective communication.

A 2011 public opinion study on palliative care revealed that many patients are worried about their treatment options regarding serious illness. They are concerned about the time and quality of communication with their doctors. Few individuals are aware of the benefits of palliative care, but after being provided with education on the scope of services available, more than 90% of respondents agree that palliative care is important. They state that they would consider it for a loved one, and services should be available for all.[12]

Palliative care is a field of medicine that delivers patient-centered care for individuals and their families. It addresses the suffering for all brought about by serious illness. It can thus be helpful at all stages of the disease trajectory. Palliative care can be helpful at any time after the diagnosis of a life-limiting condition but is often most effective early in the course of the disease in conjunction with curative care, to help manage the physical, psychological, and psychosocial needs of the patients and their families. When cure is no longer possible, relief of suffering becomes predominant and is the foundation of palliative care as both a specialty and a philosophy of care. It is essential that palliative care is differentiated from end-of-life care, which plays a small yet significant role for the palliative care provider (**Fig. 1**).

There are many misconceptions about palliative care, including the belief by many clinicians that palliative care should only be offered when there are no more curative treatments available. In the political arena, palliative care has been associated with death squads and euthanasia. Nothing could be further from the truth. The goal of palliative care is to help improve and optimize the quality of life for the patient. It

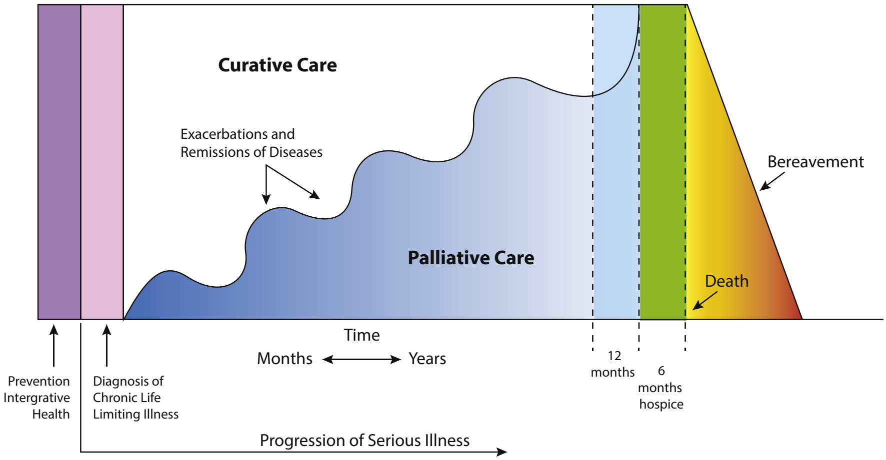

Fig. 1. Continuum of care model for patients with serious illness. (*Adapted from* Lynn J, Adamson DM. Living well at the end of life: adapting health care to serious chronic illness in old age. Santa Monica: RAND; 2003; with permission.)

aims to support patients and their families and to address their complex needs during this difficult time. Effective communication with patients and families helps patients manage the many complex issues they face at this point in life. It helps to restore an appropriate balance between comfort and curative care.

Palliative care uses a multidisciplinary team-based approach to care. It addresses the major priorities of relieving suffering, establishing goals of care, and managing physical symptoms. It also integrates the psychosocial, cultural, spiritual, and existential complexities of coping with a chronic complex disease as one nears the end of life (Fig. 2).

