# 23

# End-of-Life Care

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## Chronic Disease and the Change in How People Die

Throughout human history, death was an unpredictable and often random event that could strike anyone at any time at any age. People were used to being around death, which was usually due to infection, injury, starvation, or childbirth. In the last century, with the dramatic increase in life expectancy, the experience and expectations around death have changed. Advances in science have medicalized death to the point where it is seen as a failure of the system and something to be fought all the way to intensive care, if needed, and with aggressive therapies such as chemotherapy and life support, even if these interventions provide little if any chance of restoring meaningful life. The experience of death has been taken out of the home and placed in hospitals.

As the population ages and medical technology continues to develop, people question the utility and morality of prolonging life at all cost, especially when their loved one is not restored to health and has poor quality of life. Along with these concerns comes the advent of new attitudes such as increased intolerance of pain and suffering and the right to personal autonomy and self-determination. These demographic and cultural trends have brought awareness and preferences for a "good death" to the forefront, and the experience and circumstances of how people die is seen as a significant issue in health care for society and a crucial aspect of population health [1].

Most people now die from chronic diseases such as heart disease, stroke, cancer, and diabetes, all of which are treatable at some stage. It is often not clear when it is time to stop treatment and the default has been to keep going. Death from chronic disease is rarely sudden and tends to follow one of three trajectories [1]. Those with cancer tend to be relatively stable and then enter a period of rapid decline. Those with organ failure tend to have ups and downs against a background of steadily declining function, while people with frailty and dementia tend to slowly dwindle (Fig. 23.1). These trajectories occur in the background of emotional, physical, and spiritual changes for the patient and his or her family. Addressing these issues through compassionate palliative care is considered by many governing, legal, and religious organizations to be a human right [2].

## Birth of Modern Hospice and Palliative Care Movement

The modern hospice movement began with three women who brought public and professional attention to the plight of dying people and their families [3]. Cicely Saunders, considered the founder of the modern hospice movement, promoted teaching and research on the dying based on her clinical work at St. Christopher's Hospice in London, which she established in 1967. One of her protégés was Florence Wald, then dean of Yale's School of Nursing, who studied with Saunders and launched the American hospice movement, establishing Connecticut Hospice in 1974. Elisabeth Kübler-Ross brought the concept of death with dignity and her theory of the five stages of grief to the attention of the public with her international best seller *On Death and Dying*, published in 1965 [4]. Awareness of the tension between what technology is capable of and what is ethical caused further reflection in the American public by highly publicized cases such as that of Karen Ann Quinlan, a young woman in a vegetative state who was granted the right to have life support withdrawn based on evidence of what her personal wishes had been, leading to the widespread use of advance care planning. In 1990, the US Supreme Court affirmed the

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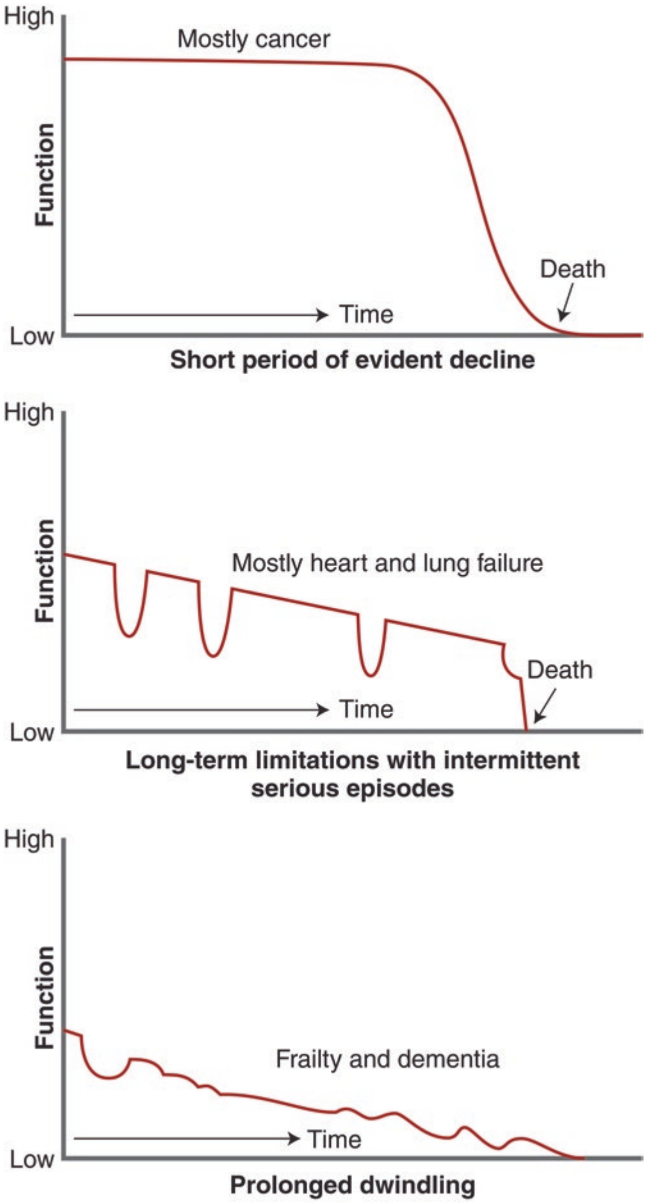

**Fig. 23.1** Trajectories of death (Modified from Lynn and Adamson [1])

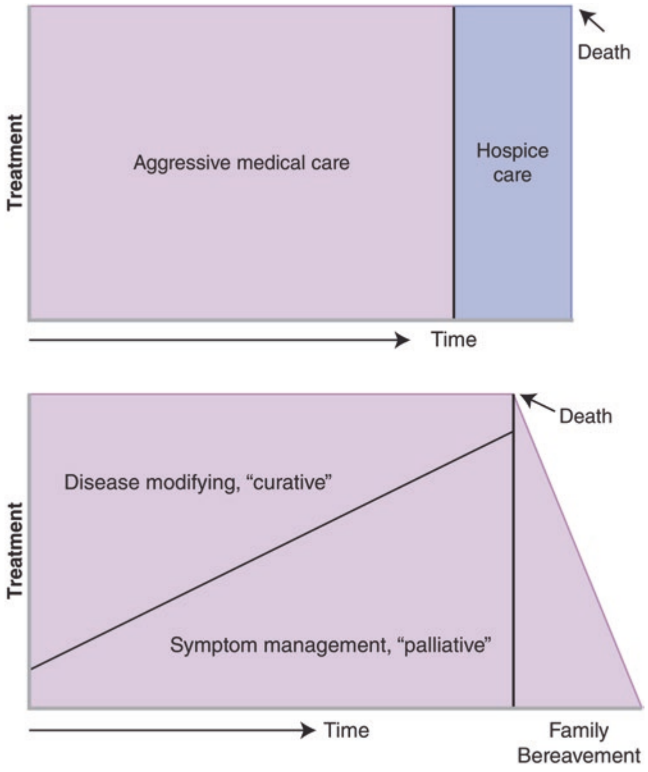

**Fig. 23.2** An older model (*top*) drew a sharp distinction between curative care and hospice, a line that patients and families were often reluctant to cross. A newer model (*bottom*) allows the integration of palliative care into the care continuum earlier in the disease process (Modified from Lynn and Adamson [1])

right of a patient to refuse unwanted treatment in the case of Nancy Cruzan, another young woman in a persistent vegetative state. This led to a federal law, the Patient Self-Determination Act, which requires medical institutions to counsel patients about their right to state their wishes regarding end-of-life care, should they become unable to do so themselves. Congress further advanced the discipline with the passage of a Medicare hospice benefit in 1982, made permanent in 1986. While well-intended, this provision drew a sharp distinction between curative care and comfort care, as patients crossed from one payment program to the other. Patients and their families were reluctant to cross that line and usually did so late in the course of the illness. This lead to growth in palliative care which attends to patient suffering across the disease spectrum and allows for the integration of care that manages distressing symptoms while curative care efforts are still ongoing, whether the patient is expected to live days or years (Fig. 23.2) [1].

In 2006, the American Board of Medical Specialties approved hospice and palliative medicine as a subspecialty with the first board certification examination offered in 2008. The Accreditation Council for Graduate Medical Education (ACGME) standardized the program requirements for fellowship training with an emphasis on compassion, guidance in decision-making, and competence in reducing the burden of serious illness and supporting the best quality of life possible for the patient and the family through the course of the disease [5].

Palliative care and hospice have evolved into distinct roles (Table 23.1). Palliative care focuses on improving quality of life for people who are living with any serious illness, using a multidisciplinary approach that addresses pain, other symptoms, and psychological and spiritual distress [6]. It is provided in addition to any ongoing curative treatments. Hospice is more specific in that it provides palliative care to dying patients in the last months of life. Patients are eligible

**Table 23.1** Distinction between palliative care and hospice

| | Palliative care | Hospice |
|---|---|---|
| Providers | Multidisciplinary team of physicians, nurses, social workers, chaplains | Multidisciplinary team of physicians, nurses, social workers, chaplains, volunteers |
| Goal | Improve quality of life | Improve quality of life, relieve suffering, address emotional and spiritual issues of dying |
| Eligibility | Patients of all ages with any chronic illness; life-prolonging and disease-related treatments may continue | Patients of all ages who are expected to live less than 6 months; curative treatments are foregone |
| Place of care | Hospitals, outpatient, nursing homes, home | Home, assisted-living facilities, nursing homes, residential hospice facilities, inpatient hospice units |
| Payment | Provider fees covered by Medicare Part B; hospital care covered by Medicare Part A or commercial insurance; flexible bundled payments under Medicare advantage, managed Medicaid, Accountable Care Organizations, and other commercial payers | Medicare hospice benefit; standard hospice benefit from commercial payers is usually modeled after Medicare; Medicaid (varies by state); medications and supplies are covered for illnesses related to the terminal illness |

Adapted from Kelley and Morrison [6]

and appropriate for hospice care if their prognosis of survival is 6 months or less and no further curative treatments will be sought. When hospice care was established in the USA in the 1970s, most of the enrolled patients had cancer. Today, cancer diagnoses account for 36% of hospice admissions with the majority now due to other diseases, with the top four non-cancer diagnoses being dementia (15%), heart disease (15%), lung disease (9%), and stroke or coma (6%) [7].

