





## Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life

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## 2

## The Delivery of Person-Centered, Family-Oriented End-of-Life Care

For most people, death does not come suddenly. Instead, dying is an inevitable result of one or more diseases that must be managed carefully and compassionately over weeks, months, or even years, through many ups and downs. This chapter examines the ways in which health care providers manage that process. Evidence shows that—regardless of whether curative treatments also are undertaken—a palliative approach often offers the best chance of maintaining the highest possible quality of life for the longest possible time for those living with advanced serious illness.

Death is not a strictly medical event. Ideally, health care harmonizes with social, psychological, and spiritual supports. Health care makes important contributions as patients near the end of life: it relieves pain, discomfort, and other symptoms and effects of disease; it can facilitate achieving maximum possible functioning; it can help alleviate depression and anxiety; it can ease the burden on loved ones and facilitate constructive family dynamics; and sometimes it can extend life for a period of time. It can achieve all these things by combining science with compassion; by adjusting treatments to the unique needs of the individual patient; and by taking into account the patient's and family's spiritual and cultural context, interests, roles, and strengths. The committee believes, therefore, care of people nearing the end of life should be preeminently patient-centered and family-oriented.

The importance of family is emphasized throughout this chapter. As articulated in the guiding principles presented in Chapter 1 (Box 1-3), the committee construes the term “family” broadly to encompass spouses, blood relatives, in-laws, step-relatives, fiancés, significant others, friends, caring neighbors, colleagues, fellow parishioners or congregants, and other people with a personal attachment to the person with advanced serious illness—in other words, the people “for whom it matters.”

Also emphasized throughout this chapter—as throughout this report—is the importance of providing the services needed by people with advanced serious illnesses in a *coordinated* way. This coordination can be accomplished through many different types of structures and arrangements, depending on available resources, payment schemes, and cultural and social preferences. No one service delivery pattern fits all.

This chapter begins by reviewing the current situation with respect to end of life: the trajectories and symptoms of death; salient features of current end-of life care delivery, including the providers of care, the importance of primary care, the problem of burdensome transitions across care settings, and the challenge of unwanted and uncoordinated care. Next is an examination of palliative care, including hospice, as an established approach to providing the

best possible quality of life for people of all ages who have an advanced serious illness or are likely approaching death. The chapter then looks at efforts to measure and report on the quality of care near the end of life, and suggests a set of core quality components. This is followed by a discussion of the problem of prognosis alluded to in Chapter 1. The chapter then focuses on family caregivers, who constitute a generally invisible, undertrained, financially and emotionally stressed, and growing workforce. After outlining research needs related to the delivery of patient-centered, family-oriented end-of-life care, the chapter ends with the committee's findings, conclusions, and recommendation for broad-scale improvement in this area.

## REVIEW OF THE CURRENT SITUATION

### Trajectories and Symptoms Near the End of Life

The Institute of Medicine (IOM) report *Approaching Death: Improving Care at the End of Life* (IOM, 1997) depicts three prototypical trajectories near the end of life:

- a sudden death from an unexpected cause (such as a motor vehicle accident, myocardial infarction, or stroke);
- a steady decline from a progressive disease with a terminal phase (such as cancer); and
- an advanced illness marked by a slow decline with periodic crises and eventual sudden death (such as chronic lung disease or congestive heart failure).

For children (as described in Appendix F), the three most common trajectories near the end of life are sudden death (from trauma), fluctuating decline (such as worsening heart failure), and constant medical fragility (as with some neurologic impairments).

To a patient or family, these categories may appear to overlap. A person dying suddenly from an unexpected cause may have had serious underlying health problems; someone experiencing a steady decline may also enjoy many good days; and a person with a generally slow decline may suffer a sudden steep deterioration in health status.

Another way to view trajectories near the end of life is to focus on functional status. In a prospective cohort study that included 491 participants who initially were not disabled, were at least 70 years old at the start of the study, and died during the 13-year course of the study, disabilities (or “restricting symptoms”) remained relatively constant from 12 months before death until 5 months before death, when they began to increase rapidly (Chaudhry et al., 2013). Twenty percent of the study population demonstrated disability 1 year before death, 27 percent at 5 months before death, and nearly 60 percent in the month before death. Similarly, in a study of 8,232 decedents enrolled in the Health and Retirement Study between 1995 and 2010, the prevalence of disability increased from 28 percent 2 years before death to 56 percent in the month before death (Smith et al., 2013b).

As is emphasized later in this chapter in the section on prognosis, it is difficult to predict an individual patient's disease or disability trajectory. While the course of a disease varies greatly from one individual to another, and people often have multiple diseases and debilitating conditions near the end of life, it may be possible to identify likely patient needs based on patient and disease characteristics, informing service delivery needs. At the individual level, the

committee believes health care providers are best advised to develop, frequently review and revise, and implement care plans tailored to individual circumstances.

Individual circumstances that influence personalized care plans include the disease process; the patient's physical, social, spiritual, and cultural environments and supports (e.g., difficulties in obtaining culturally and linguistically appropriate care); and the patient's experience with both physical and psychological symptoms. Some of the major physical and psychological symptoms people face toward the end of life are identified in *Approaching Death* in a list that remains relevant today (IOM, 1997, pp. 76-78):

- pain;
- diminished appetite and wasting (anorexia-cachexia syndrome);
- weakness and fatigue (asthenia);
- shortness of breath (dyspnea) and cough;
- nausea and vomiting;
- difficulty swallowing (dysphagia);
- bowel problems (constipation, diarrhea);
- mouth problems (dry mouth, sores, dental problems, infections);
- skin problems (itching, dryness, chapping, acne, sweating, sensitivity to touch, pressure sores, dark spots);
- tissue swelling (lymphedema);
- accumulation of liquid in the abdomen (ascites);
- confusion;
- dementia;
- anxiety; and
- depression.

Other problems experienced by many patients nearing the end of life are not necessarily disease related but common to the experience of aging. Examples include incontinence, falls and mobility problems, delirium, depression, and abuse and neglect.

Children nearing the end of life face symptoms similar to those of adults. Studies of children with cancer have found the patient symptoms most frequently reported by parents to be pain, fatigue, dyspnea, change in behavior, and loss of appetite (Pritchard et al., 2010; Wolfe et al., 2000).

The varied trajectories and symptoms experienced by people with advanced serious illnesses pose special challenges for health care providers, especially if the patient has multiple coexisting conditions. A drug or treatment prescribed for one condition may be contraindicated for another; unexpected interactions among drugs may occur. Moreover, the availability of personal, physical, social, and other resources influences how care needs related to decreases in functional status are addressed. Box 2-1 highlights another important challenge noted also in Chapter 1: many elderly people with advanced serious illnesses have dementia or cognitive impairments.

**BOX 2-1****Dementia as an Example of the Challenges in End-of-life Care**

Many elderly people in their final months or years have combinations of chronic diseases that include dementia. People with dementia cannot consistently communicate effectively with health care workers or participate actively and routinely in their care. A study of 163 elderly, non-critically ill patients in the emergency department of an academic medical center found that 37 percent had cognitive dysfunction (Carpenter et al., 2011). Such impairments hamper clinicians' efforts to obtain accurate medical histories, make timely and accurate medical diagnoses, and initiate proper treatment (Han et al., 2011). Such impairments also can prevent patients from adhering to discharge instructions designed to prevent future problems and emergencies (Hustey et al., 2003).

Dementia may add another layer of complexity to disparities in medical decision making among racial and ethnic minority groups. A systematic review of 20 articles on end-of-life care among African Americans, Hispanics, Asian Americans, and Caucasians with dementia found treatment differences at the end of life that may be due to "the double disadvantage of dementia and ethnic minority status" (Connolly et al., 2012, p. 359). The study found that Asian Americans and African Americans with dementia were more likely than others to initiate artificial nutrition, and African Americans were more likely to receive blood transfusions, mechanical ventilation, and intensive care unit (ICU) care, and less likely to have treatment withheld or to complete advance directives.

**Providers of Care Near the End of Life**

The health care institutions most involved in care near the end of life are hospitals, nursing homes, long-term acute care facilities, home health agencies, and hospices, as well as outpatient clinical settings. The health professions most involved are physicians, nurses, and social workers. Besides specialists trained and certified in hospice and palliative medicine, the involved physicians include primary care clinicians; hospitalists; and specialists in treating advanced serious diseases, such as cancer and heart disease. Nursing personnel involved in end-of-life care include advanced practice nurses, other registered nurses, practical nurses, and nursing assistants, with specialty certifications available at all these levels. Social workers, chaplains, pharmacists, rehabilitation therapists, direct care workers (such as home health aides), family caregivers, and hospice volunteers also participate in end-of-life care in large numbers. Family caregivers are discussed later in this chapter, while other personnel are discussed in Chapter 4.

**The Importance of Primary Care**

Primary care<sup>1</sup> plays a crucial role for many people with advanced serious illnesses because primary care clinicians often are best positioned to coordinate the patient's health services across multiple specialties, ensure continuity of care across the patient's life span, and understand the capabilities of family members. Primary care clinicians include family physicians, general internists, general pediatricians, and geriatricians; primary care nurse

<sup>1</sup>An IOM report defines primary care as "the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community" (IOM, 1996, p. 31).

practitioners; and some physician assistants. These clinicians often treat patients who are nearing the end of life and require identification and treatment of multiple physical symptoms, as well as psychosocial support. In addition to treatment of one or more advanced serious illnesses and their comorbidities, their patients variously may need assistance in advance care planning and health care decision making, counseling, referrals to hospice and specialty palliative care, referrals to other relevant specialists and to social service and home health agencies, and coordination of care.

Care coordination, including communication among all providers and between providers and the patient and family, is especially crucial because care near the end of life can involve many health professionals, multiple chronic conditions, and rapidly emerging complex problems with medical and social dimensions. Primary care often is expected to carry out this care coordination function. However, the high use of specialty care by elderly people with multiple chronic conditions makes coordination difficult. This difficulty is illustrated by a cross-sectional study in Washington State of 2,000 Group Health plan members who had chronic conditions and were eligible to enroll in a Medicare Advantage Special Needs Plan. In that study, continuity of primary care was associated with more coordinated care for patients who were low users of specialty care, but not for patients who were high specialty care users<sup>2</sup> (Liss et al., 2011).

*As my 88-year-old father-in-law was in decline with eight different chronic conditions, he had more specialists than we could keep track of, and nobody was steering the ship. Most of all, his pain was poorly managed, but finding an outpatient palliative care physician was impossible, even in a city like Los Angeles. He resisted hospice mainly because he thought that meant he was giving up, so he continued to suffer and experience recurring runs to the emergency room. When he finally agreed to home hospice, his care and condition improved dramatically, and during the final month he lived under hospice he was comfortable, he had heartfelt conversations with all 11 of his children, and he died in peace and dignity in his home. It was a good death, but the period of serious, progressive illness before hospice was a nightmare, because hospice-type care is kept out of reach until the last moments of life.\**

\*Quotation from a response submitted through the online public testimony questionnaire for this study. See Appendix C.

A literature review of coordination in end-of-life cancer care between primary care physicians and oncologists found “preliminary evidence that the continued involvement of primary care physicians in cancer care is valued by patients, may influence care experiences and outcomes, and serves identifiable functions,” such as “meeting patients’ needs for communication and emotional support” (Han and Rayson, 2010, p. 33). The authors of this literature review further noted, “Data are particularly lacking on the nature and outcomes of care coordination occurring specifically between primary care physicians and oncologists (Han and Rayson, 2010, p. 34). For example, one study using the Surveillance, Epidemiology, and End Results (SEER)-Medicare database<sup>3</sup> for 1992-2002 found that advanced lung cancer patients who were seen by their usual primary care provider during their final hospitalization had 25 percent reduced odds of admission to critical care units (Sharma et al., 2009).

<sup>2</sup>In this study, coordination was defined based partly on the coordination measure from the short form of the Ambulatory Care Experiences Survey, continuity of care was based on a formula that involved the number of primary care clinicians seen by a patient during 1 year and the number of visits to each primary care clinician, and high use of specialty care was defined as 10 or more specialty care visits in 1 year.