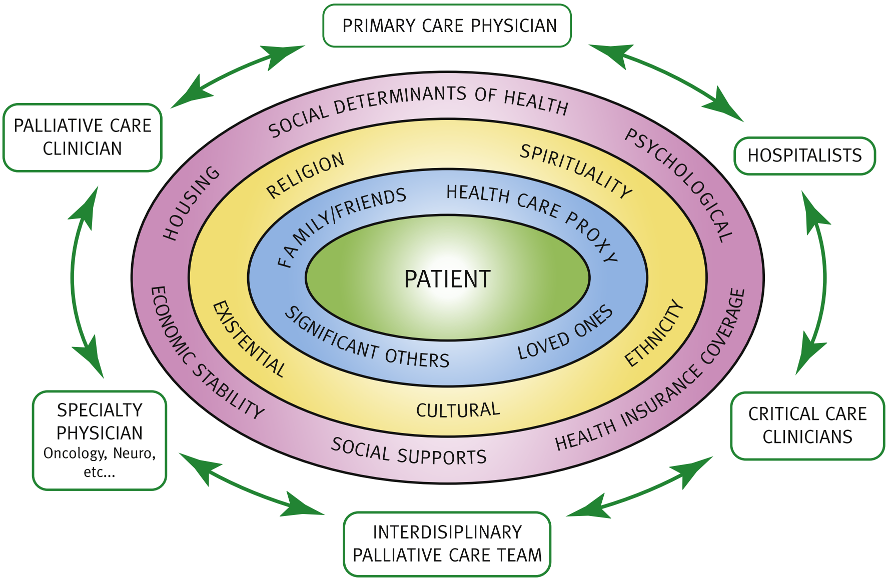

Fig. 2. The complexities of palliative care.

DEFINITIONS

There are many definitions of palliative care, and the World Health Organization definition of palliative care states the following:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care carries out the following:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- Will enhance quality of life and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.[13]

CENTERS FOR MEDICARE AND MEDICAID SERVICES DEFINITION

"Palliative care" means patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.[14]

Center to Advance Palliative Care Definition

Palliative care is specialized medical care for people with serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a specially trained team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.[15]

HOSPICE VERSUS PALLIATIVE CARE

Palliative care is an approach to care for patients and their families that focuses on comfort and quality of life and can be used at any time after the diagnosis of a chronic complex or life-limiting illness. Emphasis is placed on the physical, psychosocial, and spiritual needs of patients. A multidisciplinary team-based approach to care uses primary care and specialty physicians as well as palliative care specialists and a supportive ancillary team. Patients using palliative care do not need to have a terminal diagnosis and may continue to pursue curative therapy, such as chemotherapy and organ transplantation.[16]

Hospice is both a philosophy of care and an insurance benefit that focuses on patients who have a life expectancy of less than 6 months. Patients give up their regular insurance benefit and give up the ability to continue curative therapy and in its place choose aggressive comfort care, which places an emphasis on quality of life rather than quantity and on preparing patients and their families for the end of life. The loss of the ability to continue curative treatments is one of the major barriers to the selection of hospice care.[17] Patients must meet disease-specific criteria and be certified by the primary provider and hospice medical director to have a prognosis of less than 6 months if the disease follows its expected trajectory. The hospice benefit usually includes two 90-day periods followed by an unlimited number of 60-day periods each of which must be certified by the hospice medical director.[18] There are no penalties to patients, families, or providers if the patient outlives the 6-month period. Hospice care is most often given in the home but can also be provided in an inpatient setting, including hospital, nursing home, or stand-alone hospice facilities. Hospice requires a multidisciplinary team-based approach to care and relies on families, friends, and other loved ones as well as volunteers to assist in quality care. Included in the hospice benefit are bereavement services, which assist patient's families for 13 months following the death of the patient.

SCOPE OF SERVICES/DOMAINS OF CARE

Palliative care is rapidly expanding as a specialty in the United States and throughout the world. More than 1700 hospitals currently have palliative care consultation services, and many are now expanding to the ambulatory care setting.[19] Palliative care can be delivered in many settings. In the hospital, there are palliative care consultations services, inpatient units, and ambulatory care programs. Skilled nursing facilities can also offer palliative care consultation services as well as hospice levels of care. Home-based palliative care programs now exist in many communities for patients who continue to pursue aggressive care and are not ready for the transition to hospice (**Box 1**).

Palliative care addresses both pain and nonpain symptom management, but most important, as a field of medicine, requires strong interpersonal and communication skills to address the needs of patients and their families suffering from serious critical illness. Strong prognostication skills are essential to frame difficult discussions related to goals of care, advance care planning, and future treatment plans. Being able to assist in the navigation of the health care system using a team-based approach to care is paramount to successful care and enhanced patient satisfaction.

The identification of which patients are appropriate for palliative care services requires knowledge of the disease trajectory, severity of symptoms and disease burden, and the complex and multifactorial needs of the patient and families. The discussion of when palliative care should be discussed is one of the clinician's most difficult decisions in patient care. An old saying that "it's never too early until it's too late" is most appropriate in the palliative care setting. For this reason, the optimal time for discussion of palliative care services is at the time of diagnosis of chronic complex or serious life-threatening illness (**Box 2**).