## Decisions and Communication

Health-care providers must determine which patients are suitable for palliative care or hospice and then support patients and families with an approach that allows for management of difficult symptoms, limitation of futile medical procedures and practices, psychosocial support, and assistance with decision-making. Timely transition to palliative care optimizes the likelihood of appropriate care but often does not occur until late in the disease process without time to allow for the full provision of supportive services [8]. Almost a third of patients referred to hospice use those services for 3 days or less, and nearly half of these short hospice stays come from acute care hospitals after a mean hospital stay of almost 8 days [9]. Another indicator of the challenges involved in deciding to transition to hospice care is the finding that 12% of people who died in hospice care had three or more hospitalizations in the last 90 days of life, including time in an intensive care unit. While even 1 day of hospice services may be viewed as beneficial by the family of a dying patient, it is not certain that this is consistent with patient preference, improved quality of life, or a reduction in resource utilization. While some late referrals to hospice occur because physicians did not communicate this option or prognostication is difficult, a third of patients who were referred for short stays in hospice had a sudden change in their medical condition or had previously refused hospice so were not able to be referred to hospice at an earlier point in time [10]. The health-care system should be prepared and able to provide short-term hospice care.

Timely referral to end-of-life care is dependent on the establishment of a prognosis, which will always be an inexact science. Identifying who is suitable for palliative care can be challenging even for physicians with years of clinical experience. Though disease trajectories are better understood, there is uncertainty in predicting what will happen to an individual patient. Some have proposed that providers ask themselves “Would I be surprised if my patient were to die in the next 12 months?” as a guidepost as to whether a discussion of palliative care should be initiated [11]. The introduction of palliative care should not be seen as an abrupt cessation of curative treatment, rather it is an approach that is gradually adopted as the disease progresses [12]. Given the challenge of predicting life expectancy, palliative care should be offered based on a desire for comfort care, rather than on prognostication. Estimating life expectancy in people with advanced dementia is particularly challenging [13, 14]. Patients with dementia who are reasonably functional and patients with strokes are especially likely to survive more than 6 months after enrollment in hospice [15]. These cases contribute to the significant minority of patients (10–15%) referred to hospice who survive for more than 6 months [7, 15]. In 2011, the US Centers for Medicare and Medicaid Services (CMS) required that patients who have been enrolled long-term in hospice have a face-to-face visit by a physician or nurse practitioner to ensure that they continue to meet eligibility criteria. These visits must occur to determine the continued eligibility of that patient prior to the 180-day recertification. This requirement for more scrutiny has not increased hospice discharges [16].

Physicians should not feel like they are abandoning patients when they consider palliative care, rather they are fulfilling their responsibility to provide compassionate, sensitive, and timely care for patients who are hopelessly ill or dying [17]. It can also be reassuring for physicians to realize that patients and their families benefit from earlier initiation of palliative care which can improve quality of life, allow for the patient’s wishes to be followed, reduce family stress, and even prolong survival [18, 19]. Provision of end-of-life care that is consistent with a patient's goals and values is an important part of high-quality care and a priority for the health-care system [20].

Once a physician identifies the patient who is likely to benefit from palliative care, the next step is to effectively communicate with patients and families. While this may be uncomfortable for physicians, it is a skill that can be taught [21]. A structured approach may be helpful, with clinicians trained to identify patients with serious illnesses who are appropriate for palliative care and taught to use a guide for advance care planning conversations with the patient and family that can then be documented [22].

There is a range of styles in decision-making, from paternalism, where the doctor knows best and makes the decisions, to a merely informative model, where the physician objectively provides information but otherwise plays a relatively passive role, leaving the decisions to the patient and family [23]. Neither of these styles is ideal. The medical evolution away from a physician-centered style toward patient-centered care, where the patient's perspective is considered, is applicable [24]. The best approach is usually a shared decision-making process using "enhanced autonomy," where deliberation and negotiation occurs and includes the physician's expertise and experience while also considering patient and family preferences and perspectives [25]. Still, there are times when a physician may override expressed values and use reasonable medical judgment when an intervention such as cardiopulmonary resuscitation is futile [26].

## Decision Aids and Documentation

Explaining complicated medical information and dealing with the emotions involved in contemplating death, all in the setting of uncertainty, are challenging for clinicians, families, and patients. Discussions regarding palliation, hospice, and goals of care can be assisted by decision support tools [27]. Decision aids provide a framework for discussion that leads to informed decisions consistent with the patient's values, needs, and wishes [28]. In advance care planning, they can encourage truthful discussions with physicians, improve patient knowledge and awareness of choices, increase ease of decision-making, reduce decisional conflict, reduce futile care, increase comfort care, and improve documentation [29]. Video decision aids that are complimented by discussions with the nursing home staff improve communication regarding the disease process, comfort measures, and goals of care and reduce hospital transfers without an adverse effect on survival [30].

Most states have Internet sites that provide forms that are variably known as Medical Orders indicating Scope of Treatment or Physician Orders for Life-Sustaining Treatment (MOST or POLST) and do not resuscitate (DNR) forms which increase the documentation of treatment preferences and reduce the likelihood of medical interventions and hospitalization [31, 32]. The state of Oregon reduced hospitalization rates and intensive care use in the last 30 days of life and increased the likelihood of death at home since initiating its POLST program, though this is attributable not only to the form but also to educational efforts, a statewide registry, regulation that allows EMS providers to honor the POLST form, and readily available home hospice services [33]. Other established materials are available online at www.agingwithdignity.org/five-wishes and www.acpdecisions.org.

Patients should be encouraged to name a health-care proxy and ensure that person is aware of care preferences. These wishes can be conveyed through a living will which spells out a person's directives regarding medical treatment should he or she become incapacitated. Public interest in such documents is high and forms are readily available on the Internet. Still, patients cannot accurately predict the circumstances around the closing days of their lives and what medical interventions might be available, and the effect of written directives is limited by inattention to them and by consideration of other priorities over the patient's autonomy [34]. Living wills should thus be complimented by the designation of another person to interpret the patient's preferences and make decisions for them. Known variably as a surrogate, proxy, or health-care power of attorney, this person should consider the patient's written or oral advance directives and then choose treatment options that align with those preferences [35]. When the directives are not clear for the situation at hand, the proxy will use substituted judgment according to what they think the patient would want or make a decision on what they perceive as being in the patient's best interest.

## Ethical Issues

The right of an individual to refuse care is well established and based on the principle of autonomy and the right of self-governance. Many landmark cases in the legal system have confirmed this based on ethics and constitutional law.

### Withdrawing, Withholding, and Refusing Care

Withdrawal of life-sustaining medical support is a common event in the intensive care unit, and guidelines have been developed that address the medical, legal, cultural, and ethical considerations that are involved [36, 37]. This can be morally justified as omission rather than an act meaning that the practice lets someone die and is not an active act of killing [38]. There is general legal and ethical consensus that withdrawal is equivalent to withholding treatment. In practice, they are different in that doctors may withhold information about interventions they judge to be futile while withdrawal of care requires a discussion with patients and families [39].

## Physician-Assisted Death

Though a majority of Americans believe individuals have a right to end their own lives in the face of suffering and pain with no hope of improvement, the public is closely divided on the issue of physician-assisted suicide, which is the practice where a doctor is aware of the patient's desire to end his or her life and provides that patient with the means (usually a medication) to do so [40]. Euthanasia is the act of ending the life of a hopelessly sick and suffering individual at the patient's request. Currently, euthanasia or physician-assisted suicide is legal in the Netherlands, Belgium, Luxembourg, Colombia, and Canada [41]. Physician-assisted suicide, excluding euthanasia, is legal in five US states (Oregon, Washington, Montana, Vermont, and California) and Switzerland. In these jurisdictions, between 0.3% and 4.6% of all deaths are reported as euthanasia or physician-assisted suicide. In no jurisdiction is there evidence that vulnerable patients are more likely to die in this manner compared to the general population.

## Palliative Sedation

The concept of terminal sedation was first described in 1991 and is the practice of drug-induced sedation for painful symptoms that are difficult to control [42]. Many expressed concern that this practice was "slow euthanasia" or mercy killing [43, 44]. To clarify that the intent is not to end the life of the patient but to provide medications for the express purpose of limiting awareness of intractable and intolerable suffering in a patient who is dying, the term palliative sedation is now widely accepted. Multiple organizations have issued guidelines that state that palliative sedation is different from euthanasia [45–48]. This has not resolved the ongoing controversy about the practice. While it is acknowledged that the intent is sedation, there may be "mission creep" based on beliefs regarding aging, dependence, suffering, and dying [49]. Palliative sedation is seen by some as a diminishment of the hospice philosophy of a holistic and caring approach to human suffering and a turn toward the medicalization of end-of-life care.

## Quality of Care

Public health and modern medicine provide the opportunity for many people to live longer lives than probably ever in human history, whether the person is productive and functional or afflicted by significant chronic illness. In the latter case, supporting the survival of people who have advanced illness can be viewed as prolonging the dying process with unnecessary physical and emotional suffering [50–53]. Families, patients, and society may worry about prolonged emotional and financial costs and a medicalized, impersonal, and painful dying process with loss of control and the use of unnecessary and futile interventions [54, 55]. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) documented many shortcomings in end-of-life care, including poor communication and misunderstanding between physicians and patients regarding resuscitation preferences, which led to increased consumption of hospital resources [56, 57]. These findings have fostered efforts to improve care of seriously ill and dying patients including in the public arena where written advance directives are widely accepted and most people are aware of the right-to-die movement. The medical community has responded in kind and the maturation of palliative care as a medical specialty has created a growing evidence base for practices that improve care. The National Consensus Project (NCP) for Quality Palliative Care espouses the value of high-quality palliative care and the importance of delivering it in an organized manner [58]. The NCP consists of multidisciplinary organizations with professional roles in hospice and palliative care and uses consensus to address policy and quality issues for end-of-life providers, caregivers, consumers, and payers. Their guidelines are available at www.nationalconsensusproject.org. Other collaboratives such as the Global Palliative Care Quality Alliance, Palliative Care Quality Network, and the project Educate, Nurture, Advise, Before Life Ends (ENABLE) enhance and standardize the quality of palliative care for persons with serious illness [59].