<sup>3</sup>The SEER-Medicare database comprises Medicare beneficiaries diagnosed with cancer.

Current trends support the development of “medical homes,” which are distinguished by seven essential features: a personal physician, physician-directed medical practice, a whole-person orientation, coordination (or at least integration) of care, quality and safety as hallmarks, enhanced access to care, and appropriate payment mechanisms (American Academy of Family Physicians et al., 2007). One of the “joint principles” of medical homes adopted by the American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, and American Osteopathic Association describes a whole-person orientation:

The personal physician is responsible for providing for all the patient’s health care needs or taking responsibility for appropriately arranging care with other qualified professionals. This includes care for all stages of life: acute care, chronic care, preventive services, and *end of life care* (American Academy of Family Physicians et al., 2007, p. 1, emphasis added).

Attention to the spectrum of needs of persons near the end of life and their families thus is highly consistent with the goals of the medical home approach.

Medical homes are commonly used in the care of children. Pediatricians in medical homes provide end-of-life care “...by proactively coordinating care; facilitating consistent communication for better decision-making; providing anticipatory guidance; and helping to manage symptoms and social distress; and helping with medical decision-making” (Tripathi et al., 2012, p. 113). These activities are seen as consistent with palliative care, as described later in this chapter, and should be offered from the time of diagnosis onward, according to the American Academy of Pediatrics (AAP, 2013).

Strongly related to the primary care needs of many older people with advanced serious illnesses are their needs for geriatric care. Geriatricians routinely provide care for vulnerable older adults with complex conditions (Warshaw et al., 2008). Providing appropriate palliative care is a core value of this subspecialty of both internal medicine and family medicine (Besdine et al., 2005). Many of the needs of older people also can be met by gerontological advanced practice nurses (Hendrix and Wojciechowski, 2005).

Addressing the palliative needs of people near the end of life and their families is consistent with the expertise, approach, and values of primary care across the life span.

### **The Problem of Burdensome Transitions**

Patients often experience multiple transitions near the end of life, and they suffer the consequences of the resultant discontinuities in care. Medication errors, disruptions in care planning, and failures to coordinate care all are implicated in poorly managed transitions between care settings, including between hospitals and nursing homes or private homes. Following discharge from hospital to home, the lack of a single point of contact and of nurse involvement in follow-up care can be unsettling to patients and families (Swan, 2012). Transitions characterized by these deficits or those that are simply difficult for sick, confused patients and their families to manage are considered “burdensome.” Transitions between care settings can be confusing and overwhelming to patients, especially seriously ill patients, and their families and can result in preventable readmissions or emergency department visits. Often, appropriate follow-up referrals are not made, follow-up with relevant health care professionals is not sufficiently timely, psychological and social needs are not addressed, and potentially useful

personnel such as social workers, pharmacists, health educators, and rehabilitation therapists are not engaged (Feigenbaum et al., 2012; Abrashkin et al., 2012).

Preventable hospital readmissions are frequently a consequence of poorly managed transitions. As many as one-fifth of Medicare fee-for-service beneficiaries discharged from the hospital to the community in 2003-2004 were readmitted within 30 days, and half of them did not see their physician in the interim (Jencks et al., 2009). Between 2000 and 2009, the rate of health care transitions—both in the last 90 days and in the last 3 days of life—among fee-for-service Medicare beneficiaries increased (Teno et al., 2013). Among transitions in the last 3 days of life, more than 20 percent were to an acute care hospital.

In what may be the start of a favorable trend, the Medicare readmission rate did fall slightly in 2012, to 18.4 percent (Gerhardt et al., 2013). This decline was perhaps related to recent initiatives aimed at reducing readmissions. For example, Aetna Medicare Advantage members in the mid-Atlantic region who received care under what was called the Transitional Care Model had a 29 percent 3-month readmission rate, compared with a 39 percent rate among matched nonparticipants; they also experienced far fewer hospital days on average during the 3 months postdischarge (Naylor et al., 2013). The Transitional Care Model entailed assignment of a transitional care nurse at the time of admission to assess needs and develop and implement the discharge plan. Similarly, an intervention designed to encourage patients and family caregivers to play a more active role in care transitions led to lower readmission rates at both 30 and 90 days in a large integrated care delivery system in Colorado (Coleman et al., 2006). This intervention included guidance from a “transitions coach,” as well as encouragement and tools to improve communication across settings. Another intervention, in an academic medical center, led to lower hospital utilization within 30 days of discharge by using a “nurse discharge advocate” to conduct patient education, arrange follow-up appointments, and assist with reconciliation of medications (Jack et al., 2009). More recently, the Centers for Medicare & Medicaid Services’ (CMS) Quality Improvement Organization Program, Community-based Care Transitions Program, and Hospital Readmissions Reductions Program introduced a penalty that reduces payments to hospitals with a disproportionate readmission rate for particular conditions beginning in 2012. This initiative, which incorporates aspects of several of these other programs, has demonstrated success in reducing hospital readmission rates (Brock et al., 2013; CMS, 2013a, 2014a,b; James, 2013).

To reduce readmission rates and improve primary care, the Department of Veterans Affairs (VA) has used Patient Aligned Care Teams (PACTs) with nurse case managers. In Madison, Wisconsin, a VA program called Coordinated-Transitional Care (C-TraC) used experienced nurses as case managers to consult with patients by telephone, rather than in home visits (Kind et al., 2012). These nurses followed protocols intended to educate and empower the patient and caregiver in medication management, ensure medical follow-up, educate the patient and caregiver to respond to “red flags” indicating a worsening medical condition, and ensure that the patient and caregiver knew whom to contact. Readmission rates were 23 percent among C-TraC patients in 2010-2012, compared with 34 percent at baseline. The 23 percent rate is still higher than the 18.4 percent national average for 2012 noted above, but this difference may reflect differences in patient characteristics.

According to a meta-review of 57 meta-analyses of randomized clinical trials, community-based disease management programs<sup>4</sup> have been shown to reduce hospital

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<sup>4</sup>Disease management programs coordinate services, over time and across settings, for patients with multiple serious conditions (Ellrod et al., 1997).



readmission rates for patients with heart failure, coronary heart disease, and asthma (Benbassat and Taragin, 2013). On the other hand, disease management programs for several other types of patients and inpatient-based programs generally have been less successful. A systematic review of 21 randomized clinical trials involving transitions of patients from the hospital to another setting found that 9 of the interventions resulted in a statistically significant positive effect on readmission (Naylor et al., 2011); all 9 interventions involved nurses, and 6 of these involved home visits.

Transfers to and from nursing homes are also important to end-of-life care in at least two ways. First, as noted in Chapter 1, the percentage of deaths occurring in nursing homes has been greater recently than it was in the years prior to the publication of *Approaching Death* (IOM, 1997). As end-of-life care moves away from hospitals and toward nursing homes and individual homes, the quality of care near the end of life in nonhospital settings becomes more important (Flory et al., 2004). Second, many nursing home residents with dementia, in particular, face burdensome transitions and may experience interventions that cause discomfort and produce little if any gain:

The late stages of dementia are characterized by major challenges to quality of life, including inability to communicate, initiate movement, or walk; difficulty eating and swallowing; agitation; incontinence; and a high risk of infection and pressure ulcers. The sources of suffering for individuals with dementia go beyond fear, depression, and confusion and include significant physical symptoms, including pain, coughing, choking, dyspnea, agitation, and weakness....Nearly all family members of nursing home residents with advanced dementia report that comfort is the primary goal for their care. Nonetheless, a minority of Medicare decedents with dementia are referred to hospice before death, and repeated burdensome transitions between hospitals and nursing homes and feeding tube placement commonly occur, despite lack of evidence of quality of life or survival benefit (Unroe and Meier, 2013, p. 1212).

In one sense, nursing homes face a dilemma in providing care near the end of life. Although nursing homes typically are a frail elderly person's final residence, federal and state agencies and national accreditation entities hold them to standards that can be more suitable to life-prolonging care than to addressing quality of life and comfort near the end of life. As a result, "evidence indicates that nursing homes undertreat pain, especially in cognitively impaired and minority residents" (IOM, 2011, p. 141).

### Unwanted Care and Lack of Coordination and Continuity: An Illustration

Box 2-2 presents a family narrative illustrating several dimensions of care near the end of life that is neither needed nor desired, neither coordinated nor continuous. Those dimensions include a failure to implement advance directives, an excessive number of burdensome transitions, repeated miscommunications with the family, inadequate pain management and apparent overuse of sedation, insensitive communication with the patient, and an inordinate delay in referral to hospice. Chapter 3 examines in detail the importance of communication about patients' values, goals, and informed preferences. Such communication can help patients avoid unwanted care and ensure that they receive care that is consistent with their personal goals and values.

#### BOX 2-2

##### The Impact of Unwanted, Uncoordinated Treatment: A Family Narrative

The subject of this narrative is a New England man who died at age 98, several years after telling his family and signing directives to exclude “heroic” measures at the end of his life. His daughter recounts his experience:

*In 2010, he had been suffering from a form of senile dementia progressively for at least 10 years, though his physical health was excellent. The death of his wife, however, in May of that year, caused him greater confusion and anxiety than he had ever experienced....*

*Early in the morning on December 7, 2010 the staff at the assisted living facility, where he lived in Maine, found him on the floor. They phoned an ambulance and he was taken to a nearby hospital, where a left hip fracture was diagnosed....*

*The surgery was “successful” and my father “recovered” post-operatively very well. However, his agitation—presumably prompted by pain, unfamiliar surroundings, lack of comprehension of the circumstances—increased daily....*

*In the four weeks prior to his death, my father lived under the care of five different institutions in two states. Only the last place, the hospice, appeared willing or able to provide care and comfort to a man who was obviously at the end of his life.*

*After he had been in the hospital in Maine for 12 days, a social worker phoned one morning to say an ambulance was on its way to take him to a hospital in Haverhill, Massachusetts, where his medications would be “adjusted”.... The transfer was already in progress; we, the family, were merely being notified.*

*When we arrived at the hospital in Maine, distraught at the short notice, we asked to see the doctor who was discharging my father. A psychiatrist, he explained the reasons for my father’s abrupt discharge. According to medical practice, it was well known (from patients who could give a reliable history) that post-op pain is gone after three days. Given the state my father was in—he was groaning in evident agony—I began to suspect that the situation was purposely misunderstood by the professionals in charge of his care.*

*It was clear that there was no good future for my father: I knew his comprehension could not be improved medically; only his physical activity and his mental agitation could be subdued by drugs. Distressed myself, I pleaded with this psychiatrist that all my father needed was “care and comfort,” a phrase my own doctor had assured me was the medically acceptable option. At this, the psychiatrist looked me straight in the eye and said, “I’m sorry, but because of my own personal and religious beliefs, I am not able to discuss that with you.”*

*When we arrived at the Haverhill facility—which we only then discovered was a mental hospital—my father was already admitted to a ward of mostly elderly patients who, we had been told, were being treated for medical as well as psychiatric problems. However, it was there that an aide, trying to help my father to the toilet, recoiled in horror when he saw the staples still holding the incision site together, asking, “How do we get him to the toilet with a broken hip?”*

*A staff social worker...seemed surprised that this new patient had come from Maine, but then remembered that their marketing person had just visited the Maine hospital. My father’s transfer was apparently the first success of their new marketing campaign.*

*She told us that on Monday morning we would be called for a family meeting to consider my father’s care....His distress and confusion steadily increased. By Sunday, he was hostile, even to us (we had never seen that before) and obviously paranoid....*

*Monday morning came, and no one contacted us. I phoned both the social worker and the nurses’ station on the floor, but no one was available to talk to me about my father. Fifteen minutes after my last phone call, my sister received a call from the Haverhill hospital to inform her that they were transferring my father to a nearby regional hospital emergency room. Why? Because he was dehydrated and had an elevated white cell count.*

*When we got to the emergency department and saw my father, he was heavily sedated....We were later told that my father was not dehydrated and that actually his white cell count was only slightly elevated. The Haverhill mental hospital had kept him the three nights required for reimbursement by Medicare and then got rid of him.*

*The staff at the regional hospital were terrific....We agreed to have him admitted to their “Adult Behavior Unit”....Despite his dementia, my father had somehow retained the old-fashioned courtesy and personal decorum of a by-gone era—being addressed by well-meaning young staff members as “Sweetie” added to his bewilderment. He hated being there....A few days after Christmas, when it was evident that my father wasn’t going to improve and neither could he stay there, a thoughtful and efficient social worker suggested a hospice center also in Haverhill.*

*The hospice staff was uniformly kind, supportive, unhurried, and caring; they provided a wonderfully peaceful place to live while dying. He died four days later, and we still regret that he didn’t get there sooner.*

*[He] died on January 2, 2011, 65 years to the day that he was discharged from the Army after serving in the Pacific during World War II.*

SOURCE: Stephens, 2011. Reprinted with permission from WBUR and Sarah Stephens.