TEAM-BASED APPROACH

Palliative care is delivered most optimally and comprehensively when using a team-based approach to care. Because of the complexity of medical, psychosocial, and

Box 1
Domains of palliative care

- Assessment and management of pain
  - Opioids, nonopioid analgesics, adjunctive pain medications
  - Use of cannabinoids
  - Rehabilitation, physical therapy, massage
  - Interventional pain management
  - Psychological approaches (guided imagery, biofeedback)
  - Integrative approaches (manual medicine, acupuncture, reiki, meditation)
  - Surgery, palliative chemotherapy, and radiation therapy
- Nonpain symptom assessment and management
  - Dyspnea, nausea, vomiting, diarrhea, constipation, pruritus, hiccups, cough, hemoptysis, secretions, mucositis, xerostomia anorexia, cachexia, weight loss, fatigue, fever, lymphedema delirium, anxiety, depression, insomnia, anticipatory grief, complicated grief
- Prognostication
- Assessment of treatment goals of care
- Communication skills
  - Delivering bad news
  - Conducting goals of care family conference
- Address spiritual, religious, existential, and cultural aspects of care
- Psychosocial issues
- Advance care planning discussions
  - Health care proxies, surrogate decision maker, durable power of attorney for health care
  - Living wills, medical directives, POLST/MOLST forms
- Determination of decision-making capacity
- Discussions surrounding informed consent/shared decision making
- Assessment and treatment of palliative care emergencies
  - Impending spinal cord compression, airway obstruction, superior vena cava syndrome, intractable pain, cardiac tamponade, massive hemorrhage, hypercalcemia, seizures, intestinal obstruction, urinary retention, deep venous thrombosis, and pulmonary embolism
- Care of the actively dying patient
- Discussing issues related to artificial hydration and nutrition (AHN) including the insertion of PEG tubes
- Palliative procedures
  - Paracentesis, thoracentesis, interventional pain management, malignant wound care
- Withdrawal and withholding treatments
  - Mechanical ventilation, noninvasive positive pressure ventilation
  - Dialysis, AHN, automatic implantable cardioverter-defibrillator
- The use of palliative sedation
- Medical futility or other ethical and legal complexities
- Interdisciplinary team assessment and care coordination
- Assure continuity of care across settings
- Discharge planning and disposition
- Bereavement

Box 2
Patients appropriate for palliative care

- Anyone with a prognosis of less than 3 years
- Advanced chronic complex serious medical illness
  - Congestive heart failure, chronic obstructive pulmonary disease, end-stage liver disease
  - End-stage renal disease before starting and for those on dialysis
  - Advanced, noncurable or metastatic cancer at the time of diagnosis
  - Neurodegenerative disorders: dementia, amyotrophic lateral sclerosis, Parkinson disease, advanced HIV/AIDS
  - Status post cardiac arrest/anoxic brain injuries
  - Serious trauma and fractures in advanced age
  - Significant head trauma, intracerebral hemorrhage, or strokes
- Critically ill patients, those requiring prolonged ICU care, or return to ICU from floor level care
- Care of the actively dying patient
  - Elderly patients with increased dependence, frailty, debility, failure to thrive, or pressure injuries
- Patients with multiple comorbidities
- Uncontrolled pain or other nonpain symptoms
- Patients with frequent emergency department visits and hospitalizations or readmissions
- Patients with developmental and intellectual disabilities
- Potential organ donor or recipient candidates
- Requests for hastened death, euthanasia, or physician-assisted suicide
- Homebound, nursing home, or hospice patients
- Poor functional or performance status or recent significant decline
- Conflicts in medical decision making or patient and family conflict about treatment decisions
- Medical futility or other ethical and legal complexities

spiritual issues, significant time is needed to appropriately deliver patient care. Additional time needs to be spent with patients as well as their significant others. Family/significant other meetings to address goals of care and advance care planning can often take hours. The previously stated can be difficult under the current hospital and office-based visit time constraints. The interdisciplinary team works collaboratively to coordinate all aspects of care. They deal with the multiple complexities of chronic illness and dying. They need to be especially adept at dealing with patient and family suffering. The team approach helps improve care as well as communication between the patient, family, and caregivers. The team approach also provides a benefit to the caregivers. It affords them a forum for supporting each other. The team members may often be dealing with their own family and self-care issues. Their personal, emotional, and psychosocial care needs coincide with their work in dealing with patients and families who have serious illness and may be facing death (Box 3).