The PEACE project is a CMS-initiated effort to develop hospice and palliative care quality measures including measurements of physical, psychological, and social aspects of palliative care [60–62]. The Measuring What Matters (MWM) project convened a panel of experts who recommended the most important, valid, and clinically relevant indicators for measuring the quality of hospice and palliative care [63]. The final ten indicators are listed in Table 23.2. Designing workable ways to collect, report, and respond to these quality measures within the complex and busy environment of palliative care delivery is challenging but will need to become routine [64]. Other countries including Australia [65], Belgium [66], and the Netherlands [67] are developing quality measurement projects and will contribute to ongoing quality improvement efforts.

**Table 23.2** Top-ranked quality indicators for hospice and palliative care

| | Quality indicator |
|---|---|
| National Consensus Project domain | Each indicator has an established measure or one in development |
| Structure and process of care | *Comprehensive assessment* including documentation of prognosis; functional assessment; screening for physical, emotional, and psychological symptoms; assessment of social and spiritual concerns |
| Physical aspects of care | *Screening for physical symptoms* (pain, dyspnea, nausea, and constipation) |
| | *Pain screening and management* with medication or nonmedication treatment |
| | *Dyspnea* screening and management with a documented plan of care |
| Psychological and psychiatric aspects of care | *Discussion of emotional or psychological needs* |
| | Documentation of emotional or psychological needs with a documented plan of care |
| Social aspects of care | Deemed important, but appropriate indicators lacking |
| Spiritual, religious, and existential aspects of care | *Discussion of spiritual/religious concerns* or documentation that the patient/caregiver/family did not want to discuss |
| Cultural aspects of care | Deemed important, but appropriate indicators lacking |
| Care of the patient at the end of life | Deemed important, but appropriate indicators lacking |
| Ethical and legal aspects of care | *Documentation of surrogate* or documentation that there is none |
| | *Treatment preferences* with chart documentation of preferences for life-sustaining treatments |
| | *Care consistency* with documented care preferences such as a DNR order, no tube feeding, or no hospital transfer |
| Global measure | *Patient and/or family assessments* of the quality of care provided by palliative or hospice providers |

Adapted from Dy et al. [63]

## Relief of Suffering

### Physical Suffering

Regardless of whether the disease is heart, lung, or kidney failure, cancer, or dementia, terminally ill patients can experience breathlessness, fatigue, anorexia, nausea and vomiting, constipation, dry mouth, oropharyngeal secretions, poor sleep, confusion, anxiety, or depression, in addition to pain, which is usually the condition that most concerns patients, families, and providers [6, 68]. Despite national guidelines in addressing these symptoms, they often remain insufficiently addressed [69]. Primary care physicians, specialists, and other health-care providers should be proficient at managing the common symptoms of dying patients, and references are widely available to help them do so [70–72].

### Psychological Suffering

The emotional suffering experienced by patients and families as the end of life approaches varies among individuals and is a complex interplay of cognitive, behavioral, social, cultural, and spiritual factors. There are efforts in palliative medicine to better conceptualize psychological distress to aid in the provision of effective interventions as well as create measures that may be used to ascertain quality of care [73].

Even if people can find meaning in the death of a chronically ill loved one, family caregivers may be anxious or depressed, feel exhausted, or even develop an existential crisis [74]. Emotional support of family caregivers can lower levels of grief, improve psychological and physical health, and increase the chance that the patients may die at home [75]. The US National Consensus Project (2013) recommends and the Medicare hospice benefit covers grief services to patients and families prior to and for at least 13 months after the death of the patient. The European Association for Palliative Care recommends assessing bereavement support needs with referral as indicated [76]. Bereavement support can include memorial services, therapy, education, and emotional support [77–79]. Such support may alleviate or even prevent complicated grief disorder or prolonged grief, which is characterized by intense grief that lasts longer than would be expected and causes impairment in daily functioning and feelings of disbelief and preoccupation with the deceased love one, sometimes requiring professional support [80]. Depression, high pre-loss grief levels, and low preparedness for the patient's death are predictors of complicated grief [81, 82]. Larger hospice organizations are more likely to provide screening for depression and complicated grief and access to bereavement therapy [83].

## Places for End-of-Life Care

Chronic illness that is progressive and does not involve cognitive impairment provides opportunities to consider preferences at the end of life including place of death. Many people, whether healthy or chronically ill, indicate that they would prefer to die at home and find nursing homes the least preferred place of death [84, 85]. However, there is limited evidence about how often patients change their mind, whether they actually have a preference, or how strongly they feel about the preference [86].

## Hospitals

Although many people express a wish to die at home, it cannot be assumed that *most* patients have this preference. Some prefer the hospital for safety and effective symptom control or do not want to be a burden for their family. Family members may not be comfortable with medicalizing the home environment with equipment and outside staff or may worry about exchanging the good memories associated with home with the legacy of a death at home. Given these feelings, it is likely that hospitals will continue to be the place of death for many and should be prepared to support dying patients and their families [87].

For patients with chronic diseases such as dementia, hospitalizations in the last weeks of life are burdensome, may be medically unnecessary, or are discordant with the patients' preferences [88]. Such hospitalizations occur in up to 20% of nursing home patients with advanced dementia, a rate that can be lowered with advance care planning in the form of a do-not-hospitalize order [88, 89].

## Home

In the USA, more people are dying at home and hospice use has increased [9]. People who die of chronic diseases with organ failure or neurological deterioration are less likely to die at home than people with cancer [90]. Home death with palliative care is more likely in women, older people, married people, and when fewer hospital beds are available in the region. Patterns and predictors of home death vary between countries likely due to policy and cultural differences.

## Nursing Homes

Rates of nursing home hospice use more than doubled between 1999 and 2006 [91]. This increase is related to the growing trend of using hospice for non-cancer diagnoses as well as to an increase in hospice providers. There is good evidence that the provision of hospice care to nursing home residents improves pain management, reduces hospitalizations, and improves family satisfaction with end-of-life care [92–94]. However, the increasingly long stays of nursing home patients in hospice care have raised concern about higher Medicare hospice expenditures. The challenge is how to reign in the costs of long hospice stays without removing the accessibility of a comfort care approach to dying patients in nursing homes. This can be addressed by varying payments based on length of enrollment in hospice (see financial section below). Experienced physicians who work in nursing homes can effectively provide comfort to dying patients without outside hospice care, and most patients who die there are perceived to do so quietly and without suffering [95]. Patients whose deaths are unexpected or caused by pneumonia appear to suffer more during the final hours of life.

Hospice patients in nursing homes or assisted living facilities receive more nurse's aid care than those who are at home, likely appropriate for patients in the final stages of dementia, which are patterns that may eventually affect payment practices [96]. Nursing home staff have a profound and beneficial impact on the lives of their patients who are terminally ill, are themselves deeply affected by their encounters when caring for dying patients, and have a favorable view of hospice services [97, 98]. Still, there can be negative feelings between staff and outside hospice services due to poor communication and unclear expectations and roles [99]. There may be opportunities in the future to ensure that nursing home staff are trained in comfort care. Similarly, new models that increase physician presence in nursing homes would likely increase physician engagement and expertise in end-of-life care [100]. Whether committed and trained staffing at both the nursing and provider level can provide the same level of quality end-of-life care as an outside hospice agency is an area ripe for study.

## Outpatient Palliative Care

Community-based care to seriously ill patients has generally only been available through hospice programs and, therefore, only available to patients with a prognosis of survival of 6 months or less [6]. Many patients who are seriously ill at home or in nursing homes are in need of palliative care but are not yet eligible for hospice. Community-based palliative care programs can seamlessly link inpatient and outpatient settings, providing longitudinal care that is consistent, continuous, coordinated, collaborative, and fully integrated into the health-care system [101] (Fig. 23.3). New payment incentives under the Affordable Care Act and the shift from fee-for-service to capitated models of reimbursement support cost-saving quality care innovations for patients who are seriously ill but not eligible for hospice. The expansion of outpatient palliative care improves patient, family, and provider satisfaction, symptom control, and quality of life while reducing intensity of health resource use [102, 103].