How frequently does this scenario occur? The incident recounted in Box 2-2 took place despite the active involvement of at least one clearly articulate family advocate; many people near the end of life lack this advantage. Other accounts of unwanted treatment that fails to accord with patient preferences are reported in generalist publications (Krieger, 2012; Rauch, 2013; Butler, 2013), in comments submitted to the committee online by members of the public, and in subsequent chapters of this report.

The IOM Committee on Improving the Quality of Cancer Care recently underscored the importance of patient preferences, saying, “In the setting of advanced cancer, the cancer care team should provide patients with end-of-life care consistent with their needs, values, and preferences” (IOM, 2013, p. 138). Current conditions appear to fall far short of this goal. The same IOM report notes that according to recent studies, clinicians ask for patient preferences in medical decisions only about half the time. (See also Chapter 3.)

## THE PALLIATIVE APPROACH

Palliative care can be considered an umbrella term that encompasses a spectrum of approaches to delivering care for people with serious advanced illness. Various organizations have put forward conceptual or functional definitions of palliative care, suggesting that it

- “seeks to prevent relieve, reduce, or soothe the symptoms of disease or disorder without effecting a cure” (IOM, 1997, p. 31).
- “is a broader term that includes hospice care as well as other care that emphasizes symptom control, but does not necessarily require the presence of an imminently terminal condition or a time-limited prognosis. Palliative care may include a balance of comfort measures and curative interventions that varies across a wide spectrum” (VA, 2008, p. 2).
- is “specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family” (CAPC, 2013).
- is “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological, and spiritual” (WHO, 2002, p. 84).
- “focuses on achieving the best possible quality of life for patients and their family caregivers, based on patient and family needs and goals and independent of prognosis. Interdisciplinary palliative care teams assess and treat symptoms, support decision-making and help match treatments to informed patient and family goals, mobilize practical aid for patients and their family caregivers, identify community resources to ensure a safe and secure living environment, and promote collaborative

- and seamless models of care across a range of care settings (i.e., hospital, home, and nursing home)” (Meier, 2011, p. 344).
- “provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or 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 patients 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” (WHO, 2013).<sup>5</sup>
  - “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” (HHS, 2008; Dahlin, 2013).

A content analysis of these seven definitions was developed for this report. That analysis revealed four essential attributes of palliative care, used in constructing the definition of palliative care used in this report:

*Palliative care provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness and their families.*

Palliative care may begin early in the course of treatment for a serious illness and may be delivered in a number of ways and across the continuum of health care settings, including the home, assisted living facilities, nursing homes, long-term acute care facilities, acute care hospitals, and outpatient clinics. It encompasses

- *hospice care*, usually including services required under the Medicare Hospice Benefit (described in more detail in Chapter 5);
- *basic (or, as it is sometimes called in the literature, “primary”) palliative care*, delivered by health care professionals who are *not* palliative care specialists, such as primary care clinicians; physicians who are disease-oriented specialists (such as oncologists and cardiologists); and nurses, social workers, pharmacists, chaplains, and others who care for this population but are not certified in palliative care; and
- *specialty palliative care*, delivered by health care professionals who *are* palliative care specialists, such as physicians who are board certified in this specialty, palliative-certified nurses,<sup>6</sup> and palliative care-certified social workers, pharmacists, and chaplains.

<sup>5</sup> A separate World Health Organization definition of palliative care for children is cited later in this chapter.

<sup>6</sup> Palliative nurses are certified in one of seven certification programs, such as programs for advanced certified hospice and palliative nurse and certified hospice and palliative nursing assistant (National Board for Certification of Hospice and Palliative Nurses, 2013). Chapter 4 reviews these programs.

Specialty palliative care currently is most commonly hospital based and offered as a consultative service, although growth recently has been seen in specialty palliative care services in outpatient settings, at home, in nursing homes, and in long-term acute care facilities (CAPC, 2011; NHPCO, 2012a, 2013). A survey of 20 outpatient palliative care practices revealed that almost all anticipate substantial growth (Smith et al., 2013a).

The delivery of palliative care has been studied in racially and ethnically diverse patients. In a review of care provided to 1,999 seriously ill African American and Hispanic patients at a safety net hospital, 65 percent of African Americans and 70 percent of Hispanics elected do-not-resuscitate (DNR) orders following palliative care consultation (Sacco et al., 2013). On admission, by comparison, 80 percent of African American patients and 71 percent of Hispanic patients had unknown DNR status, and 20 percent and 29 percent, respectively, had elected no DNR status; 29 percent of all patients were referred to hospice. These findings suggest that palliative care consultations can help overcome gaps in information that lead to unwanted, intensive interventions near the end of life. Language barriers may also hamper palliative care consultations for some populations. Elderly people who communicate in Asian languages, for example, have been found to have difficulty finding nursing homes where they can communicate with staff members (Vega, 2014).

### Growth in Hospice Use

Hospice is an essential approach to addressing the palliative care needs of patients with limited life expectancy and their families. In 1995, 17 percent of all U.S. deaths—some 390,000 decedents—were users of hospice (IOM, 1997); by 2011, this figure had risen to 45 percent of U.S. deaths, or more than a million decedents (NHPCO, 2012a).

Hospice emerged as a modern concept in the United Kingdom in the mid-20th century as a result of the pioneering work of Dame Cicely Saunders, a physician, nurse, and social worker. The approach and concept were popularized in the United States partly through the writing of Elisabeth Kubler-Ross (NHPCO, undated). For people with a terminal illness or at high risk of dying in the near future, hospice is a comprehensive, socially supportive, pain-reducing, and comforting alternative to technologically elaborate, medically centered interventions. It therefore has many features in common with palliative care, and indeed in this report is considered a subset of palliative care. Various definitions of hospice exist that reiterate these points:

- The IOM report *Approaching Death* offers three definitions: a discrete site of care; an organization that provides and/or arranges for services to patients in homes or other settings; and “an approach to care for dying patients based on clinical, social, and metaphysical or spiritual principles” (IOM, 1997, p. 31).
- The VA defines hospice as “a mode of palliative care, often associated with specific characteristics of the individual receiving the care, diagnosed with a known terminal condition with a prognosis less than 6 months, and desiring therapies with a palliative intent for the terminal condition” (VA, 2008).
- The National Quality Forum (NQF), in *A National Framework and Preferred Practices for Palliative and Hospice Care Quality*, defines hospice as “a service delivery system that provides palliative care for patients who have a limited life expectancy and require comprehensive biomedical, psychosocial, and spiritual support as they enter the terminal stage of an illness or condition. It also supports

family members coping with the complex consequences of illness, disability, and aging as death nears” (NQF, 2006, p. 3).

With the understanding that in discussing particular studies, the terms employed by their authors are used, this report uses the NQF definition of hospice.

As noted in Chapter 1, whereas hospice programs originally were designed primarily to serve people with cancer, hospices now also serve large numbers of people with heart problems; Alzheimer’s disease; kidney disease; and other conditions, including (especially before improvements in drug treatments) HIV/AIDS. As one clinician told the committee in open testimony, “Hospices are known and trusted in their communities” (Harrold, 2013), and hospice use has attained mainstream status.

By 2012 there were 5,500 hospice programs in the United States, reflecting a steady increase since the first such program opened in 1974 (NHPCO, 2013). (Note that one commercial or nonprofit entity may operate multiple hospice programs, each at a different site.) Nearly three in five of these programs were free-standing or independent, while the rest were part of a hospital system, home health agency, or nursing home. In 2012, more than three-fourths of the programs admitted fewer than 500 patients, and the (mean) average daily census of the programs was 149 patients. New hospice programs opening in 2008-2009 were more likely to be for-profit than those that began operation in earlier years. There also is a trend toward larger hospices (Thompson et al., 2012). The VA has shown a commitment to providing veterans with high-quality hospice and specialty palliative care (Edes et al., 2007; Daratsos and Howe, 2007). Hospice and palliative care is part of the VA’s standard medical benefits package, and palliative care consultation teams are available at all VA hospitals in the United States.

Hospice services are available to many children with serious chronic diseases, as described in Appendix F. That appendix points to an increasing share of deaths among seriously ill children occurring at home, but with substantial racial differences (such as a smaller proportion of African American children dying at home) nationally and in some states. Still, children appear to have far less access than adults to hospice. Hospices responding to a 2007 survey typically cared for only 1-20 children per year (Friebert, 2009).

Volunteers are an important part of hospice services and, in fact, are required under hospice conditions of participation for Medicare and Medicaid.<sup>7</sup> A 2006 study of volunteer participation in 305 hospice programs found an average of 0.7 volunteer hours per patient per week (Block et al., 2010). The researchers then matched use of volunteers with an associated survey of 57,000 family members of decedents. Hospice programs with the greatest use of volunteers had the highest overall ratings for quality of care. Using volunteers also can increase access to hospice care in some circumstances. For example, prison volunteers have helped make hospice a viable service for fellow inmates who are dying, including elderly prisoners serving long sentences and prisoners with AIDS (Mitchell, 2013; Casavecchia, 2011).

People frequently associate hospice use with earlier death and abandonment of treatment. The reality is very different. Some evidence suggests that on average, hospice patients live longer than similarly ill nonhospice patients. For example, hospice patients outlived nonhospice patients by an average of 29 days in a study of almost 4,500 Medicare beneficiaries in the late 1990s and early 2000s (Connor et al., 2007). In a study of 7,879 Medicare beneficiaries who died of advanced non-small-cell lung cancer between 1991 and 1999, 26 percent of hospice patients

<sup>7</sup>42 CFR § 418.78 Conditions of Participation: Volunteers.

and 21 percent of nonhospice patients survived 1 year from diagnosis, and 6.9 percent of hospice patients and 5.5 percent of nonhospice patients survived 2 years (Saito et al., 2011).

As the discussion of the evidence for the effectiveness of palliative care later in this chapter further shows, addressing the physical, emotional, and support needs of patients through a palliative approach may actually extend life expectancy, in addition to improving the quality of life and increasing patient and family satisfaction. Box 2-3, for example, describes a case in which hospice tailored services to meet the needs of a seriously ill elderly woman who was contemplating suicide.

### **BOX 2-3**

#### **Hospice Responds to a Patient's Unique Needs**

In an interview with a hospice and palliative medicine specialist, an introspective 86-year-old woman with progressive congestive heart failure and multiple comorbidities, including depression, was contemplating suicide. The physician suggested she consider hospice to maximize her quality of life, prevent her from feeling like a burden to her family, and help her and the family make medical and social decisions concordant with her goals (Kutner, 2010). At the beginning of her ensuing hospice stay, the woman was “upset about hospice in general, specific caregivers, and medical decisions” (Triveldi and Delbanco, 2011, p. 645). But discussions with family members and health professionals, including assurances that she could disenroll from hospice, proved reassuring (Kutner, 2010). Members of her health care team later reported: “In the end, she and the hospice caregivers developed a style that suited all concerned, enabled her to stay in her home, relieved her discomfort, and facilitated her death at home. With hospice’s assistance, she was able to die as she wished—in her home with dignity, control, and comfort” (Triveldi and Delbanco, 2011, p. 645). Death came 22 months after the initial interview with the physician.