PRIMARY VERSUS SPECIALTY PALLIATIVE CARE

With the aging of our population and individuals living longer with chronic complex illness along with a greater acceptance of hospice and palliative care in general, there is a current and projected severe nationwide shortage of palliative care

Box 3
The interdisciplinary team

Patient, family, and friends
Primary care physician
Specialty physicians
Hospitalists
Critical care clinicians
Palliative care consultants
Physicians assistants and nurse practitioners
Nurses
Social workers
Psychologists
Dietitians
Chaplains
Physical therapists
Occupational therapy, speech, and language pathologists
Physical medicine and rehabilitation
Wound care specialists
Clinical pharmacologists
Music/art therapy
Administrators
Ethics consultant
Community health workers
Volunteers

providers. The current US supply of hospice and palliative medicine (HPM) specialists is inadequate. Given the current training of 325 hospice and palliative fellows each year, it is estimated that there will be a pool of professionals that will range from 8100 to 19,000. Simultaneously, it is estimated that the United States will require up to 24,000 physicians to meet our nation's needs in the future.[20] It is thus clear that to meet the needs of our patients, one must rely on specialty HPM physicians and to meet the needs of the patients one must rely on primary care as well as specialty clinicians to provide primary palliative care services. All clinicians must be trained in basic principles of palliative care. They must be afforded training in essential palliative care clinical skills. The skills should include basic pain and symptom management, psychosocial support, accurate prognostication, and the communications skills needed for advance care planning. Clinicians must be provided with hands-on skills needed to provide patients and their significant others with unwelcomed news and in some cases bad news. They must be trained in how to conduct patient/family meetings wherein they will present and help define the goals of care.

The primary care physician who has the trust of the patient and family as well as a continuing relationship is well suited to provide basic palliative care. The best place to address the complexities brought about by a serious chronic illness is in the setting of the primary care physician's office. A nonemergent setting is optimal for these discussions. Referral for specialty palliative care may be necessary for more complex pain and symptom management. Specialty palliative care can also provide skilled intervention to address severe psychosocial distress, discussions about conflicting goals of care as well as addressing family conflict. Optimal patient outcomes occur when the primary care provider continues as an integral member of the multidisciplinary team even when specialty services are needed.

PROGNOSTICATION

The cornerstone of care in patients with chronic complex illness is the establishment of realistic patient- and family-focused appropriate goals of care. A prognosis is a prediction of possible future outcomes of a treatment or a disease course based on medical knowledge and experience.[21] To establish appropriate goals of care, it is essential to formulate a prognosis that is as accurate as possible. Patients and their families may then be able to set reasonable expectations of care and prioritize what is important to them during the course of their illness. Prognostication helps patients begin to think seriously about end of life and afford themselves insights into their dying. It assists in the patient and significant other decision-making process and facilitates clinicians in their decision making. Patients and families want to know the prognosis because plans will differ greatly if the prognosis is days, weeks, months, or years. Being able to establish a prognosis of less than 6 months is necessary to determine hospice eligibility for most Medicare and Medicaid beneficiaries. A late referral to hospice care is sometimes related to delays in formulating an accurate prognosis. This result may make it more difficult for patients and families to make difficult decisions about their treatment goals until very close to the end of life. Again, an earlier introduction to palliative care allows for time to plan for end of life.

Acquiring appropriate prognostication skills is essential for both the primary care physician and the palliative care specialist. What is formally known as the clinician prediction of survival when used alone has been shown to be inferior to standard prediction models used in palliative care.[22,23] Most studies show that physicians are accurate in survival predictions in only 20% of cases. They will most often overestimate prognosis. This occurs in more than 60% of the cases. This inaccuracy is even greater if the clinician has a closer relationship with the patient. This is often described as primary or general physician bias. It has been demonstrated to overestimate survival by 3- to 5-fold.[24] This inaccuracy has a negative impact on patient and family communication, trust, and the setting of appropriate goals of care.

Accurate prognostication requires a thorough patient evaluation, which includes a complete history and physical examination. The process includes an analysis of prior treatment successes and failures, a review of laboratory and other diagnostic studies as well as discussions with primary care, specialty, and critical care clinicians. Enabling patients and families to establish appropriate and attainable goals is best achieved by integrating several components. These components include a discussion of the natural progression of all diseases as well as specific disease trajectory models. Integrating prior treatments and the utilization of general indicators of health and disease-specific prognostication tools along with sound clinical judgment will help solidify prognostication accuracy.