## Transitions

Palliative care consultation is now widely available in hospitals but has limited effect without meaningful post-acute care. Reduction in cost of care and rates of readmission after discharge are not achieved unless inpatient consultation is followed

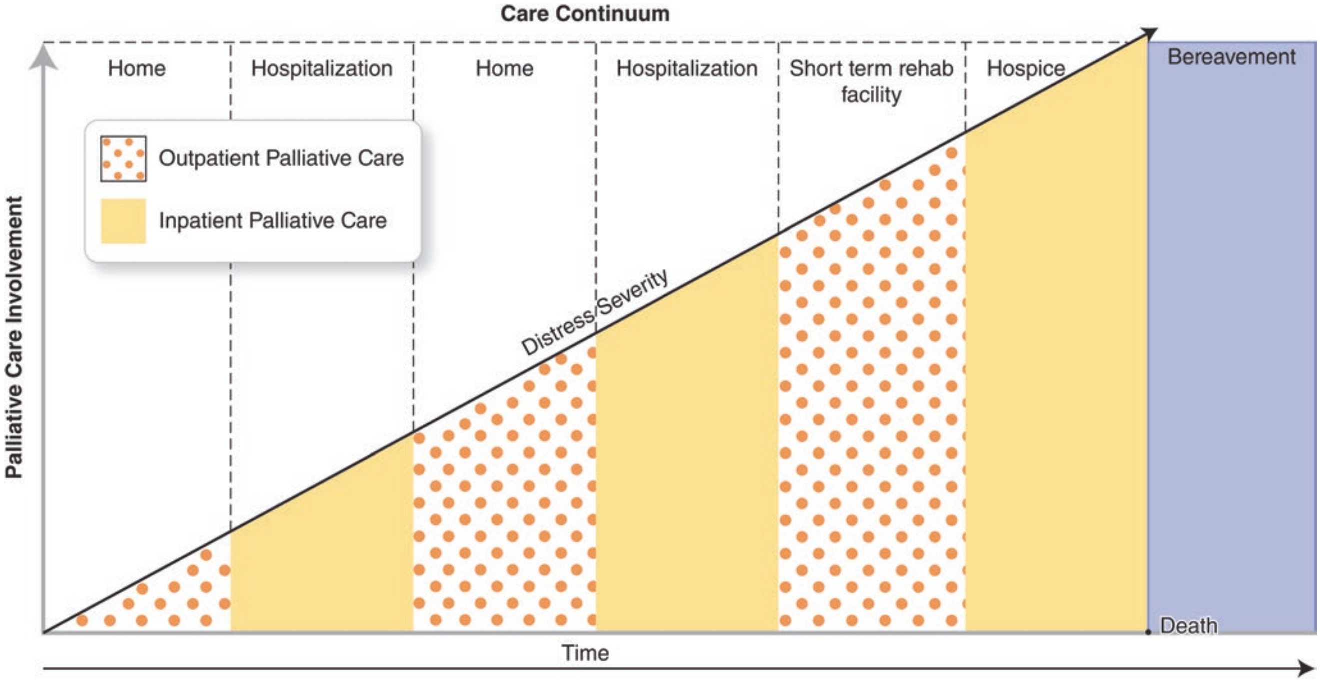

**Fig. 23.3** Community-based palliative care creates a continuum of care for a patient, regardless of location, linking home, institutional care, and hospice. Without such a system, gaps may occur in palliative care needs, including during periods of worsening illness and deterioration

by hospice care after discharge [104]. Transitional care planning is an essential part of inpatient palliative care and ensures a continuum of care that effectively provides quality end-of-life care and consistently honors patient care preferences.

## Financial Reimbursement and Cost Savings

The Medicare hospice benefit was created in 1983 with the dual intent of providing compassionate and quality end-of-life care while simultaneously reducing costs. Hospice enrollment lowers Medicare expenditures, hospitalization, intensive care unit use, and in-hospital deaths in both short-term (1–30 days) and long-term (53–105 days) hospice use [105]. Palliative care consultation in the hospital reduces direct costs by almost $1700 per admission ($174 per day) for live discharges and of almost $5000 per admission ($374 per day) for patients who died which for an average 400-bed hospital translates into a net savings of $1.3 million per year [106].

The public has accepted that hospice improves the quality of care to both the patient and family at the end of life. In 2012, 47% of Medicare beneficiaries received hospice care prior to death, and in 2013 Medicare spent $15 billion on hospice, representing 420% growth over the past 13 years [107]. Hospice programs are available to almost all Americans, and the number of hospice programs, including those that are for-profit, has risen substantially over the past 20 years [108, 109].

Though hospice improves care at the end of life, the well-documented savings in the last months before death may diminish as hospice stays increase beyond 180 days after which the costs of prolonged care exceed the potential savings from hospitalizations. Due to concern that the flat per diem payment structure incentivized the recruitment of more stable patients, the Centers for Medicare and Medicaid Services (CMS) changed the payment model effective January 1, 2016, to a two-tiered per diem payment practice where hospice services are reimbursed at a higher rate for the first 60 days of care with a lower rate for subsequent days as patients are potentially relatively stable, with an allowance for increased payments in the last week of life as acuity of symptoms and need for care increases [110]. Another important change since January 1, 2016, is the provision of payment for advance care planning discussions between physicians, patients, and families [110]. The Center for Medicare and Medicaid Innovation in CMS is conducting a demonstration that allows hospice-eligible patients to access palliative care without having to forgo curative treatments as had always been required in the Medicare hospice benefit, with providers receiving a monthly payment for providing this care.

## Special Populations

### Dementia

Dementia is a chronic, progressive, and incurable disease. People with dementia often die from complications such as pneumonia due to swallowing problems or food and fluid intake problems [111]. These problems can begin when people have moderate dementia and continue until they are in the advanced stages where they can die from these complications or can continue to live for a surprisingly long time. Prognostication is difficult because it is hard to predict when a fatal infection or intake problem will develop [76, 112].

Caring for people with dementia is often burdensome for families who usually grieve while watching their loved one decline both cognitively and physically and then may have to manage challenging behavior. Admission to a facility is sometimes unavoidable, and in western countries most people with dementia (two-thirds in the USA) spend the last part of their life in a nursing home [113]. People with dementia and their families have variable needs along the disease trajectory and may benefit from palliative care, which is aimed at maintaining or improving quality of life. With advancing dementia, communication and shared decision-making often established comfort as the goal of care rather than life prolongation [76]. Palliative care in dementia is distinct from palliative care in cancer. Because of the inevitable cognitive decline along with an uncertain trajectory, early advance care planning with the patient and the family is important. However, applying palliative care early in the disease is somewhat controversial in dementia care and is still often limited to the terminal stage. This can place people with dementia at risk for overtreatment with burdensome interventions and undertreatment of pain and other symptoms because of their difficulty verbalizing complaints. Palliative care monitoring of symptoms should include observational scales that assess facial expressions and body language to recognize pain, discomfort, or other problems [114].

Nearly 90% of patients with dementia develop eating problems [115]. This can be distressing for family caregivers and providers alike who believe that providing artificial feeding through a percutaneous endoscopic gastrostomy (PEG) feeding tube will prolong life [116]. However, this is not the case regardless of the timing of the placement (early or late after the development of feeding problems) [117]. Feeding tubes neither prolong survival nor prevent aspiration in persons with advanced dementia [118–120]. They do, however, increase health-care costs [121]. By the time chronically ill persons are unable to eat, the quality of their life is so poor that insertion of a feeding tube likely just prolongs the dying process without the addition of days of meaningful life. Several organizations recommend against tube feeding in patients with advanced dementia [122, 123]. These messages seem effective as the proportion of US nursing home residents with advanced dementia and inability to eat who receive feeding tubes decreased by 50% between 2000 and 2014 [124].

Dementia-specific hospice programs that emphasize comfort rather than maximal survival time were first proposed in 1986 [125]. Over time, many western countries have expanded hospice and palliative care programs to include people with dementia. Medicare beneficiaries with dementia who sign up for the Medicare hospice benefit receive less aggressive care at the end of life, such as fewer feeding tubes, and are less likely to die in hospitals [126]. Raising awareness that dementia is a terminal disease to which palliative or hospice care applies is important in the education and training of health-care professionals, families, and the general public [127, 128].

## People with Intellectual Disabilities or Mental Illness

An intellectual disability is usually a permanent condition while a mental illness may be temporary, but both bring special challenges in communication and ethics when it comes to end-of-life care.

### Intellectual Disability

In the USA, about 3% of people of all ages have an intellectual disability, which affects nearly one in ten families at some point [129]. Life expectancy for people with intellectual disability has increased due to improved health and social care but remains below that of the general population [130]. The difference may be attributed to genetic causes but health inequalities also play a role [131]. Still, the overall increase in life expectancy for people chronically affected by intellectual disability increases their chance of developing a life-limiting condition such as cancer [132, 133]. People with intellectual disabilities are especially at increased risk of developing dementia [134]. People with intellectual disability are at risk of being under-referred including to specialist palliative care or hospice. The American Association on Intellectual and Developmental Disabilities (AAIDD) calls for access to high-quality end-of-life care for people with intellectual disability that includes dignity, respect for autonomy, protection of life, and equality [135]. AAIDD and the European Association for Palliative Care recommend that discussions about the end of life begin before the anticipated last 6 months of life or before the need for palliative care [131].

Some people with intellectual disability may not have a chance to contribute to advance care planning discussions, but others are able to communicate about death and dying and indicate preferences including a desire to be involved in their own care, have friends and family around, stay occupied, and be physically comfortable [136]. Special communication and assessment skills are particularly relevant with these patients [132]. This can also prevent the well-intended but sometimes inappropriate tendency for relatives or others to protect people with intellectual disability from hearing bad news [137]. Unless it is demonstrated otherwise, people with intellectual disabilities should be assumed to have capacity to make decisions around their care and treatment and provided with support in end-of-life decision-making.

Symptom management in end-of-life care in people with intellectual disability requires special skill as it may not be clear whether a symptom is behavioral or reflects pain. Assessment tools such as the Disability Distress Assessment Tool (DisDAT) use baseline mapping of usual behaviors so that changes to that pattern can be recognized as a sign of distress [138]. Early referral to palliative care services is helpful so that the team can learn about the patient's usual behavior and build familiarity and trust with the patient, the family, and all members of the care team. People with intellectual disabilities have often been at the center of the family and caregivers' lives, and they can be deeply affected by the loss of this beloved person and often need support in grief and bereavement [131].

### Mental Illness

In the USA, 18% of adults have some form of mental illness including 4% with serious mental illness [139]. Mental illness increases risk of a life-threatening physical illness for a number of reasons, including not attending cancer screening, unhealthy lifestyles, and physical complaints that are not well examined but ascribed to the mental illness or are self-medicated rather than evaluated by a physician. People with psychiatric illness and palliative conditions often do not receive the care they need [140]. Similar to intellectual disability, psychiatric disease increases the risk of impaired decision-making capacity. Good communication, collaboration, and multidisciplinary teamwork are essential in providing good end-of-life care. This may be facilitated through a liaison who acts as a bridge between mental health and palliative care services [140].