### **Growing Support for Palliative Care**

First hospice and later a broader palliative care approach arose during the latter part of the 20<sup>th</sup> century. Palliative care is consistent with the biopsychosocial model of care, prominent in the mental health field for the past three decades, which views patients in a broader context than their disease state and attends to relationships between physical and mental health (Curlin, 2013; Engel, 1980). In the United States, higher percentages of dying patients—and far more patients with noncancer diagnoses—receive hospice or palliative care services compared with other countries, such as England, Canada, and Germany (Klinger et al., 2013).

Much of the appeal of palliative care flows from its dual emphasis on (1) providing support that enables patients to remain for as long as possible at home or in the least restrictive and least intensive setting of care, and (2) ensuring that patients receive care consistent with their values, goals, and informed preferences, including avoiding the discomfort of unwanted tests and procedures that may not be necessary or beneficial. With palliative care,

Patients are able to remain in their homes as a consequence of better family support, care coordination, and home care and hospice referrals; more hospital admissions go directly to the palliative care service or hospice program instead of a high-cost intensive care unit (ICU) bed; patients not benefiting from an ICU setting are transferred to more supportive settings; and non-beneficial or harmful



imaging, laboratory, specialty consultation, and procedures are avoided (Meier, 2011, p. 350).

Over the past two decades, hospital-based palliative care programs have grown from very small numbers to, by 2011, a presence in 67 percent of U.S. hospitals with at least 50 beds (CAPC, 2013), 85 percent of U.S. hospitals with more than 300 beds, 54 percent of public hospitals, and 26 percent of for-profit hospitals (CAPC, 2011). Such programs are especially common in large hospitals and those affiliated with medical schools (CAPC, 2013). In seven states and the District of Columbia, 80 percent of all hospitals had these services in 2011, while six states had such services in fewer than 40 percent of hospitals (CAPC, 2011). In addition, almost 70 percent of children's hospitals had a palliative care program in 2012 (Feudtner et al., 2013). Access to inpatient palliative care varies by geography and type of hospital, with hospitals in the south, for-profit and public hospitals, and those that are sole community providers less likely to offer it (Goldsmith et al., 2008).

Several factors have contributed to the rise of palliative care since the release of *Approaching Death* (IOM, 1997):

- increases in the numbers and needs of elderly Americans,
- recognition of the numbers and needs of family caregivers,
- greater prevalence of chronic diseases, and
- public attention to controversies and legal cases regarding the right to die and assisted suicide (Meier, 2010).

In addition, a growing body of research and data has emerged to support the use of palliative care, as discussed in the evidence review below.

Successful clinical experiences and the support of consumer groups, influenced by high rates of patient and family satisfaction, also have contributed to broader use of palliative care. For example, the cancer advocacy group C-Change strongly supports “increasing the use of palliative care throughout treatment” (Santiago, 2013, p. 5).

*My long-time best friend just died of a slowly progressive brain tumor. Over the five years since his diagnosis, he slowly lost ability to use his left side, his vision, and finally his speech. However, thanks to the diligence of family and hospice, friends, and a few respectful caregivers, he spent the last few weeks of his life comfortably at home, almost constantly in the presence of family, friends, and his most diligent wife. He spent these days listening to his favorite music, reading poetry, discussing new ideas and old ones, holding hands, and giving hugs. His final weeks were the most peaceful imaginable! Such a profoundly meaningful exit is indeed rare.*

*The “medicalization” of the end of life which is pervasive in America creates many obstacles to the experience of my friend. The relatively “new” (but very old) palliative care movement in this country cannot come to fruition soon enough!\**

\*Quotation from a response submitted through the online public testimony questionnaire for this study. See Appendix C.

Other specialty societies and authorities are beginning to recommend integration of palliative care into disease-specific treatment and care. Beyond the field of cancer, palliative care is supported by groups advocating improved care in renal disease (Molony, 2013) and neurology (Shaw, 2010). Authorities also recommend integrating evidence-based specialty medical care and palliative care for patients with heart failure (Goodlin, 2009).

In general, however, acceptance of recommendations to counsel patients about palliative care appears to be slow. In a national survey of cardiologists, for example, fewer than half of respondents said they would discuss palliative care in the case of two hypothetical elderly patients with late-stage heart failure, as recommended by clinical guidelines (Matlock et al., 2010). This departure from cardiology guidelines was especially pronounced in regions with high use of health care services in the last 6 months of life.

### **Illustrative Palliative Care Processes**

The MD Anderson Cancer Center's Supportive and Palliative Care Service illustrates how palliative care can function in hospital and outpatient settings. A palliative care consultant meets with patients and families, and together they develop treatment goals and identify problems. Early introduction of palliative care helps ensure a greater level of comfort for patients during the entire course of treatment (Bruera and Hui, 2010).

The clinical process begins with an assessment, using one of several validated assessment instruments (Hui, 2008).<sup>8</sup> To meet palliative care needs throughout an illness, regular palliative care assessment is then incorporated into patient care. Box 2-4 summarizes recent efforts to improve and standardize the assessment process.

Using initial assessment results, palliative care consultants can help direct relevant assistance, in conformance with patient and family treatment goals. For example, one problem common among cancer patients but difficult to identify is depression. As appropriate, the palliative care team helps minimize medications that may contribute to depression, rules out comorbidities that may contribute to depression, provides or arranges for counseling or psychotherapy, and prescribes antidepressant medications as needed (Dev and Sivesind, 2008).

Other palliative care processes focus on spiritual and cultural aspects of care. For example, chaplaincy services, the most visible mode of spiritual services, are described in Chapter 4. The importance of spiritual services is underscored by the spiritual distress experienced by many patients near the end of life (Hui et al., 2011).

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<sup>8</sup>Examples include the Edmonton Symptom Assessment System; the Memorial Delirium Assessment Scale; and instruments used to assess the patient's performance status, which helps determine eligibility for certain cancer therapies and is believed to help predict survival, quality of life, and functioning (Hui, 2008).

### **BOX 2-4 Palliative Care Screening in the Hospital**

Hospital palliative care is most commonly provided by a consultation service based in the hospital. A key question is which inpatients could benefit from a palliative care consultation, and when. The Center to Advance Palliative Care convened a consensus panel to develop checklists for identifying these patients.

The panel determined that every hospital, including specialty hospitals, should identify patients at high risk for unmet palliative care needs using a screening process on admission that looks for

- a potentially life-limiting or life-threatening condition; and
- five primary criteria of (a) whether the attending physician would not be surprised if the patient died within 12 months or before adulthood; (b) frequent hospital admissions; (c) admissions prompted by physical or psychological symptoms that are difficult to control; (d) complex care requirements; and (e) a decline in function, feeding intolerance, or unintended decline in weight; and when possible to identify, also looks for
- secondary criteria, including, for example, admission from a nursing home or similar facility, hip fracture, and lack of advance care planning.

The panel also proposed a similar but separate checklist for assessing patients daily during their hospital stay, as appropriate. This checklist looks for

- a potentially life-limiting or life-threatening condition; and
- five primary criteria of (a) whether the attending physician would not be surprised if the patient died within 12 months or before adulthood; (b) physical or psychological symptoms that are difficult to control; (c) intensive care unit (ICU) stay of 7 or more days; (d) lack of documentation of or clarity about goals of care; (e) disagreements or uncertainty among patient, family, and/or staff about medical decisions and treatment preferences; and when possible to identify, also looks for
- secondary criteria, including, for example, emotional distress of the patient or family, medical team considering patient as a candidate for feeding tube placement, tracheostomy, ethics consults, or other similar procedures or services.

The main components of palliative care assessment include pain and other symptoms, social and spiritual factors, patient's understanding of the illness and prognosis and treatment options, development of patient-centered goals of care, and discharge planning.

SOURCE: Weissman and Meier, 2011.

### **Palliative Care for Children**

The World Health Organization (WHO) has developed a definition of palliative care specifically for children, which states in part: “Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family” (WHO, 2013).<sup>9</sup> Palliative care for children differs from adult palliative care based on the stage of child

<sup>9</sup>The WHO definition includes the following additional characteristics of pediatric palliative care, which WHO states should apply to other pediatric chronic disorders, not just life-threatening illnesses: “It begins when illness is

development, which affects communication and the patient's understanding of illness and death; differences between children's diseases and causes of death and those of adults; greater involvement of family members as direct caregivers and decision makers; and the emotional impact of the child's illness on parents and siblings (Zhukovsky, 2008).

One important development since the IOM report *When Children Die* (IOM, 2003) was issued the emergence of several sets of guidelines for pediatric palliative care. These include guidelines of the National Hospice and Palliative Care Organization (NHPCO, 2009) and the Children's Oncology Group and Association of Pediatric Hematology and Oncology Nurses (Ethier et al., 2010), and the National Cancer Institute's "PDQ" for health professionals on pediatric supportive care, including care at the end of life (NCI, 2014).

Assessment scales that are age- and developmentally appropriate are used in evaluating pediatric patients. For pain, for example, behavioral observation scales often are used for children under 4 years of age, while faces, photographic or drawing scales, color-analog scales, body maps, and other tools may be appropriate for children ages 3-7 (Zhukovsky, 2008). Adult visual analog scales and verbal rating scales often are used for children over age 8. Likewise, diverse interventions are used to manage pain, including the cognitive-behavioral strategies of distraction, imagery, thought stopping, exercise, relaxation, modeling, desensitization, art therapy, music therapy, and play therapy.

As noted in Appendix F, most pediatric deaths take place in hospitals, and the majority of these deaths occur in critical care units, often with an escalating array of procedures, such as mechanical ventilation. Since 2005, children's hospitals, in particular, have developed pediatric palliative care teams for children with long-term advanced serious illness and or a broad array of symptoms. The pediatric palliative care approach combines the continuity of care and patient-centeredness usually associated with primary care with highly specialized clinical services. It complements, rather than replaces, curative and related life-extending specialty services.

Since 1997, for example, a palliative care program at Children's Hospital Boston and Dana-Farber Cancer Institute has coordinated care, helped families make difficult treatment decisions, focused on easing the child's pain and suffering, and provided extensive bereavement services (Groopman, 2014). A longitudinal cohort study of 515 patients receiving care from six hospital-based pediatric palliative care programs found that 70 percent of the patients survived at least 1 year after receiving their first palliative care consultation (Feudtner et al., 2011).

States implementing pediatric palliative care programs through Medicaid include California, Colorado, Florida, New York, North Carolina, North Dakota, and Washington (NHPCO, 2012b). Massachusetts has independently funded and implemented a pediatric palliative care program (Bona et al., 2011). Excellus BlueCross BlueShield, serving Upstate New York, developed CompassionNet, a pediatric palliative care program in 2001, serving more than a thousand families of children with life-threatening illnesses (Excellus BlueCross BlueShield, 2011). The program enhances regular health insurance coverage with social and support services, many of which are not traditionally covered by health insurance, to improve quality of life for both child and family. Services are carefully tailored to each family's unique needs.

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diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes" (WHO, 2013).

Support for family members is an essential part of pediatric palliative care, beginning in the first days of life. Today, babies born even 16 weeks prematurely often survive, but their survival may require painful and uncomfortable interventions and may result in serious, lifelong disabilities, which places a significant burden on parents who must make fateful decisions. As a result, it has been suggested that the same attention given to end-of-life decisions for adults be given to end-of-life decisions for children (Dworetz, 2013).

Finally, although adult and pediatric palliative care differ in important ways, lessons from such care for children can be applied by policy makers and clinicians to improve the care provided to adults, as described in Box 2-5.

**BOX 2-5**  
**Lessons from Pediatric Care**

Pediatrics has long been associated with an emphasis on the importance of the family. The benefits of this family focus remain applicable as patients grow older. Pediatric patient- and family-centered care reflects six core values: listening to and respecting each child and family; flexibility in policies, procedures, and practices; sharing information with patients and families; providing and ensuring formal and informal support; collaborating with patients and families at all levels of health care; and empowering children and families (Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012).

In addition, as described in the text, pediatrics assesses a child's behavioral readiness to determine his or her role in making medical decisions, rather than relying on a vague, subjective opinion. End-of-life pediatric care also includes a strong component of bereavement services and consideration of family survivorship.