Subsequently, all medical decision making should be guided by the established care goals and, as the illness progresses, goals will frequently change based on the changing clinical condition and therefore changes in prognosis. The fluctuating course of medical illness, which limits the sensitivity of accurate prognostication, is one of the major challenges associated with selecting patients that are appropriate for palliative care. To be as accurate as possible, the clinician must be educated on the art and science of prognostication. Unfortunately, this important skill has not been emphasized in modern clinical medicine, research, and education.[21] Meticulous clinical judgment using all available information, the clinical picture, and an accurate assessment of the patient's reasonable goals of care is essential for the formulation of an as accurate prognosis as possible.

THE DYING TRAJECTORY

The dying trajectory refers to changes in health status over time as a patient approaches death. The dying trajectory is an important component of prognostication. A century ago, most people died suddenly and often unexpectedly from acute illnesses, such as infections, or from accidents or childbirth. With advances in medical science, individuals are living longer and suffering from multiple complex medical illnesses. Some diseases, such as cancer, take a more predictable course with a steady decline over the last months of life. The chronic organ failure trajectory in progressive conditions, such as congestive heart failure and chronic obstructive pulmonary disease, are more difficult to predict because the disease is associated with repeated exacerbations and remissions.[25] Each decompensating event will often lead to a hospitalization or emergency department visit with the patient not returning to the same functional level as before the illness. The difficulty with these conditions is that it is often never known which episode will lead to a terminal event. Those suffering from dementia or the frail elderly suffer from a slow but steady decline over several years and will sometimes have a sudden demise from cardiac events, infections, or falls. A limitation of the dying trajectory model is that many patients with serious illness often have multiple comorbidities, and many conditions may be associated with sudden death, such as the patient with cancer with a hypercoagulable state suffering a pulmonary embolism (Fig. 3).

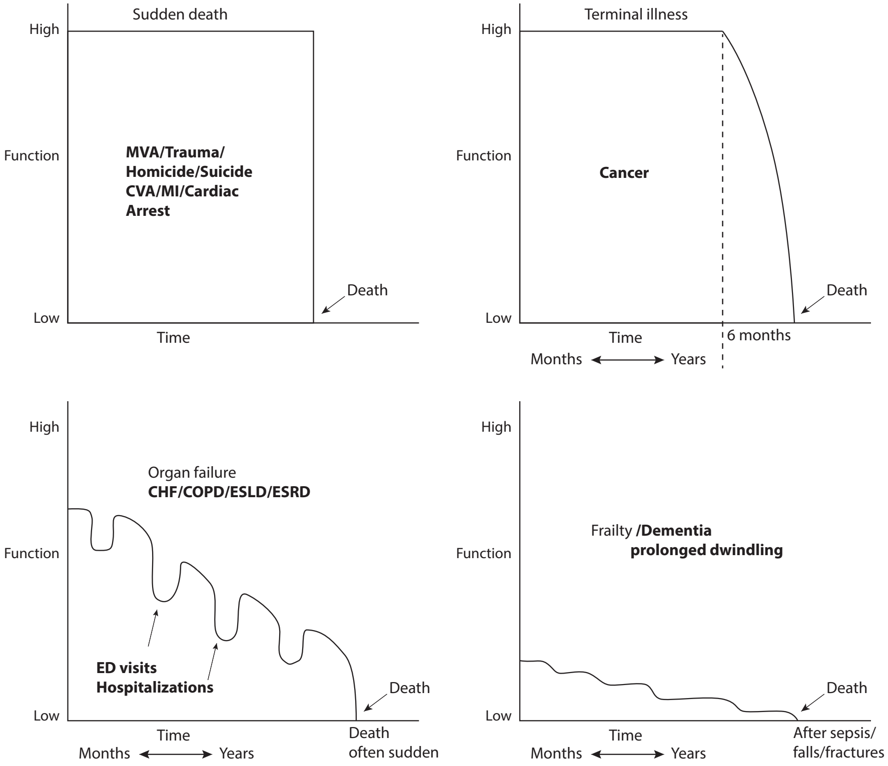

Fig. 3. Proposed trajectories of dying. CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; CVA, cerebrovascular accident; ESLD, end-stage liver disease; ESRD, end-stage renal disease; MI, myocardial infarction; MVA, motor vehicle accident. (*Adapted from* Lynn J, Adamson DM. Living well at the end of life: adapting health care to serious chronic illness in old age. Santa Monica: RAND; 2003; with permission.)