## Children

In the USA, unintentional injury is the leading cause of death in children after the first year of life with congenital anomalies the leading cause of death in infants under the age of 1 [141]. Malignant neoplasms are the second most frequent cause of death among those aged 5–9 years and can also cause death in toddlers and preschoolers. Psychosocial suffering and symptom burden are especially high in children with cancer [142, 143]. Heart disease and chronic respiratory disease are other progressive conditions that can affect children. While any of these conditions can cause death, many children with chronic, life-shortening illnesses are now living into adolescence and young adulthood [144].

The American Academy of Pediatrics has advocated an integrated model of palliative care for children with high-risk cancer and other life-threatening conditions [144]. This integration between ongoing curative efforts and palliative care can be facilitated by consultation with a palliative care expert, a collaboration that normalizes the concept and supports continuity of care and a continued focus on quality of life [142]. The focus may change depending on the location in the disease trajectory (whether far from or close to the end of life), but at any point managing and clarifying goals of care are important. Cohesive care transitions should occur between the hospital, ambulatory care, home care, and respite support services [143].

Palliative care in pediatrics potentially involves a broad target population of those involved in the child's social and relational spheres, such as parents, siblings, grandparents, and extended relatives. Parents or guardians need support in living with the prospect of a premature death and in subsequent bereavement, given the general expectation that children outlive their parents. Parents are distressed by seeing their children in pain, and patients may experience complex psychosocial symptoms with exponentiation of these symptoms at the end of life. Parents would like to know if professional caregivers are uncertain about the best treatment or prognosis, although not all wish to be responsible for end-of-life decision-making [145]. Professional caregivers can improve their comfort level regarding their responsibility to have these emotional conversations by preparing ahead of time and providing accurate and honest information while avoiding medical jargon [143–145]. Parents may be ambivalent about advance care planning, and a sensitive and gradual approach with the same trusted professional with whom there is also room to discuss nonmedical concerns may accommodate such ambivalence [146]. Excellent interpersonal and communication skills is one of the six core competencies for all trainees in US residency programs, including those who will practice pediatric hospice and palliative medicine [147]. Different settings and location in the disease trajectory (whether far from or close to the end of life) require different conversations, but typically, patients and families simultaneously pursue disease-modifying therapies and palliative care, and managing and clarifying goals of care is of utmost importance. Specific to pediatric palliative care is also different bereavement after the loss of a child, different physiology in the context of change and growth, and communication with children adapted to their cognitive ability, although the overall approach to symptom management is similar, regardless of age.

Pediatric palliative care is under-resourced and often misunderstood, with little evidence available regarding treatment of symptoms, which means that guidelines are mostly based on expert views [148]. There are efforts to improve and extend the provision of children's palliative care. The International Children's Palliative Care Network (ICPCN) provides a global network of advocacy (www.icpcn.org). There are pediatric networks such as that within the European Association for Palliative Care which provide a platform to share knowledge and expertise between resource-rich and resource-poor countries in Europe as well as pediatric standards available through the National Hospice and Palliative Care Organization in the USA [149, 150].

## Future Directions

### Workforce and Access

The National Priorities Partnership identified palliative care as one of six priorities in improving the quality of US health care [151]. Given the significant growth in the number of patients in need of palliative care, a major challenge will be the provision of an adequately trained workforce. There is a significant shortage of physicians specially trained and certified in hospice and palliative care [152]. This means that others will need to help. In its report "Dying in America," the Institute of Medicine stresses that "all clinicians across disciplines and specialties who care for people with advanced serious illness should be competent in basic palliative care, including communication skills, interprofessional collaboration, and symptom management" [50]. While physicians trained in the specialty of palliative care have expertise and comfort in such conversations, there are not nearly enough of them to meet the needs of the population [152]. It is critical that primary care physicians are trained and comfortable with end-of-life care. Graduate medical education should teach palliative medicine to all clinicians who serve patients with serious chronic illness. Practicing physicians should be provided opportunities for professional development in end-of-life care. The ongoing involvement of the patient's primary care physician can reduce the intensity and cost of end-of-life care [153].

Other innovations such as telehealth will increase access. The ENABLE project demonstrated the effectiveness of a telehealth model of palliative care that provided support and expertise to the primary caregivers of a rural-dwelling population of adults with advanced heart failure [154].

### Decision Aids

The default to undesired and aggressive nonbeneficial care harms patients and wastes resources. In response to these known risks, the Institute of Medicine publication *Dying in America* emphasizes the need to enhance advance care planning and improve decision-making for patients with serious illness [50]. Patients should be offered an effective and validated decision tool to assist them with advance care planning and treatment decision-making. Ongoing development of such tools, their introduction in a timely manner in the appropriate context, and subsequent monitoring of their quality and impact will be important to develop an evidence base [155].

### Electronic Medical Records

In the USA, the public has embraced advance care planning, and most older adults with chronic conditions have made advance care plans. However, these plans are not consistently communicated with providers and are rarely documented in the electronic medical record (EMR) [156]. This is especially problematic in the emergency room (ER) setting, where despite high completion rates of advance directives among older adults in the ER, only 4% had this documented in the EMR [156]. This gap between patient preferences and documentation defeats the whole purpose of advance care planning and often results in the delivery of inappropriate and unwanted care. The EMR can also help identify patients for whom advance care planning is appropriate, taking the onus off physicians and other staffers who may not remember to do this in the course of a busy day [155]. EMR-based reminder systems significantly improve advance care documentation [157]. Ready availability of advance directives is critical in fulfilling the responsibility of delivering appropriate care and honoring the wishes of the patient and his or her caregivers, and furthering the capacity of the EMR to assist in communicating these plans will undoubtedly play a role in this effort.

### Racial and Cultural Diversity

As western democracies grow increasingly diverse, an understanding of racial or ethnic variation in end-of-life decision-making will allow for more culturally sensitive approaches to care. In general, studies indicate that African Americans prefer the use of life support while people of Asian and Hispanic heritage place a high value on family-centered decision-making [158]. Among religious people, whites are more likely than blacks or Hispanics to halt medical treatment in the face of an incurable disease with suffering and pain [40]. Muslim patients and families are often reluctant to stop aggressive therapy but may do so if the treatment is deemed futile by physicians [159].

Socioeconomic status is of consequence as well. In the USA, people with more education and higher incomes are more likely than those with less education and lower incomes to have communicated their wishes for end-of-life care. Research and training should continue to better prepare providers who provide end-of-life care to a population that is increasingly racially, culturally, and ethnically diverse.

## Value-Based Payment Models

The changes to Medicare payment policies for end-of-life care since January 1, 2016, will be thoroughly evaluated to determine whether the historical expectations that hospice should reduce overall costs can be realized [160]. Will the higher payment in the first 60 days after hospice enrollment lead to earlier use and reduce the practice of late enrollment? Will it decrease long hospice stays? Will the changes impact quality of care? This is particularly important as Medicare moves toward value-based payments based on quality measures. Palliative care and hospice are behind other parts of the health-care system in moving toward new payment models.

Paying physicians to discuss advance care directives will also be studied to determine whether this practice affects decisions or impacts referrals to hospice or palliative care or, for those who do not formally enroll in such programs, increases the practice of comfort care, with fewer medically complex interventions that provide little benefit to the patient.

The CMS demonstration project that allows hospice enrollees to continue curative care will be carefully studied to determine if this flexibility increases hospice enrollment, improves quality of life, and reduces costs. Medicare spending on end-of-life care is significant. The unquestioning offering of expensive life-prolonging technologies regardless of cost and no matter how marginal the benefit is considered by some to be ethically questionable, since it comes at the expense of other publicly-funded social priorities such as universal access to health care, clean air and water, education, and needed infrastructure [161].

## Quadruple Aim

In addition to the widely referenced triple aim of enhancing patient experience, improving population health, and reducing costs, a fourth aim that addresses widespread burnout and dissatisfaction among clinicians and staff will enhance the functioning of the health-care system. Improving the work life of health-care providers leads to better care, better health, and lower costs [162]. Providers who work in end-of-life care are vulnerable to burnout due to chronic stress from working with terminally ill patients with the associated frequent exposure to death and loss, physical and emotional suffering, increasing workloads, and competing role demands. Nurses often have the most interaction with patients and may experience family-like grief, especially with more intense and longer relationships [163]. Nurses mature emotionally with experience and find reward in end-of-life care with opportunities for personal and professional growth [164–166]. Exposure to death and dying can lead palliative and hospice care professionals to live in the present and cultivate a spiritual life which can include coping mechanisms that decrease chances of burnt-out, such as clinical variety, transcendental meditation and quiet reflection, realistic expectations, and remembering patients [167, 168]. Innovations that promote resiliency and self-awareness using mindfulness, health education, cognitive strategies, and other coping skills will support the people working in the expanding field of end-of-life care [169–171].