Moreover, in light of today's changing population demographics (see Chapter 1), pediatrics offers a perspective on how to deal with new family structures—single parents, smaller families and households, and blended families—and the care needs of people of diverse ethnic, cultural, and racial backgrounds.

**Palliative Care in Nonhospital Settings**

Although most palliative care programs are hospital based, the palliative approach ideally is available as well wherever patients with serious advanced illness are, including in long-term care facilities, in outpatient clinical settings, and at home. A literature review focused on four “sentinel articles” found that palliative care outside inpatient settings can enhance patient satisfaction; improve symptom control and quality of life; reduce health care utilization; and, in a population of lung cancer patients, lengthen survival (Rabow et al., 2013).

Some nursing homes provide residents with access to palliative care through palliative care consultants, services provided by hospice staff to residents not enrolled in hospice, or enhanced training of nursing home staff (CAPC, 2008; Meier, 2010). Training in some instances has focused on pain management and quality improvement (Robert Wood Johnson Foundation, 2004). Community-based palliative care programs, other than those provided by hospices, also are beginning to appear, although these programs are developing unsystematically, and so at present lack standardization with respect to management processes, services, and methods of integration with other health services (Kamal et al., 2013). Home health agencies, too, are beginning to offer palliative care services (Labson et al., 2013). Advances in communication technology, such as remote monitoring systems that can alert off-site health professionals to

changes in a patient's vital signs or medical status, may spur additional growth in such programs.<sup>10</sup>

In New Mexico, a Hospital at Home<sup>®</sup> project, conducted by Presbyterian Healthcare Services and inspired by developmental work at The Johns Hopkins University, assisted patients with congestive heart failure, chronic obstructive pulmonary disease (COPD), and other serious conditions that put them at risk of repeated hospital admissions (Cryer et al., 2012). Services included diagnostic services, arrangements for medical supplies and equipment, transportation, daily physician house calls, and home visits from a nurse once or twice a day. The project succeeded in meeting Presbyterian's core quality metrics 100 percent of the time for 323 patients and achieved higher patient satisfaction ratings than usual care. Other examples appear in Chapter 5.

Palliative care does not always have to be provided by specialist clinicians. In fact, to meet the palliative care needs of all people with advanced serious illness who are likely approaching death, palliative care precepts must be integrated across the continuum of care and generally embraced by clinicians who care for this population. For example, an article by oncology palliative care specialists describes the important role of basic, or "primary," palliative care as "delivered every day in the oncology office" (Cheng et al., 2013, p. 84). These authors stress the importance of several actions by the office-based oncologist: a "repeating conversation" on coping with cancer, use of a symptom assessment scale, a spiritual assessment, and referral to a hospice information visit for patients with a prognosis of 3-6 months. Delivery of basic palliative care by primary care and regular specialist physicians would help meet a rising demand that exceeds the supply of palliative care specialists, simplify demands on patients and families, and reinforce existing relationships (Quill and Abernethy, 2013).

### Interdisciplinary Team Approach

The interdisciplinary team approach that typically distinguishes palliative care contributes to the development and implementation of comprehensive plans of care, helps ensure coordination of care, enhances the anticipation and remediation of problems that arise during transitions and crises, facilitates quality improvement, and contributes to good pain management (Meier, 2011). According to Mitchell and colleagues (2012, p. 3), "The high-performing team is now widely recognized as an essential tool for constructing a more patient-centered, coordinated, and effective health care delivery system," with the patient and family at the team's center.

Since the publication of *Approaching Death* in 1997, hospice and palliative medicine has become a defined physician specialty, and palliative care also has become a specialty area in the professions of nursing, social work, and chaplaincy (as described in more detail in Chapter 4) (ABMS, 2013; American Osteopathic Association, 2013; APC, 2013; NASW, 2013; National Board for Certification of Hospice and Palliative Nurses, 2013). In addition to palliative medicine specialists, palliative nurses, social workers, and chaplains, team members may include, for example, pharmacists, dietitians or nutritionists, physical therapists, occupational therapists, psychotherapists, speech-language pathologists, and others such as art or music

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<sup>10</sup>Monitoring technologies in development in 2013 included a sensor mat that is placed under the mattress to monitor a patient's sleep patterns, heart rate, and breathing rate; a videoconferencing "robot" to help physicians conduct real-time virtual consultations; cloud-based applications to help patients track vital signs and access their plan of care; and remote monitoring sensors that can be placed throughout the home to detect falls and missed medications. Several of these products already have been approved by the Food and Drug Administration (InformationWeek, 2013).

therapists and child life specialists (Adams et al., 2011; American Occupational Therapy Association, 2011; American Society of Health System Pharmacists, 2002; Cruz, 2013; Hebert et al., 2011; NASW, 2013, 2014; Pollens, 2004; Puchalski et al., 2009; Vitello, 2008). A team with such broad composition is most likely to have the competence and time to meet patients' needs involving medication management, loss of appetite, functional limitations, depression, difficulties in swallowing and communicating, spiritual guidance, and other problems arising, perhaps for the patient's first time, during an advanced stage of illness (NQF, 2006).<sup>11</sup>

The interdisciplinary approach should begin with the initial patient assessment. For example, a nurse may perform the initial assessment, which leads to the involvement of other professional team members as appropriate. The composition of the team depends, to a large extent, on resource availability. In a smaller hospital, in rural settings, and under conditions of a shortage of specialized personnel, teams may be more rudimentary than is the case in large, well-staffed academic medical centers. Identification of which interdisciplinary team members are necessary in any particular situation is part of the assessment process.

### **Evidence for the Effectiveness of Palliative Care**

As noted, a growing evidence base supports the effectiveness of palliative care for those nearing the end of life. A study of 524 dying patients at five VA medical centers and affiliated nursing homes and clinics in 2006-2007 showed that those who received inpatient palliative care consultations had significantly better outcomes in five of six domains studied: information and communication, access to home care services, emotional and spiritual support, well-being and dignity, and care around the time of death (Casarett et al., 2008). A trend toward higher scores for the sixth domain, bereavement services, was not statistically significant. The VA's well-established, highly rated Home Based Primary Care Program for patients with complex chronic disabling diseases includes palliative care services (Beales and Edes, 2009). This program has been in place for four decades, and provides comprehensive longitudinal primary care and palliative care delivered by an interdisciplinary team in the homes of veterans with serious chronic disabling conditions. The program is associated with a 24 percent lower total cost of VA care per patient per year.

A landmark study of palliative care published in 2010 found that it can lead to improved quality of life and greater longevity when provided concurrently with disease-focused care (Temel et al., 2010). In this 3-year study, 151 patients with metastatic non-small-cell lung cancer at Massachusetts General Hospital were randomly assigned at the time of diagnosis to either palliative care or no palliative care, and all patients also received standard oncology treatment. Quality-of-life scores were an average of 6.5 points higher for the palliative care group on the 136-point FACT-L scale. Symptoms of depression were nearly 2.5 times more common in the non-palliative care group (38 percent versus 16 percent). Moreover, median survival was 30 percent longer for the palliative care group (11.6 months versus 8.9 months), even though fewer patients in that group received aggressive care near the end of life (defined in the study as receipt

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<sup>11</sup>To give one example of team composition, Kaiser Permanente's TriCentral Palliative Care program, a model that serves patients at home instead of only in the hospital, has estimated the following full-time equivalent staff complement for a census of 30 palliative care patients: 0.4 physician, 2.2 registered nurses, 1.2 social workers, 1.2 certified home health aides, 0.3 intake and liaison registered nurse, 0.6 clinical nurse specialist supervisor, 0.2 chaplain, 0.3 program director, and 1.0 clerk, for a total staff-to-patient ratio of 1:4, plus volunteers. The program includes patient care conferences every 1-2 weeks (Brumley and Hillary, 2002, p. 26). In pediatric palliative care, as noted in Appendix F, staffing patterns are "remarkably diverse."

of chemotherapy within 2 weeks of death, admission to hospice 3 days or less before death, or no admission to hospice care) (33 percent versus 54 percent). The authors conclude that palliative care, begun early in the course of treatment, led to significant improvements in quality of life and mood and was associated with longer survival in this population.<sup>12</sup> Illustrating this study's importance, the American Society of Clinical Oncology cited it as a "strong evidence base" in formulating a provisional clinical opinion (now also adopted in guidelines of the National Comprehensive Cancer Network) advising oncologists to offer palliative care concurrently with standard specialty care, beginning at the time of diagnosis (NCCN, 2013; Smith et al., 2012; Simone and Jones, 2013).

Other studies tend to confirm that palliative care benefits patients. A systematic review of 23 studies conducted in the United States, the United Kingdom, Sweden, Norway, Italy, Spain, Canada, and Australia found that use of expert home palliative care teams more than doubled the odds of dying at home (Gomes et al., 2013). This review further found that home palliative care reduced the symptom burden for patients, while usual care increased it.

In a randomized controlled trial of 512 patients hospitalized with life-limiting diseases in Denver, Portland (Oregon), and San Francisco in 2002-2003, palliative care patients, compared with "usual care" patients, had greater satisfaction with communication and the care experience and fewer critical care unit admissions. No differences in survival or symptom control were found (Gade et al., 2008).

A randomized controlled trial of 322 patients with advanced cancer in New Hampshire and Vermont in 2003-2008 found that a specific psychoeducational palliative care intervention led to higher scores on quality of life and mood (Bakitas et al., 2009). No differences were found in symptom intensity, hospital days, critical care unit admissions, or emergency department visits. The intervention (Educate, Nurture, Advise Before Life Ends, or ENABLE) consisted of four weekly education sessions, with monthly follow-up sessions conducted by an advanced practice nurse.

A number of studies suggest that specialty palliative care has the capacity to

- improve information and communication, access to home care services, emotional and spiritual support, well-being and dignity, and care around the time of death (Casarett et al., 2008);
- reduce depression, enhance quality of life, and increase survival (Temel et al., 2010);
- reduce critical care unit mortality (Elsayem et al., 2006); and
- prevent emergency department visits, hospitalizations, and deaths away from home (Brumley et al., 2007).

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<sup>12</sup>A follow-up analysis of this study explored whether the increased survival rates of the palliative care patients resulted from improvements (that is, reductions) in depression alone. The analysts found that "...the data do not support the hypothesis that treatment of depression mediated the observed survival benefit from [early palliative care]" (Pirl et al., 2012, p. 1310). The effect of palliative care on patient longevity is of considerable interest. However, the effects of palliative care on life span—and the factors that may account for those effects—remain unclear. According to Meier (2011, p. 349), "Conjectures accounting for the possibility that palliative care and hospice may prolong life include reduction in depression, which is an independent predictor of mortality in multiple disease types; avoidance of the hazards of hospitalization and high-risk medical interventions; reduction in symptom burden; and improved support for family caregivers that permits patients to remain safely at home." The association between palliative care and increased life span is a promising target for further research.



The case for greater use of and support for specialty palliative care can be made based on clinical, economic, and ethical considerations: “Early provision of specialty palliative care improves quality of life, lowers spending, and helps clarify treatment preferences and goals of care” (Parikh et al., 2013, p. 2350).

With respect to hospice, high quality of care in hospice overall has been well established in the literature for three decades. As early as 1984, hospice was associated with greater patient satisfaction when compared with conventional care for patients with serious illness nearing the end of life (Kane et al., 1984). As noted earlier, there is suggestive evidence that hospice use may be associated with longer survival (Connor et al., 2007; Saito et al., 2011). Hospice also was found to improve care for people with the difficult diagnosis of dementia in a survey of 538 bereaved family members in Alabama, Florida, Massachusetts, Minnesota, and Texas (Teno et al., 2011). In that study, the family members of patients who received hospice services “at the right time” reported fewer unmet needs, fewer concerns about quality of care, higher quality of care, and better quality of dying. In a survey of 292 family members of deceased nursing home residents enrolled in hospice, 64 percent rated the quality of care rendered before hospice care began as good or excellent for both physical and emotional symptoms (Baer and Hanson, 2000). For quality of care after hospice care began, ratings increased to 93 percent for physical symptoms and 90 percent for emotional symptoms. And in a 10-item family satisfaction survey involving bereaved family members of nearly 1,600 people who died of chronic diseases in 2000, overall satisfaction was found to be better in home hospices than in hospitals, nursing homes, and home health agencies (Teno et al., 2004) (see Table 2-1).