FUNCTIONAL ASSESSMENT

The assessment of performance status and functional ability has been studied extensively in palliative care and has been shown to be the single most important predictor of survival. There are numerous scales that have been developed, including the Karnofsky performance status (KPS), the palliative performance scale (PPS), and the Eastern Cooperative Oncology Group–Performance Status (ECOG-PS). The PPS is an advancement of the KPS and evaluates ambulation, level of activity, evidence of disease, ability for self-care, oral intake, and level of consciousness. The scale has been shown to have good overall interrater reliability as well as being a useful predictor of mortality.[26,27] The ECOG-PS is an important scale that uses similar parameters and is used extensively by oncologists to determine prognosis, disease progression, and the appropriateness of further cancer treatments, including surgery, chemotherapy, or radiation therapy.[28] Each tool is important for monitoring functional decline as the patient's condition worsens and is a strong prognostic predictor of survival. Decreases in appetite and the ability to eat especially when combined with a weight loss of greater than 10% is a specific and compelling separate indicator of survival. When combined with patient- and disease-specific data, functional assessment is an essential tool in managing all patients as they approach the end of life.

LABORATORY CHANGES

Monitoring of basic laboratory tests as patients chronic conditions worsen may be helpful in conjunction with other clinical data in estimating prognosis. Elevations of calcium, B-type natriuretic peptide, white blood cell counts, as well as inflammatory markers, such as C-reactive protein, are helpful in documenting worsening of disease. Anemia as well as deterioration of liver function and renal function can be helpful as a general indicator of worsening of health.[29] Decreases in cholesterol and albumin are seen commonly as patients deteriorate and are good indicators of declining nutritional status. An albumin of less than 2.5 or rapidly decreasing levels indicate a declining prognosis. A study of frail elderly revealed that a lipid level of less than 160, associated with a decrease in hemoglobin and albumin, was associated with an 84% 1-year mortality versus a 7% mortality in those with normal laboratory findings.[30] Laboratory studies, especially when trended over time, are a helpful resource when used along with functional assessment and disease-specific scales.

COMMUNICATING PROGNOSIS

Patient and family engagement using shared decision making is the cornerstone of effective patient care. The communication skills required to coordinate care for the complex needs of patients with advanced chronic illness is paramount to improved quality of life as well as patient and family satisfaction. Being able to empathetically communicate prognosis is an essential skill needed for all primary and specialty physicians who care for patients with chronic complex illness especially as they approach the end of life. Communicating news related to serious illness as well as death and dying is one of the most difficult tasks for all clinicians. The communication skills needed for delivering bad news and conducting a goals-of-care family meeting is a tool that must be taught at all levels of medical education. There is clearly a need for improved communication between patients, families, and providers. Numerous studies of end-of-life patients and their families show that improved communication is clearly related to enhanced patient and family satisfaction with their care.[7,8] Patients prefer direct and empathetic communication that is neither overly optimistic nor overly pessimistic and includes a practical exchange of information so that the most appropriate decisions can be made. Patient-centered, goal-oriented shared decision making is the cornerstone of effective communication at the time of diagnosis of complex serious medical illness. Numerous benefits of effective communication include encouraging healing relationships, more accurate exchange of information, and better management of uncertainty.[31] There are numerous barriers to effective communication, including culture, religion, spirituality, unrealistic expectations, lack of experience with death and dying, and a lack of trust in the health care system.[32] Personal goals as one approaches end of life often vary greatly and can sometimes be conflicting. It is essential to elicit what is most important to the patient. Is it the longest quantity of life versus the best quality of life, to be pain and symptom free and surrounded by loved ones? Honest, explicit, and open discussions with patients and families concerning their values, hopes, fears, burdens, and treatment preferences will best enable the establishment of realistic and attainable goals of care (Fig. 4).