## References

1. Lynn J, Adamson DM. Living well at the end of life. Adapting health care to serious chronic illness in old age. DTIC Document; 2003.
2. Brennan F. Palliative care as an international human right. J Pain Symptom Manag. 2007;33(5):494–9.
3. Meier DE, Isaacs SL, Hughes R. Palliative care: transforming the care of serious illness. New York: Wiley; 2011.
4. Kűbler-Ross E. On death and dying. London: Tavistock Publications; 1969.
5. ACGME. Program requirements for hospital and palliative care medicine. 2016.
6. Kelley AS, Morrison RS. Palliative care for the seriously ill. N Engl J Med. 2015;373(8):747–55.
7. National Hospice and Palliative Care Organization. NHPCO facts and figures: hospice care in America. Alexandria: National Hospice and Palliative Care Organization; 2015.
8. Zimmermann C, Riechelmann R, Krzyzanowska M, Rodin G, Tannock I. Effectiveness of specialized palliative care: a systematic review. JAMA. 2008;299(14):1698–709.
9. Teno JM, Gozalo PL, Bynum JP, Leland NE, Miller SC, Morden NE, et al. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. JAMA. 2013;309(5):470–7.
10. Teno JM, Casarett D, Spence C, Connor S. It is "Too Late" or is it? Bereaved family member perceptions of hospice referral when their family member was on hospice for seven days or less. J Pain Symptom Manag. 2012;43(4):732–8.
11. Murray SA, Boyd K, Sheikh A. Palliative care in chronic illness. BMJ (Clinical research ed). 2005;330(7492):611–2.
12. Schofield P, Carey M, Love A, Nehill C, Wein S. 'Would you like to talk about your future treatment options'? Discussing the transition from curative cancer treatment to palliative care. Palliat Med. 2006;20(4):397–406.
13. Mitchell SL, Miller SC, Teno JM, Kiely DK, Davis RB, Shaffer ML. Prediction of 6-month survival of nursing home residents with advanced dementia using ADEPT vs hospice eligibility guidelines. JAMA. 2010;304(17):1929–35.
14. Jayes RL, Arnold RM, Fromme EK. Does this dementia patient meet the prognosis eligibility requirements for hospice enrollment? J Pain Symptom Manag. 2012;44(5):750–6.
15. Harris PS, Stalam T, Ache KA, Harrold JE, Craig T, Teno J, et al. Can hospices predict which patients will die within six months? J Palliat Med. 2014;17(8):894–8.
16. Harrold J, Harris P, Green D, Craig T, Casarett DJ. Effect of the Medicare face-to-face visit requirement on hospice utilization. J Palliat Med. 2013;16(2):163–6.
17. Wanzer SH, Federman DD, Adelstein SJ, Cassel CK, Cassem EH, Cranford RE, et al. The physician's responsibility toward hopelessly ill patients. A second look. N Engl J Med. 1989;320(13):844–9.

18. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, et al. Early palliative care for patients with metastatic non–small-cell lung cancer. N Engl J Med. 2010;363(8):733–42.
19. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. BMJ (Clinical research ed). 2010;340:c1345.
20. Pizzo P, Walker D, Bomba P. Dying in America: improving quality and honoring individual preferences near the end of life. Washington, DC: Institute of Medicine; 2014.
21. Sullivan AM, Lakoma MD, Billings JA, Peters AS, Block SD. Teaching and learning end-of-life care: evaluation of a faculty development program in palliative care. Acad Med: J Assoc Am Med Coll. 2005;80(7):657–68.
22. Bernacki R, Hutchings M, Vick J, Smith G, Paladino J, Lipsitz S, et al. Development of the serious illness care program: a randomised controlled trial of a palliative care communication intervention. BMJ Open. 2015;5(10):e009032.
23. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. JAMA. 1992;267(16):2221–6.
24. Laine C, Davidoff F. Patient-centered medicine. A professional evolution. JAMA. 1996;275(2):152–6.
25. Quill TE, Brody H. Physician recommendations and patient autonomy: finding a balance between physician power and patient choice. Ann Intern Med. 1996;125(9):763–9.
26. Tomlinson T, Brody H. Futility and the ethics of resuscitation. JAMA. 1990;264(10):1276–80.
27. Butler M, Ratner E, McCreedy E, Shippee N, Kane RL. Decision aids for advance care planning: an overview of the state of the science. Ann Intern Med. 2014;161(6):408–18.
28. Stacey D, Legare F, Col NF, Bennett CL, Barry MJ, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2014(1):Cd001431.
29. Austin CA, Mohottige D, Sudore RL, Smith AK, Hanson LC. Tools to promote shared decision making in serious illness: a systematic review. JAMA Intern Med. 2015;175(7):1213–21.
30. Hanson LC, Zimmerman S, Song M-K, Lin F-C, Rosemond C, Carey TS, et al. Effect of the goals of care intervention for advanced dementia: a randomized clinical trial. JAMA Intern Med. 2017;177(1):24–31.
31. Meier DE, Beresford L. POLST offers next stage in honoring patient preferences. J Palliat Med. 2009;12(4):291–5.
32. Hickman SE, Nelson CA, Perrin NA, Moss AH, Hammes BJ, Tolle SW. A comparison of methods to communicate treatment preferences in nursing facilities: traditional practices versus the physician orders for life-sustaining treatment program. J Am Geriatr Soc. 2010;58(7):1241–8.
33. Tolle SW, Teno JM. Lessons from Oregon in embracing complexity in end-of-life care. N Engl J Med. 2017;376(11):1078–82.
34. Danis M, Southerland LI, Garrett JM, Smith JL, Hielema F, Pickard CG, et al. A prospective study of advance directives for life-sustaining care. N Engl J Med. 1991;324(13):882–8.
35. Buchanan A, Brock DW. Deciding for others. Milbank Q. 1986;64(Suppl. 2):17–94.
36. Truog RD, Campbell ML, Curtis JR, Haas CE, Luce JM, Rubenfeld GD, et al. Recommendations for end-of-life care in the intensive care unit: a consensus statement by the American College [corrected] of Critical Care Medicine. Crit Care Med. 2008;36(3):953–63.
37. Downar J, Delaney JW, Hawryluck L, Kenny L. Guidelines for the withdrawal of life-sustaining measures. Intensive Care Med. 2016;42(6):1003–17.
38. McGee A. Acting to let someone die. Bioethics. 2015;29(2):74–81.
39. Gedge E, Giacomini M, Cook D. Withholding and withdrawing life support in critical care settings: ethical issues concerning consent. J Med Ethics. 2007;33(4):215–8.
40. Pew Research Center. Views on end-of-life medical treatments. 2013.
41. Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, Cohen J. Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. JAMA. 2016;316(1):79–90.
42. Enck RE. Drug-induced terminal sedation for symptom control. Am J Hosp Palliat Care. 1991;8(5):3–5.
43. Billings JA, Block SD. Slow euthanasia. J Palliat Care. 1996;12(4):21–30.
44. Howland J. Questions about palliative sedation: an act of mercy or mercy killing? Ethics Medics. 2005;30(8):1–2.
45. Kirk TW, Mahon MM. National Hospice and Palliative Care Organization (NHPCO) position statement and commentary on the use of palliative sedation in imminently dying terminally ill patients. J Pain Symptom Manag. 2010;39(5):914–23.
46. Verkerk M, van Wijlick E, Legemaate J, de Graeff A. A national guideline for palliative sedation in the Netherlands. J Pain Symptom Manag. 2007;34(6):666–70.
47. The ethics of palliative sedation as a therapy of last resort. Am J Hosp Palliat Care. 2006;23(6):483–91.
48. Cherny NI, Radbruch L. European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. Palliat Med. 2009;23(7):581–93.
49. ten Have H, Welie JV. Palliative sedation versus euthanasia: an ethical assessment. J Pain Symptom Manag. 2014;47(1):123–36.
50. Issues IoMCoADAKE-o-L. Dying in America: improving quality and honoring individual preferences near the end of life. 2015.
51. Walling AM, Tisnado D, Asch SM, Malin JM, Pantoja P, Dy SM, et al. The quality of supportive cancer care in the veterans affairs health system and targets for improvement. JAMA Intern Med. 2013;173(22):2071–9.
52. Fisch MJ, Lee J-W, Weiss M, Wagner LI, Chang VT, Cella D, et al. Prospective, observational study of pain and analgesic prescribing in medical oncology outpatients with breast, colorectal, lung, or prostate cancer. J Clin Oncol. 2012;30(16):1980–8.
53. Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, et al. Family perspectives on end-of-life care at the last place of care. JAMA. 2004;291(1):88–93.
54. McCue JD. The naturalness of dying. JAMA. 1995;273(13):1039–43.
55. Blackhall LJ. Must we always use CPR? N Engl J Med. 1987;317(20):1281–5.
56. Teno JM, Lynn J, Phillips RS, Murphy D, Youngner SJ, Bellamy P, et al. Do formal advance directives affect resuscitation decisions and the use of resources for seriously ill patients? SUPPORT Investigators. Study to understand prognoses and preferences for outcomes and risks of treatments. J Clin Ethics. 1994;5(1):23–30.
57. Teno JM, Hakim RB, Knaus WA, Wenger NS, Phillips RS, Wu AW, et al. Preferences for cardiopulmonary resuscitation: physician-patient agreement and hospital resource use. The SUPPORT Investigators. J Gen Intern Med. 1995;10(4):179–86.
58. National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care. Third ed. Pittsburgh, PA, National Consensus Project for Quality Palliative Care; 2013.
59. Zubkoff L, Akyar I, Pantilat SZ, O'Riordan DL, Bragg AR, Bischoff KE, et al. Improving the quality of palliative care through national and regional collaboration efforts. Cancer Control. 2015;22(4):396–402.
60. Hanson LC, Scheunemann LP, Zimmerman S, Rokoske FS, Schenck AP. The PEACE project review of clinical instruments for hospice and palliative care. J Palliat Med. 2010;13(10):1253–60.
61. Hanson LC, Rowe C, Wessell K, Caprio A, Winzelberg G, Beyea A, et al. Measuring palliative care quality for seriously ill hospitalized patients. J Palliat Med. 2012;15(7):798–804.