**TABLE 2-1** Family Satisfaction with Alternative Models for End-of-Life Care by Last Site of Care, 2000

Indicator of Family Satisfaction	Hospital (%)	Nursing Home (%)	Home Health Services (%)	Home Hospice (%)
Patient did not receive enough help with pain	19	32	43	18
Patient did not receive enough help with shortness of breath	19	24	38	26
Patient did not receive enough emotional support	52	56	70	35
Physician did not satisfy family desire for contact	52	31	23	14
Family had enough contact with physician but had concerns about physician communication	27	18	27	18
Patient was not always treated with respect	20	32	16	4
Family had concerns about own emotional support	38	36	46	21
Family had concerns about having enough information about what to expect while patient was dying	50	44	32	29
Staff did not know enough about patient’s medical history	15	20	8	8
Overall quality of care was excellent	47	42	47	71

SOURCE: Teno et al., 2004.

## **THE PURSUIT OF QUALITY IN CARE NEAR THE END OF LIFE**

Two aspects of the quality of palliative care are especially important for establishing accountability: first, which components of palliative care contribute most to better patient care outcomes, and second, which metrics are most useful for evaluating the quality of care delivered by individual providers. Current efforts to measure and report on these aspects of care are described below. Opportunities to overcome limitations of these efforts are then reviewed, followed by the committee's proposed core components of quality care near the end of life.

### **Approaches to Improving Quality of Care Near the End of Life**

Care of patients with serious advanced illness near the end of life is complex. Various interventions have been implemented and evaluated to identify aspects of quality care near the end of life that lead to positive outcomes and patient and family satisfaction. A systematic review of 23 studies of interventions to improve continuity of care, care coordination, or transitions between settings of care for people with serious illness found the best, yet moderate, evidence for improvement in patient or family satisfaction; evidence generally was weak for other outcomes, including patient or family quality of life, caregiver burden, and utilization of health care resources (Dy et al., 2013). The greatest success in improving satisfaction was achieved through interventions that combined components of a coordinator of care, patient and/or family involvement through health education or another form of assistance, and/or additional patient assessment. Other interventions studied incorporated care plans and use of a palliative care specialist. Quantifying the impact of these components on outcomes was not possible because of the heterogeneity of the studies included in the review. The reviewers also found that “many studies were limited by numerous methodological issues such as insufficient power for reported outcomes (primarily utilization), measuring outcomes not specifically targeted by the intervention, and using measurement tools (especially for quality of life outcomes) not specific for populations with advanced disease” (p. 443).

A broader systematic review, conducted by essentially the same team, found similar methodological deficiencies in many of the 90 studies included in the analysis (AHRQ, 2012). Still, the authors found moderate evidence for improvements in satisfaction with interventions targeting continuity, coordination, and transitions between care settings. Those interventions that incorporated patient-centered quality improvement components, such as patient, family, or caregiver education and self-management, showed the strongest evidence of effectiveness. Evidence was moderate for improvements in health care utilization outcomes among interventions that targeted communication and decision making, but specific quality improvement methods were not assessed for these types of interventions.

Methodological challenges relating to individual interventions (e.g., insufficient statistical power) and larger-scale reviews of interventions (e.g., lack of meta-analysis) make it difficult to quantify the impact of specific components on quality of care and quality of life. Still, information can be gleaned from these studies and reviews, which show that moderate evidence exists to support the impact of some quality improvement interventions on outcomes including satisfaction with care among patients nearing the end of life and their families.

Use of end-of-life care pathways also has been the subject of a systematic review; in this case, researchers found no clinical trials meeting their criteria for high-quality research design that evaluated the benefits of end-of-life care pathways for quality of care and quality of life

(Chan and Webster, 2013). The researchers suggest that this gap in the literature reflects a clear need to investigate the effectiveness of pathways and other guidelines for end-of-life care.

### **Current Quality Measurement and Reporting Efforts**

In the mid-2000s, a group building on efforts of the Robert Wood Johnson Foundation's Critical Care End-of-Life Peer Workgroup used a consensus process to develop 18 proposed measures for assessing the quality of palliative care (Mularski et al., 2006). Of these, 14 address processes of care at the patient level, while 4 address structural aspects of critical care delivery. The proposed set of measures was designed to stimulate further work on measurement and enhancement of the quality of palliative care.

NQF (2012) has endorsed 14 evidence-based quality measures for palliative and end-of-life care. (NQF calls these items "measures," but because they are broad categories, they might better be termed "criteria" or "domains.") The NQF measures are:

- pain screening, for hospice and palliative care (NQF #1634);
- pain assessment, for hospice and palliative care (NQF #1637);
- patients treated with an opioid who are given a bowel regimen (NQF #1617);
- patients with advanced cancer assessed for pain at outpatient visits (NQF #1628);
- dyspnea treatment, for hospice and palliative care (NQF #1638);
- dyspnea screening, for hospice and palliative care (NQF #1639);
- patients admitted to an intensive care unit who have care preferences documented (NQF #1626);
- treatment preferences, for hospice and palliative care (NQF #1641);
- percentage of hospice patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss such concerns (NQF #1647);
- comfortable dying (NQF #0209);
- hospitalized patients who die an expected death with an implantable cardioverter defibrillator (ICD) that has been deactivated (NQF #1625);
- family evaluation of hospice care (NQF #0208);
- consumer assessments and reports of end of life (NQF #1632); and
- bereaved family survey (NQF #1623).

In 2013 the National Consensus Project for Quality Palliative Care (NCP) released a new set of Clinical Practice Guidelines, rooted, as the name suggests, more in consensus than in evidence for effectiveness (Dahlin, 2013). The NCP is a collaborative effort of the American Academy of Hospice and Palliative Medicine, Center to Advance Palliative Care, Hospice and Palliative Nurses Association, National Association of Social Workers, National Hospice and Palliative Care Organization (NHPCO), and National Palliative Care Research Center. The Clinical Practice Guidelines are divided into eight domains:

- structure and processes of care;
- physical aspects of care;
- psychological and psychiatric aspects of care;
- social aspects of care;

- spiritual, religious, and existential aspects of care;
- cultural aspects of care;
- care of the patient at the end of life; and
- ethical and legal aspects of care.<sup>13</sup>

To illustrate the complexity of these domains, the domain “care of the patient at the end of life” emphasizes multiple preferred practices, including assessment and management of symptoms; documentation and communication with patient, family, and all health care providers about signs and symptoms of the dying process; family guidance; and bereavement support both before and after death, all the while keeping social, spiritual, and cultural concerns in mind. The same domain includes four guidelines, with a list of associated criteria. The guidelines center on (1) identification, communication, and management of signs and symptoms; (2) care planning; (3) postdeath care; and (4) bereavement support. An interdisciplinary team approach is considered essential.

A large set of quality indicators was developed through a RAND Corporation effort called Assessing Care of Vulnerable Elders (ACOVE) (Wenger et al., 2007). While these indicators cover numerous conditions and care processes and the entire continuum of care, from screening and prevention to diagnosis, treatment, and follow-up, end of life is considered a particular condition within ACOVE. Illustrating how these measures can be used, researchers applied 16 ACOVE indicators for end-of-life care and pain management to the care of almost 500 patients who died at the University of California, Los Angeles, Medical Center between April 2005 and April 2006 (Walling et al., 2010). These indicators, which could be measured using information found in patient medical records, fit into three domains: eliciting goals of care, pain assessment and management, and dyspnea assessment and management. Of note, these domains have content overlap with NQF-endorsed measures. The researchers found that physician-patient/family communication was “the most striking area in need of quality improvement” (p. 1061). Deficits also were found in assessing breathing difficulties, documenting deactivation of ICDs, and establishing bowel regimens for patients taking opioids. The study found further that critical care units addressed goals of care only about half the time. High scores were obtained for pain assessments, pain treatment, and treatment for breathing difficulties (dyspnea).

In conjunction with the effort of CMS to establish quality measures for evaluating hospices, the Carolinas Center for Medical Excellence (the Quality Improvement Organization in North and South Carolina), in conducting the PEACE (Prepare, Embrace, Attend, Communicate, Empower) Project, initially identified 174 measures in the literature, from governmental agencies including the Agency for Health Research and Quality (AHRQ) and CMS and from previous quality measurement efforts by NQF and the RAND Corporation. Of these 174 measures, 88 were submitted to a technical expert panel for review (Schenck et al., 2010). The panel gave high ratings to 34 measures, falling within all eight domains of the NCP’s Clinical Practice Guidelines, but most heavily in the domain of physical aspects of care. In a related exercise, 39

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<sup>13</sup>The NCP domains are generally consistent with the quality domains suggested by the American Geriatrics Society and emphasized in the *Approaching Death* report (IOM, 1997): physical and emotional symptoms; support of function and autonomy; advance care planning; aggressive care near death—site of death, cardiopulmonary resuscitation (CPR), and hospitalization; patient and family satisfaction; global quality of life; family burden; survival time; provider continuity and skill; and bereavement.

instruments measuring mainly physical, psychological, or social aspects of palliative care, identified through a literature review, received high psychometric ratings (Hanson et al., 2010).

Specific new quality indicators have been advocated. One opinion, for example, is that quality standards should prohibit placing feeding tubes in people with advanced dementia, in line with recommendations of leading professional groups (Unroe and Meier, 2013; Fischberg et al., 2013).

### **Limitations of Current Quality Measurement and Reporting Efforts**

There are important opportunities to improve existing quality measures for care near the end of life. The NQF-endorsed measures listed above reflect substantive limitations. Of these 14 items, 4 involve pain, 3 patient preferences, 3 bereaved family or close friend perceptions of the quality of care, 2 dyspnea, 1 ICD, and 1 “comfortable dying” (NQF, 2012). While NQF’s Consumer Assessments and Reports of End of Life (CARE) survey assesses decision making using a postdeath survey of the bereaved family, there is no NQF-endorsed measure of shared decision making that asks the seriously ill person about his/her perceptions of the quality of care and the quality of shared decision making. Current NQF-endorsed measures also do not adequately measure the experience of caregiving, advance care planning, concordance with patient preferences, burdensome transitions, or the timeliness of referral to palliative care services. Presumably, these omissions result from a lack of evidence validating specific measures in any of these areas.

Patient and family satisfaction has been used as a relatively common indicator of the quality of end-of-life care. But the measurement of family satisfaction is subject to methodological inconsistencies—for example, the use of qualitative versus quantitative methods or direct versus indirect questions to ascertain satisfaction (Aspinal et al., 2003). Indirect methods may illuminate specific components of care that affect satisfaction and perceived quality of care. An examination of 117,000 surveys from 819 hospices in 2005, for instance, found that family members were more likely to rate hospice services as excellent if they, as family members, were regularly informed about the patient’s condition and treatment, if they could identify a single nurse as being in charge of the patient’s care, and if they believed the hospice was providing them with the right amount of emotional support (Rhodes et al., 2008). Still, the measurement of satisfaction may be influenced by factors other than quality per se, such as sociodemographic factors or fulfilment of expectations (Aspinal et al., 2003).

Efforts to establish criteria for evaluating the quality of care near the end of life are ongoing. As previously mentioned, a preliminary set of 18 quality measures or criteria was developed through a consensus process in the mid-2000s (Mularski et al., 2006). However, a systematic review of 16 publications on quality indicators for palliative care led researchers to conclude that, while a number of quality indicators have been identified, few development processes for these indicators have been described in detail, and additional specification of methodological characteristics is needed (Pasman et al., 2009). An update to that review identified an additional 13 publications containing 17 sets of quality indicators (including 9 new sets and 8 sets also identified in the previous review) and again determined that further development of indicators is needed (De Roo et al., 2013).