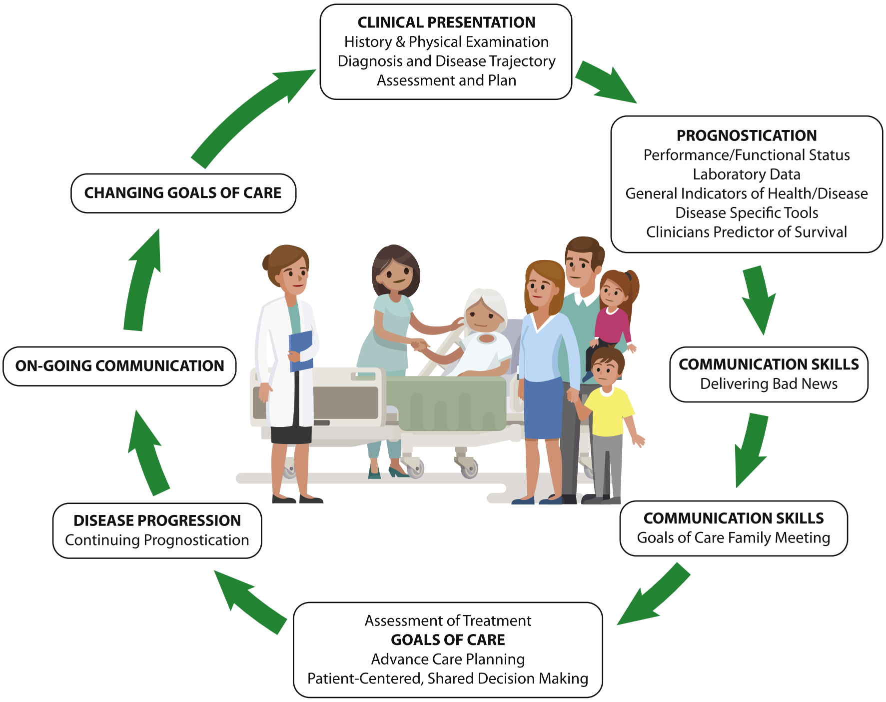

Fig. 4. Palliative goals of care model.

ADVANCE CARE PLANNING

Advance care planning is making decisions about the care you would want to receive if you become unable to speak for yourself. The decisions are yours to make, regardless of what you choose for your care, and the decisions are based on your personal values, preferences, and discussions with your loved ones. Advance care planning involves getting information of what types of life-sustaining treatments are available and deciding what kind of treatments are best for you should you be diagnosed with a life-limiting illness.[33] It is then essential that you share your decisions with your loved ones and ensure that they understand your wishes should you not be able to speak for yourself. It is essential to appoint a health care proxy or surrogate decision maker to make decisions for you if you cannot make them for yourself. The final step is putting this information into a written document that clearly expresses your wishes. Assigning a decision maker by completing a health care proxy or durable power of attorney for health care will ensure the correct person is making decisions for the patient. A written advance directive form, such as a living will or medical directive, should specify what type of treatment a patient does or does not want as they progress through the disease trajectory of chronic serious life-limiting illness. A Physicians Orders for Life Sustaining Treatment (POLST)/ Medical Orders for life Sustaining Treatment (MOLST) form is an actionable medical directive that clarifies what types of life-sustaining treatment are desired at the end of life. This type of document is most appropriate in the last years of life. Medicare and other insurance companies now reimburse physicians for advance care planning in the office and hospital setting. The encounter must be face to face with the patient or their surrogate decision maker. The advance care document does not need to be completed but requires documentation of the discussion regarding the patient's wishes and future treatment desires. There are numerous resources for advance care planning, including "The Conversation Project,"[34] "Respecting Choices,"[35] and the "Serious Illness Conversation Guide"[36] to name a few. Primary care providers who have long-term continuity and trustful relationships with patients and their families are best suited to assist in the advance care planning discussion.

SUMMARY

As noted, listening to a person's thoughts and wishes may lead us to learn that there might be a fate worse than death, such as to live in pain, to suffer alone, to be a burden to others, and especially, to live without dignity. Palliative care is a philosophy of medicine and a medical specialty aimed at meeting the complex needs of patients and families at the most difficult times of their lives. The palliative approach to care addresses the major priorities of relieving suffering, managing physical and emotional symptoms, and establishing realistic goals of care. Palliative care focuses on the psychosocial, cultural, spiritual, and existential complexities of chronic complex serious medical illness as one nears the end of life. Strong prognostication skills need to be accompanied by effective and empathetic communications skills. The physician needs to engage patients and families using patient-centered shared decision making. These components are essential and become the cornerstone of effective patient care. The overall goal of palliative care is to improve the patient's, significant other's, and family's quality of life by using an individualized comprehensive and multidisciplinary approach to care. Primary care physicians play an essential role in the delivery of essential palliative care services. It is crucial that the primary care provider remains an integral part of the team, even when there is a need to augment the service with a specialty level of providers. As a team, they maintain oversight throughout the disease trajectory, including hospice, end-of-life care, and bereavement.

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