62. Schenck AP, Rokoske FS, Durham D, Cagle JG, Hanson LC. Quality measures for hospice and palliative care: piloting the PEACE measures. J Palliat Med. 2014;17(7):769–75.
63. Dy SM, Kiley KB, Ast K, Lupu D, Norton SA, McMillan SC, et al. Measuring what matters: top-ranked quality indicators for hospice and palliative care from the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association. J Pain Symptom Manag. 2015;49(4):773–81.
64. Kamal AH, Bull J, Ritchie CS, Kutner JS, Hanson LC, Friedman F, et al. Adherence to measuring what matters measures using point-of-care data collection across diverse clinical settings. J Pain Symptom Manag. 2016;51(3):497–503.
65. Currow DC, Allingham S, Yates P, Johnson C, Clark K, Eagar K. Improving national hospice/palliative care service symptom outcomes systematically through point-of-care data collection, structured feedback and benchmarking. Support Care Cancer: Off J Multinatl Assoc Support Care Cancer. 2015;23(2):307–15.
66. Leemans K, Deliens L, Francke AL, Vander Stichele R, Van den Block L, Cohen J. Quality indicators for palliative care services: mixed-method study testing for face validity, feasibility, discriminative power and usefulness. Palliat Med. 2015;29(1):71–82.
67. Claessen SJ, Francke AL, Sixma HJ, de Veer AJ, Deliens L. Measuring relatives' perspectives on the quality of palliative care: the consumer quality index palliative care. J Pain Symptom Manag. 2013;45(5):875–84.
68. Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. J Pain Symptom Manag. 2006;31(1):58–69.
69. Singer AE, Meeker D, Teno JM, Lynn J, Lunney JR, Lorenz KA. Symptom trends in the last year of life from 1998 to 2010: a cohort study. Ann Intern Med. 2015;162(3):175–83.
70. Albert RH. End-of-life care: managing common symptoms. Am Fam Physician. 2017;95(6):356–61.
71. Groninger H, Vijayan J. Pharmacologic management of pain at the end of life. Am Fam Physician. 2014;90(1):26–32.
72. Blinderman CD, Billings JA. Comfort care for patients dying in the hospital. N Engl J Med. 2015;373(26):2549–61.
73. Carolan CM, Smith A, Forbat L. Conceptualising psychological distress in families in palliative care: findings from a systematic review. Palliat Med. 2015;29(7):605–32.
74. Stroebe M, Schut H, Stroebe W. Health outcomes of bereavement. Lancet (London, England). 2007;370(9603):1960–73.
75. Grande GE, Austin L, Ewing G, O'Leary N, Roberts C. Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial. BMJ Support Palliat Care. 2017;7(3):326–34.
76. van der Steen JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, et al. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. Palliat Med. 2014;28(3):197–209.
77. Hudson P, Remedios C, Zordan R, Thomas K, Clifton D, Crewdson M, et al. Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. J Palliat Med. 2012;15(6):696–702.
78. Waller A, Turon H, Mansfield E, Clark K, Hobden B, Sanson-Fisher R. Assisting the bereaved: a systematic review of the evidence for grief counselling. Palliat Med. 2016;30(2):132–48.
79. Wilson DM, Dhanji N, Playfair R, Nayak SS, Puplampu GL, Macleod R. A scoping review of bereavement service outcomes. Palliat Support Care. 2017;15(2):242–59.
80. Shear MK. Clinical practice. Complicated grief. N Engl J Med. 2015;372(2):153–60.
81. Nielsen MK, Neergaard MA, Jensen AB, Vedsted P, Bro F, Guldin MB. Predictors of complicated grief and depression in bereaved caregivers: a Nationwide Prospective Cohort Study. J Pain Symptom Manag. 2017;53(3):540–50.
82. Schulz R, Mendelsohn AB, Haley WE, Mahoney D, Allen RS, Zhang S, et al. End-of-life care and the effects of bereavement on family caregivers of persons with dementia. N Engl J Med. 2003;349(20):1936–42.
83. Ghesquiere AR, Aldridge MD, Johnson-Hurzeler R, Kaplan D, Bruce ML, Bradley E. Hospice services for complicated grief and depression: results from a National Survey. J Am Geriatr Soc. 2015;63(10):2173–80.
84. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC Palliat Care. 2013;12:7.
85. Calanzani N, Moens K, Cohen J, Higginson IJ, Harding R, Deliens L, et al. Choosing care homes as the least preferred place to die: a cross-national survey of public preferences in seven European countries. BMC Palliat Care. 2014;13:48.
86. Hoare S, Morris ZS, Kelly MP, Kuhn I, Barclay S. Do patients want to die at home? A systematic review of the UK literature, focused on missing preferences for place of death. PLoS One. 2015;10(11):e0142723.
87. Pollock K. Is home always the best and preferred place of death? BMJ (Clinical research ed). 2015;351:h4855.
88. Givens JL, Selby K, Goldfeld KS, Mitchell SL. Hospital transfers of nursing home residents with advanced dementia. J Am Geriatr Soc. 2012;60(5):905–9.
89. Gozalo P, Teno JM, Mitchell SL, Skinner J, Bynum J, Tyler D, et al. End-of-life transitions among nursing home residents with cognitive issues. N Engl J Med. 2011;365(13):1212–21.
90. Pivodic L, Pardon K, Morin L, Addington-Hall J, Miccinesi G, Cardenas-Turanzas M, et al. Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries. J Epidemiol Community Health. 2016;70(1):17–24.
91. Miller SC, Lima J, Gozalo PL, Mor V. The growth of hospice care in U.S. nursing homes. J Am Geriatr Soc. 2010;58(8):1481–8.
92. Miller SC, Mor V, Wu N, Gozalo P, Lapane K. Does receipt of hospice care in nursing homes improve the management of pain at the end of life? J Am Geriatr Soc. 2002;50(3):507–15.
93. Gozalo PL, Miller SC. Hospice enrollment and evaluation of its causal effect on hospitalization of dying nursing home patients. Health Serv Res. 2007;42(2):587–610.
94. Baer WM, Hanson LC. Families' perception of the added value of hospice in the nursing home. J Am Geriatr Soc. 2000;48(8):879–82.
95. van der Steen JT, Deliens L, Koopmans RT, Onwuteaka-Philipsen BD. Physicians' perceptions of suffering in people with dementia at the end of life. Palliat Support Care. 2017:1–13.
96. Unroe KT, Bernard B, Stump TE, Tu W, Callahan CM. Variation in hospice services by location of care: nursing home versus assisted living facility versus home. J Am Geriatr Soc. 2017.
97. Cagle JG, Unroe KT, Bunting M, Bernard BL, Miller SC. Caring for dying patients in the nursing home: voices from frontline nursing home staff. J Pain Symptom Manag. 2017;53(2):198–207.
98. Unroe KT, Cagle JG, Dennis ME, Lane KA, Callahan CM, Miller SC. Hospice in the nursing home: perspectives of front line nursing home staff. J Am Med Dir Assoc. 2014;15(12):881–4.
99. Parker-Oliver D, Bickel D. Nursing home experience with hospice. J Am Med Dir Assoc. 2002;3(2):46–50.
100. Katz PR, Scott K, Karuza J. Has the time come for salaried nursing home physicians? J Am Med Dir Assoc. 2012;13(8):673–4.
101. Kamal AH, Currow DC, Ritchie CS, Bull J, Abernethy AP. Community-based palliative care: the natural evolution for palliative care delivery in the U.S. J Pain Symptom Manag. 2013;46(2):254–64.