In nursing homes, place of death (in the nursing home or in the hospital) and hospice enrollment were identified as important quality measures for end-of-life care, ones that could be measured using existing administrative data, such as the Minimum Data Set, Medicare enrollment files, and Medicare claims data (Mukamel et al., 2012). Both of these measures were

found to be more effective in identifying low-quality than high-quality outliers. Illustrating how these two measures can be used, a study of decedents nationwide between 2003 and 2007 found that within nursing homes, residents with dementia were more likely than other residents to use hospice and to avoid transfer to a hospital as the place of death (Li et al., 2013). Residents of nursing homes with a high prevalence of dementia also were more likely than residents of other nursing homes to use hospice.

Measurement of care components agreed upon as constituting quality care may identify systematic variation in care quality. For example, smaller or independent hospices may be less likely than larger or chain-affiliated programs to achieve comprehensive implementation of preferred practices identified by NQF (Carlson et al., 2011).<sup>14</sup> A similar issue arises regarding place of death—namely, the probability that a person will die in a critical care unit, in another type of hospital unit, or in a more comfortable setting. On this measure, geography appears to be a significant factor, at least for people with cancer. Nationwide, from 2003 to 2007, about 29 percent of Medicare decedents with advanced cancer died in a hospital, but rates ranged from 7 percent in Mason City, Iowa, to 47 percent in Manhattan (Goodman et al., 2010).

Coordination of care is a linchpin of high-quality end-of-life and palliative care and is particularly difficult to measure. An examination of 111 root-cause analysis reports submitted by outpatient departments to the VA's National Center for Patient Safety in 2005-2012 showed that most delays in diagnosis and treatment involved poor communication and coordination among health professionals, other staff, and patients. "Failures in the process of follow-up and tracking of patients were especially prominent, mentioned in more than half of the reports" (Giardina et al., 2013, p. 1371).

At times, quality scores turn out to be unrelated to quality of care, or facilities meeting standards have widely varying performance on recognized quality measures. For example, the Health Resources and Services Administration and the Center for Medicare and Medicaid Innovation use an assessment developed by the National Committee for Quality Assurance (NCQA) to certify community health centers as patient-centered medical homes. One study found that while all 30 of the surveyed centers met criteria for becoming an NCQA-recognized patient-centered medical home, no association was found between performance on the NCQA assessment that determines this recognition and the quality of patient care (Clarke et al., 2012). In what may be of particular interest to advocates of improved end-of-life care, the authors note that the NCQA assessment does not include measures reflecting the provision of social or "enabling" services, such as assistance in obtaining government benefits, transportation, and community outreach. Experience suggests the great difficulty of devising standards that take into account factors as diverse as staff composition, clinical performance, provision of ancillary and supporting services, and quality improvement efforts. Overall, any effort to recognize high-quality care near the end of life faces formidable methodological challenges.

### **Opportunities for Enhancing Measurement and Reporting**

According to the IOM (2013, p. 301), "Cancer care quality measures provide a standardized and objective means for assessing the quality of cancer care delivered," and

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<sup>14</sup>Similarly, an American Society of Clinical Oncology initiative to measure office-based practices' adherence to cancer care guidelines found that showing physicians how well their practice performed failed to lead to measurable improvements in performance. The authors speculate that this failure may relate to small practices' lack of financial resources to institute formal quality improvement efforts (Blayney et al., 2012).

objective measures can serve the same function for end-of-life care. That report's recommendation on quality measurement (Recommendation 8) entails developing "a national quality reporting program for cancer care as part of a learning health care system" (p. 301). To this end, the report says, "the Department of Health and Human Services should work with professional societies to:

- Create and implement a formal long-term strategy for publicly reporting quality measures for cancer care that leverages existing efforts.
- Prioritize, fund, and direct the development of meaningful quality measures for cancer care with a focus on outcome measures and with performance targets for use in publicly reporting the performance of institutions, practices, and individual clinicians.
- Implement a coordinated, transparent reporting infrastructure that meets the needs of all stakeholders, including patients, and is integrated into a learning health care system" (IOM, 2013, p. 301-302).

In any setting and at any stage of life, high-quality health care is "safe, effective, patient-centered, timely, efficient, and equitable" (IOM, 2001, p. 40). The third of these characteristics, patient-centeredness, is especially important for patients near the end of life. Care marked by preset protocols and impersonal treatment can deprive patients of their essential dignity, autonomy, and comfort. The committee believes it is essential for end-of-life care to reflect awareness of the individual's personal history and unique physical, emotional, intellectual, cultural, spiritual/religious, financial, and social situation, as well as the roles of family members and other key individuals in the person's life. High-quality patient-centered care at the end of life also should, to the extent possible, reflect patients' values, goals, and informed preferences (see Chapter 3); maintain quality of life under the constraints of advancing disease; and support family and other caregivers.

Health policy makers recently have been focusing on identifying high-quality providers as a means of improving the overall quality of health care, and end-of-life care is no exception. Hospices face a financial penalty (a 2 percentage point reduction in the market basket percentage increase for a particular fiscal year) under the Affordable Care Act for failure to report on quality measures endorsed by a "consensus-based entity"<sup>15</sup> (CMS, 2013b; see also Meier, 2011, p. 353). Initial implementation of this Hospice Quality Reporting Program (HQRP) by CMS called for hospices to report on only two measures: the NQF #0209 pain measure ("the number of patients who report being uncomfortable because of pain at the initial assessment who report that pain was brought to a comfortable level within 48 hours") and a structural measure addressing the organization's Quality Assessment and Performance Improvement Plan. Beginning in 2014, however, these previously used measures will be discontinued, and hospices will be required under the HQRP to complete and submit to CMS the Hospice Item Set, which collects data on seven NQF-endorsed measures:

- patients treated with opioid who are given a bowel regimen (NQF #1617),
- pain screening (NQF #1634),

<sup>15</sup>*Patient Protection and Affordable Care Act of 2010*, Public Law 111-148, 111th Cong., 2d Sess. (January 5, 2010), §3004(c).

- pain assessment (NQF #1637),
- dyspnea treatment (NQF #1638),
- dyspnea screening (NQF #1639),
- treatment preferences (NQF # 1641), and
- beliefs/values addressed (if desired by the patient) (Modified from NQF #1647).

Starting in 2015, in addition to the Hospice Item Set quality reporting requirements, CMS will require that hospices, complete the Hospice Experience of Care Survey, which will gather information from caregivers of deceased hospice patients about patient and family experiences with hospice care (CMS, undated; HHS, 2013).

Palliative care programs, by contrast, are not required to report on the quality of the care they provide, nor are accountable care organizations or large systems. The result is a lack of transparency and accountability. There is no consensus on quality measures to use for this purpose or a general approach for determining the locus of accountability for the quality of end-of-life care—the palliative care program or the physician, the hospital where the program is based, or the entire hospital or other integrated system?

A voluntary advanced certification program for palliative care programs has been created by the Joint Commission, which accredits hospitals and other providers of care. Advanced certification is accorded to “hospital inpatient programs that demonstrate exceptional patient and family-centered care and optimize the quality of life for patients (both adult and pediatric) with serious illness” (Joint Commission, 2014a). Certification criteria include whether the program employs an organized interdisciplinary approach, uses practice guidelines, directs the clinical management of patients and coordinates care, offers around-the-clock availability of the full range of palliative care services, and includes a measurement-based quality improvement component (Joint Commission, 2014b). While programs are required to collect data on at least four performance measures, including two clinical measures, the Joint Commission does not specify which measures must be implemented; each program may choose the performance measures that are most important and relevant and thus necessitate review and analysis. As of May 2014, 66 programs had received certification under this program (Joint Commission, 2014c).<sup>16</sup>

In addition, a task force of the American Academy of Hospice and Palliative Medicine and an advisory group of the Hospice and Palliative Nurses Association have begun collaborating to identify a core set of evidence-based performance measures that would apply to all hospice and palliative care programs across care settings. This effort, called “Measuring What Matters,” has the aim of developing a list of basic, advanced, and “aspirational” measures that build on the work on the NCP domains and guidelines and the NQF measures, as well as other previously developed measures (American Academy of Hospice and Palliative Medicine, undated-a). A technical advisory panel referred 34 measures to a clinical user panel, which narrowed the list down to 12 existing measures from the PEACE Project, NQF, ACOVE, NHPCO, and National Committee for Quality Assurance/American Medical Association-Physician Consortium for Performance Improvement (NCQA/PCPI) that fall within six of the eight NCP domains (American Academy of Hospice and Palliative Medicine, undated-a, b). The

<sup>16</sup>The first five programs accorded certification, in 2012, were those based at Regions Hospital, St. Paul, Minnesota; Strong Memorial Hospital, Rochester, New York; Mount Sinai Medical Center, New York, New York; St. Joseph Mercy Oakland, Pontiac, Michigan; and The Connecticut Hospice, Inc., Branford, Connecticut (HealthPartners, 2012).



list will be culled further. The broad applicability of the selected measures and the development of a common denominator, a task that is planned for the next phase of this effort, will allow for benchmarking and comparison across programs and settings (American Academy of Hospice and Palliative Medicine, undated-c).

### Proposed Core Components of Quality End-of-life Care

Many stakeholders—patients, caregivers, families, the public, health professionals, health care administrators, payers, and policy makers—would benefit from an authoritative, validated list of the core components of quality end-of-life care. Core components would apply to care near the end of life of every type, provided in every setting. They would include not only hospice and palliative care but also the usual care received by people with advanced serious illness who likely are approaching death, which may be provided by primary care physicians, physician specialists, nurses, and other personnel in hospitals, nursing homes, assisted living facilities, outpatient clinics, private homes, and other settings.

Unfortunately, the evidence base falls short of supporting the establishment of such a validated list. Nonetheless, the committee proposes a list of components, based on existing quality indicators, the existing literature, the committee members' expert judgment, and their varied and extensive experience. This list, shown in Table 2-2, is advanced to suggest an agenda for research and policy development, since each item included should be tested to determine whether it is supported by clinical findings across a wide range of patients and by the opinions of patients, families, and clinicians involved in care near the end of life. In addition, the most valid way to measure each of the proposed components of quality end-of-life care will need to be identified.

Key to all 12 of these core components is flexibility and individual tailoring over time, reflecting patient and family priorities and preferences. Those involved in a patient's care must be nimble in responding to individual needs and evolving circumstances. Regular meetings between the care team and the patient and family may facilitate achieving these components of quality end-of-life care as the patient's and family's needs evolve over time.

**TABLE 2-2** Proposed Core Components of Quality End-of-Life Care

Component	Rationale
Frequent assessment of patient's physical, emotional, social, and spiritual well-being	Interventions and assistance must be based on accurately identified needs.
Management of emotional distress	All clinicians should be able to identify distress and direct its initial and basic management. This is part of the definition of palliative care, a basic component of hospice, and clearly of fundamental importance.
Offer referral to expert-level palliative care	People with palliative needs beyond those that can be provided by non-specialist-level clinicians deserve access to appropriate expert-level care.
Offer referral to hospice if the patient has a prognosis of 6 months or less	People who meet the hospice eligibility criteria deserve access to services designed to meet their end-of-life needs.
Management of care and direct contact with patient and family for complex situations by a specialist-	Care of people with serious illness may require specialist-level palliative care physician management, and effective physician management requires direct examination, contact, and

level palliative care physician	communication.
Round-the-clock access to coordinated care and services	Patients in advanced stages of serious illness often require assistance, such as with activities of daily living, medication management, wound care, physical comfort, and psychosocial needs. Round-the-clock access to a consistent point of contact that can coordinate care obviates the need to dial 911 and engage emergency medical services.
Management of pain and other symptoms	All clinicians should be able to identify and direct the initial and basic management of pain and other symptoms. This is part of the definition of palliative care, a basic component of hospice, and clearly of fundamental importance.
Counseling of patient and family	Even patients who are not emotionally distressed face problems in such areas as loss of functioning, prognosis, coping with diverse symptoms, finances, and family dynamics, and family members experience these problems as well, both directly and indirectly.
Family caregiver support	A focus on the family is part of the definition of palliative care; family members and caregivers both participate in the patient's care and require assistance themselves.
Attention to the patient's social context and social needs	Person-centered care requires awareness of patients' perspectives on their social environment and of their needs for social support, including at the time of death. Companionship at the bedside at time of death may be an important part of the psychological, social, and spiritual aspects of end-of-life care for some individuals.
Attention to the patient's spiritual and religious needs	The final phase of life often has a spiritual and religious component, and research shows that spiritual assistance is associated with quality of care.
Regular personalized revision of the care plan and access to services based on the changing needs of the patient and family	Care must be person-centered and fit current circumstances, which may mean that not all the above components will be important or desirable in all cases.