102. Rabow M, Kvale E, Barbour L, Cassel JB, Cohen S, Jackson V, et al. Moving upstream: a review of the evidence of the impact of outpatient palliative care. J Palliat Med. 2013;16(12):1540–9.
103. Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Database Syst Rev. 2013;(6):Cd007760.
104. Tangeman JC, Rudra CB, Kerr CW, Grant PC. A hospice-hospital partnership: reducing hospitalization costs and 30-day readmissions among seriously ill adults. J Palliat Med. 2014;17(9):1005–10.
105. Kelley AS, Deb P, Du Q, Aldridge Carlson MD, Morrison RS. Hospice enrollment saves money for Medicare and improves care quality across a number of different lengths-of-stay. Health Aff (Project Hope). 2013;32(3):552–61.
106. Morrison RS, Penrod JD, Cassel JB, Caust-Ellenbogen M, Litke A, Spragens L, et al. Cost savings associated with US hospital palliative care consultation programs. Arch Intern Med. 2008;168(16):1783–90.
107. Medicare Payment Advisory Commission. Report to congress: medicare payment policy [online]. Washington, DC: Medicare Payment Advisory Commission; 2015.
108. Carlson MD, Bradley EH, Du Q, Morrison RS. Geographic access to hospice in the United States. J Palliat Med. 2010;13(11):1331–8.
109. Thompson JW, Carlson MD, Bradley EH. US hospice industry experienced considerable turbulence from changes in ownership, growth, and shift to for-profit status. Health Aff. 2012;31(6):1286–93.
110. Medicare Cf, Medicaid Services H. Medicare program; FY 2015 hospice wage index and payment rate update; hospice quality reporting requirements and process and appeals for part D payment for drugs for beneficiaries enrolled in hospice. Final rule. Fed Regist. 2014;79(163):50451.
111. Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN, Prigerson HG, et al. The clinical course of advanced dementia. N Engl J Med. 2009;361(16):1529–38.
112. Gill TM, Gahbauer EA, Han L, Allore HG. Trajectories of disability in the last year of life. N Engl J Med. 2010;362(13):1173–80.
113. Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. J Am Geriatr Soc. 2005;53(2):299–305.
114. Ellis-Smith C, Evans CJ, Bone AE, Henson LA, Dzingina M, Kane PM, et al. Measures to assess commonly experienced symptoms for people with dementia in long-term care settings: a systematic review. BMC Med. 2016;14:38.
115. Mitchell SL, Lawson FM. Decision-making for long-term tube-feeding in cognitively impaired elderly people. CMAJ: Can Med Assoc J = J Assoc Med Can. 1999;160(12):1705–9.
116. Carey TS, Hanson L, Garrett JM, Lewis C, Phifer N, Cox CE, et al. Expectations and outcomes of gastric feeding tubes. Am J Med. 2006;119(6):527. e11–6
117. Teno JM, Gozalo PL, Mitchell SL, Kuo S, Rhodes RL, Bynum JP, et al. Does feeding tube insertion and its timing improve survival? J Am Geriatr Soc. 2012;60(10):1918–21.
118. Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. JAMA. 1999;282(14):1365–70.
119. Gillick MR. Rethinking the role of tube feeding in patients with advanced dementia. N Engl J Med. 2000;342(3):206–10.
120. Sampson EL, Candy B, Jones L. Enteral tube feeding for older people with advanced dementia. Cochrane Database Syst Rev. 2009;(2):Cd007209.
121. Hwang D, Teno JM, Gozalo P, Mitchell S. Feeding tubes and health costs postinsertion in nursing home residents with advanced dementia. J Pain Symptom Manag. 2014;47(6):1116–20.
122. American Geriatrics Society feeding tubes in advanced dementia position statement. J Am Geriatr Soc. 2014;62(8):1590–3.
123. ABIM Foundation. Feeding tubes for people with Alzheimer's disease.
124. Mitchell SL, Mor V, Gozalo PL, Servadio JL, Teno JM. Tube feeding in US nursing home residents with advanced dementia, 2000–2014. JAMA. 2016;316(7):769–70.
125. Volicer L, Rheaume Y, Brown J, Fabiszewski K, Brady R. Hospice approach to the treatment of patients with advanced dementia of the Alzheimer type. JAMA. 1986;256(16):2210–3.
126. Miller SC, Lima JC, Mitchell SL. Influence of hospice on nursing home residents with advanced dementia who received Medicare-skilled nursing facility care near the end of life. J Am Geriatr Soc. 2012;60(11):2035–41.
127. Brazil K, Galway K, Carter G, van der Steen JT. Providing optimal palliative care for persons living with dementia: a comparison of physician perceptions in the Netherlands and the United Kingdom. J Palliat Med. 2016.
128. Gessert CE, Forbes S, Bern-Klug M. Planning end-of-life care for patients with dementia: roles of families and health professionals. OMEGA-J Death Dying. 2001;42(4):273–91.
129. US Department of Health and Human Services. Administration on Intellectual and Developmental Disabilities (AIDD).
130. Heslop P, Glover G. Mortality of people with intellectual disabilities in England: a comparison of data from existing sources. J Appl Res Intellect Disabil: JARID. 2015;28(5):414–22.
131. Tuffrey-Wijne I, McLaughlin D, Curfs L, Dusart A, Hoenger C, McEnhill L, et al. Defining consensus norms for palliative care of people with intellectual disabilities in Europe, using Delphi methods: a White Paper from the European Association of Palliative Care. Palliat Med. 2016;30(5):446–55.
132. Dunkley S, Sales R. The challenges of providing palliative care for people with intellectual disabilities: a literature review. Int J Palliat Nurs. 2014;20(6):279–84.
133. Friedman SL, Helm DT, Woodman AC. Unique and universal barriers: hospice care for aging adults with intellectual disability. Am J Intellect Dev Disabil. 2012;117(6):509–32.
134. Evans E, Bhardwaj A, Brodaty H, Sachdev P, Draper B, Trollor JN. Dementia in people with intellectual disability: insights and challenges in epidemiological research with an at-risk population. Int Rev Psychiatry (Abingdon, England). 2013;25(6):755–63.
135. American Association on Intellectual and Developmental Disabilities (AAIDD). Caring at the end of life. Position statement of AAIDD.
136. Tuffrey-Wijne I, Bernal J, Butler G, Hollins S, Curfs L. Using nominal group technique to investigate the views of people with intellectual disabilities on end-of-life care provision. J Adv Nurs. 2007;58(1):80–9.
137. Ryan K, Guerin S, Dodd P, McEvoy J. Communication contexts about illness, death and dying for people with intellectual disabilities and life-limiting illness. Palliat Support Care. 2011;9(2):201–8.
138. Regnard C, Reynolds J, Watson B, Matthews D, Gibson L, Clarke C. Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). J Intellect Disabil Res: JIDR. 2007;51(Pt 4):277–92.
139. National Institute of Mental Health. Serious Mental Illness (SMI) among U.S. adults in 2014 and Any Mental Illness (AMI) among U.S. adults.
140. Ellison N. Mental health and palliative care, literature review. London: Mental Health Foundation; 2008.
141. Center for Disease Control and Prevention. National Center for Health Statistics. 10 leading causes of death by age groups. 2014.

142. Kaye EC, Friebert S, Baker JN. Early integration of palliative care for children with high-risk cancer and their families. Pediatr Blood Cancer. 2016;63(4):593–7.
143. Weaver MS, Heinze KE, Kelly KP, Wiener L, Casey RL, Bell CJ, et al. Palliative care as a standard of care in pediatric oncology. Pediatr Blood Cancer. 2015;62(Suppl 5):S829–33.
144. American Academy of Pediatrics. Committee on bioethics and committee on hospital care. Palliative care for children. Pediatrics. 2000;106((2 Pt 1)):351–7.
145. Xafis V, Gillam L, Hynson J, Sullivan J, Cossich M, Wilkinson D. Caring decisions: the development of a written resource for parents facing end-of-life decisions. J Palliat Med. 2015;18(11):945–55.
146. Lotz JD, Daxer M, Jox RJ, Borasio GD, Fuhrer M. "Hope for the best, prepare for the worst": a qualitative interview study on parents needs and fears in pediatric advance care planning. Palliat Med. 2017;31(8):764–71.
147. Klick JC, Friebert S, Hutton N, Osenga K, Pituch KJ, Vesel T, et al. Developing competencies for pediatric hospice and palliative medicine. Pediatrics. 2014;134(6):e1670–7.
148. Knops RR, Kremer LC, Verhagen AA. Paediatric palliative care: recommendations for treatment of symptoms in the Netherlands. BMC Palliat Care. 2015;14:57.
149. Graig F, Abu-Saad H, Benini F, Kuttner L, Wood C, Zernikow B. IMPaCCT: standards for paediatric palliative care in Europe. EJPC. 2007;14(3):109–14.
150. National Hospice and Palliative Care Organization. Standards for pediatric care.
151. Meier DE. Increased access to palliative care and hospice services: opportunities to improve value in health care. Milbank Q. 2011;89(3):343–80.
152. Lupu D. Estimate of current hospice and palliative medicine physician workforce shortage. J Pain Symptom Manag. 2010;40(6):899–911.
153. Ankuda CK, Petterson SM, Wingrove P, Bazemore AW. Regional variation in primary care involvement at the end of life. Ann Fam Med. 2017;15(1):63–7.
154. Dionne-Odom JN, Kono A, Frost J, Jackson L, Ellis D, Ahmed A, et al. Translating and testing the ENABLE: CHF-PC concurrent palliative care model for older adults with heart failure and their family caregivers. J Palliat Med. 2014;17(9):995–1004.
155. Tulsky JA. Decision aids in serious illness: moving what works into practice. JAMA Intern Med. 2015;175(7):1221–2.
156. Grudzen CR, Buonocore P, Steinberg J, Ortiz JM, Richardson LD. Concordance of advance care plans with inpatient directives in the electronic medical record for older patients admitted from the emergency department. J Pain Symptom Manag. 2016;51(4):647–51.
157. Hayek S, Nieva R, Corrigan F, Zhou A, Mudaliar U, Mays D, et al. End-of-life care planning: improving documentation of advance directives in the outpatient clinic using electronic medical records. J Palliat Med. 2014;17(12):1348–52.
158. Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. Gerontologist. 2005;45(5):634–41.
159. Chamsi-Pasha H, Albar MA. Ethical dilemmas at the end of life: Islamic perspective. J Relig Health. 2017;56(2):400–10.
160. Taylor D, Bhavsar N, Harker M, Kassner C. "Evaluating a new era in Medicare hospice and end-of-life policy." Health Affairs Blog. 2015. https://doi.org/10.1377/hblog20151222.052387
161. Callahan D. Conservatives, liberals, and medical progress. New Atlantis (Washington, DC). 2005;10:3–16.
162. Bodenheimer T, Sinsky C. From triple to quadruple aim: care of the patient requires care of the provider. Ann Fam Med. 2014;12(6):573–6.
163. Boerner K, Burack OR, Jopp DS, Mock SE. Grief after patient death: direct care staff in nursing homes and homecare. J Pain Symptom Manag. 2015;49(2):214–22.
164. Peters L, Cant R, Payne S, O'Connor M, McDermott F, Hood K, et al. How death anxiety impacts nurses' caring for patients at the end of life: a review of literature. Open Nurs J. 2013;7:14–21.
165. Anderson KA, Ewen HH. Death in the nursing home: an examination of grief and well-being in nursing assistants. Res Gerontol Nurs. 2011;4(2):87–94.
166. Bailey C, Murphy R, Porock D. Professional tears: developing emotional intelligence around death and dying in emergency work. J Clin Nurs. 2011;20(23–24):3364–72.
167. Koh MY, Chong PH, Neo PS, Ong YJ, Yong WC, Ong WY, et al. Burnout, psychological morbidity and use of coping mechanisms among palliative care practitioners: a multi-centre cross-sectional study. Palliat Med. 2015;29(7):633–42.
168. Sinclair S. Impact of death and dying on the personal lives and practices of palliative and hospice care professionals. CMAJ: Can Med Assoc J = J Assoc Med Can. 2011;183(2):180–7.
169. Mehta DH, Perez GK, Traeger L, Park ER, Goldman RE, Haime V, et al. Building resiliency in a palliative care team: a Pilot Study. J Pain Symptom Manag. 2016;51(3):604–8.
170. Perez GK, Haime V, Jackson V, Chittenden E, Mehta DH, Park ER. Promoting resiliency among palliative care clinicians: stressors, coping strategies, and training needs. J Palliat Med. 2015;18(4):332–7.
171. Krasner MS, Epstein RM, Beckman H, Suchman AL, Chapman B, Mooney CJ, et al. Association of an educational program in mindful communication with burnout, empathy, and attitudes among primary care physicians. JAMA. 2009;302(12):1284–93.