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NOTE: The proposed core components of quality end-of-life care listed in this table were developed by the committee. Most of the components relate to one of the domains in the Clinical Practice Guidelines for Quality Palliative Care set forth by the National Consensus Project for Quality Palliative Care (Dahlin, 2013).

### **THE PROBLEM OF PROGNOSIS**

The problem of prognosis—establishing the life expectancy of a patient with an advanced serious illness or medical condition who is likely approaching death—is important for several reasons. A patient's prognosis

- has important personal implications, affecting the patient's state of mind and decisions about how to spend the next several weeks or months and the family's support for the patient;
- has financial implications that may affect the patient's and family's decisions about earning and spending;

- has family caregiver implications, affecting family caregivers’ understanding of what will be expected of them and for how long;
- has clinical implications, affecting decisions about treatment of the illness and of comorbid conditions, and referrals to hospice and social services;
- may have legal implications, affecting the preparation and implementation of advance directives<sup>17</sup>; and
- affects eligibility for hospice care under the Medicare Hospice Benefit (see Box 2-6).

#### BOX 2-6

##### Prognosis and the Medicare Hospice Benefit

Under the Medicare Hospice Benefit, the patient’s prognosis may have negative practical consequences. As discussed in Chapter 5, one of the eligibility requirements for the Medicare Hospice Benefit is an expected prognosis of 6 months or less if the disease runs the expected course. According to the former medical director of a home hospice, for example, when a patient’s pulmonologist determined that her chronic obstructive pulmonary disease (COPD) prognosis was more than 6 months, the pulmonologist effectively discharged her from hospice against her will. She thereby lost access to regular nursing care and other supportive services and died less than 2 months later. The writer offers the opinion that patients’ eligibility for hospice should be based on “their demonstrated need for supportive care services—in other words, based on the weight of their symptoms, their level of functional impairment, or the burden their illness imposes on caregivers” (Groninger, 2012, p. 455).

#### Prognostic Uncertainties

Predicting prognosis is easier for certain diseases, such as solid-tumor metastatic cancers, than for many other common and serious conditions, such as stroke, heart failure, COPD, end-stage renal disease, frailty, dementia, and Parkinson’s disease. Among elderly people especially, assessing the overall prognosis may be difficult because these patients frequently suffer from two or more such conditions. Predicting the time course and prognosis of disabling genetic or congenital disorders that affect children is similarly problematic.

Although most people have high levels of disability by the last few months of life, the trajectory of disability, like life expectancy, is difficult to predict, even when people with the same medical condition are compared. Variation in disability trajectories “poses challenges for the proper allocation of resources to care for older persons at the end of life” (Gill et al., 2010, p. 1180). Nevertheless, an increasing level of disability, combined with frailty and accumulating symptoms, may be the most useful signal of the need for palliative care assessment and subsequent provision of palliative services.

#### Predictive Models

Expected longevity is typically the major focus of prognosis. An appendix to *Approaching Death* (IOM, 1997, Appendix D) describes efforts to develop clinical forecasting models, especially for acute myocardial infarction, coma, pediatric intensive care, and critical

<sup>17</sup>For example, the New Jersey Supreme Court’s holding that prognosis, broadly defined, affects the legality of decisions to withhold or withdraw life-sustaining treatment in accordance with patients’ determined preferences: *In re Quinlan*, 70 N.J. 10, 355 A2d 647 (1976); *Matter of Jobes*, 108 N.J. 335, 529 A2d 434 (1987); and *Matter of Peter by Johanning*, 108 N.J. 365, 529 A2d 419 (1987).

care. The discussion emphasizes several limitations of such models, some of which are technical: statistical limitations, inherent imperfections, and inadequate accounting for disease specificity and the effects of interventions. However, other limitations may be inherent in the predictive process: death is not the only outcome of interest; critical illness is a dynamic process; the models' complexity impedes their usefulness; and the perspective of the model differs from the perspective of the patient or family.

Since the release of that report, new forecasting models have emerged. Table 2-3 lists components of these models, and as this table reveals, there is little overlap. (A forecasting model for pediatric mortality is mentioned in Appendix F.)

A systematic review determined that the most accurate of 13 models for predicting life expectancy in patients with advanced, incurable cancer is the Palliative Prognostic (PaP) score, along with a PaP variant that includes dementia (D-PaP) (Krishnan et al., 2013). PaP scores estimate survival at 1 month, and the PaP model has been externally validated (Pirovano et al., 1999; Maltoni et al., 1999). The authors of the systematic review note the need for further research to establish reliable prognoses across a broader spectrum of time and to determine the effect of the use of prognostic tools on the quality of end-of-life care.

With regard to non-disease-specific models, a systematic review of 16 indices predicting mortality risk in people over age 60 in community, hospital, or nursing home settings “identified several high-quality prognostic indices.” However, the authors found that “there is insufficient evidence at this time to recommend the widespread use of prognostic indices in clinical practice” (Yourman et al., 2012, p. 190). According to the authors, limitations of the models include potential bias and failure to predict either very low or very high risk of mortality—precisely the information most likely to be useful to clinicians. The conclusion that these limitations may impede a clinician's ability to apply prognostic models in a clinical setting appears to bear out the skepticism expressed in *Approaching Death* (IOM, 1997, Appendix D).

The following are examples of the many studies presenting prognostic models:

- A British prospective cohort study based at multiple palliative care centers—the Prognosis in Palliative Care Study (PIPS)—produced a composite model for predicting survival of cancer patients at 2 weeks and 2 months (Gwilliam et al., 2011). This model has not been externally validated (Krishnan et al., 2013).
- Another study identified criteria for determining the likelihood of dying within 1 year. According to the study authors, these “CARING” criteria can be used at the time of hospital admission to determine whether the patient is ready for palliative care (Fischer et al., 2006). This model has been validated (Youngwerth et al., 2013).
- Still another study used 1998 Health and Retirement Study data for people over age 50 living in the community to identify 12 independent predictors of mortality within 4 years (Lee et al., 2006). According to the systematic review of non-disease-specific indices cited above, this model “was well calibrated and showed very good discrimination,” although it was not externally validated (Yourman et al., 2012, p. 186). While this model shows promise, its relevance to the population that is near the end of life has not yet been demonstrated given that it is currently validated only for mortality within 4 years.

Acute physiology and chronic health evaluation (APACHE) and ePrognosis are two tools that can be used to assess prognosis in clinical settings. APACHE is a scoring system that uses

predictor variables and measures collected shortly after a patient's admission to the intensive care unit to determine severity of disease and likelihood of in-hospital mortality (Knaus et al., 1985, 1991; Wong and Knaus, 1991). ePrognosis is a website and software application that aggregates prognostic indices to provide clinicians with information about patients' possible mortality outcomes based on answers to questions about certain predictor variables (such as those listed in Table 2-3) (ePrognosis, 2014).

**TABLE 2-3** Factors Used to Predict Mortality in Five Illustrative Prognostic Models

Factors	PIPS*	PaP	CARING	HRS	Cheng
Cancer or metastatic disease (any site)	X		X	X	
Malignant effusion					X
Liver metastases	X				
Lung disease				X	
Heart failure				X	
Diabetes				X	
Anorexia or loss of weight	X	X			X
Dyspnea		X			
Age (with more points for each older age category; applies to adults only)				X	
Sex				X	
General health status	X				
Mental test score	X				
Performance status	X	X			X
Critical care unit admission with multiorgan failure			X		
Hospital admissions (two or more)			X		
Nursing home residence			X		
Applicability of two or more noncancer hospice guidelines			X		
Current tobacco use				X	
Body mass index				X	
Pulse rate	X				
White blood count	X	X			
Platelet count	X				
Lymphocyte count or lymphopenia		X			
Hypercalcemia					X
C-reactive protein	X				
Urea	X				
Bathing				X	
Walking several blocks				X	
Pushing/pulling large objects				X	
Managing money				X	
Physician's survival prediction (in weeks)		X			

NOTES: CARING = Cancer, Admissions  $\geq 2$ , Residence in a nursing home, Intensive care unit admit with multiorgan failure,  $\geq 2$  Noncancer hospice Guidelines; HRS = Health and Retirement Study; PaP = Palliative Prognostic; PIPS = Prognosis in Palliative Care Study.

\*These factors were found in the PIPS study to predict survival at both 2 weeks and 2 months. Factors found to predict survival at 2 weeks only were dyspnea, dysphagia, bone metastases, and alanine transaminase. Factors found to predict survival at 2 months only were primary breast cancer, male genital

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cancer, tiredness, loss of weight, lymphocyte count, neutrophil count, alkaline phosphatase, and albumin. SOURCES: PIPS: Gwilliam et al., 2011; PaP: Pirovano et al., 1999; CARING: Fischer et al., 2006; HRS: Lee et al., 2006; Cheng: Cheng et al., 2013.

There are also informal methods for developing prognoses, with less proven reliability. A group of palliative care specialists in oncology, for example, concluded that “it is relatively easy to predict which patients have less than six months to live” (Cheng et al., 2013, p. 85). According to these authors, four factors (“Cheng” factors shown in Table 2-3) “should all trigger discussion about hospice” (p. 85).

Another informal tool that has been used to identify patients for whom palliative care may be appropriate is the “surprise” question: “Would I be surprised if this patient died in the next 12 months?” (Moss et al., 2008, 2010). While not perfect, the “surprise” question can be applied simply and effectively by health care professionals as a way to identify patients with a poor prognosis.

It should be cautioned, however, that “there will always be some uncertainty in prognosis” (Smith et al., 2013c, p. 2448). For example, if a physician knows a patient belongs to a group with a 25 percent risk of dying within 6 months, the physician still does not know whether this particular patient is in the 25 percent subset or the 75 percent subset. Smith and colleagues (2013c) recommend that physicians be honest with patients about the boundaries of predictive knowledge, address patients’ and families’ emotions about uncertainty, and help them live in the present despite an uncertain prognosis (see also Chapter 3).

## **FAMILY CAREGIVERS**

Family caregivers (with family defined broadly; see the guiding principles in Box 1-3 in Chapter 1) provide many types of assistance to people with a chronic disease or disabling condition. An estimated 66 million Americans, or 29 percent of the adult population, are caregivers; nearly two-thirds are women (National Alliance for Caregiving, 2009). They provide an average of 20 hours of services per week and are heavily involved in assisting with instrumental activities of daily living. Information about the number and responsibilities of family caregivers is not available specifically for the population nearing the end of life. This report uses the term “family caregivers” to describe people in this role; other terms used include “informal caregivers,” “carers,” “primary caregivers,” and “volunteer caregivers.” Whatever the term, these individuals often exhibit extraordinary commitment, provide incalculable value, and face significant burdens in carrying out the caregiver role.

While many family members readily assume this responsibility—and may not consider it a “burden” at all—it takes a largely unrecognized toll. The toll increases when family caregivers must administer medications (including opioid pain relievers); maintain complex equipment; and perform the physical labor of feeding (and possibly preparing special diets), bathing, toileting, changing and cleaning, dressing, turning, and transporting a family member (National Alliance for Caregiving, 2009; Reinhard et al., 2012). Caregiving takes a psychological toll when family members worry about performing all those tasks safely and well, when caregiving keeps them from meeting responsibilities to other family members, when their loved one is frightened or in pain, when they receive little training or guidance, and when they do not receive help in managing their own fears (National Alliance for Caregiving, 2009). When the patient is a child, the family caregiver role is made more difficult by the relative youth and inexperience of the

parents, the frequent need to travel long distances to obtain subspecialty pediatric care, deep strains on the parents' relationship with each other, and the vulnerability of siblings to profound emotional stress (Sourkes, 2013).

*I belong to a caregivers group which is supportive. People who are not caregivers don't understand the continuous burden of the role and seem to think it can be walked away from or put aside forever or for a while. Not so. The stress feels as if I'm constantly holding my breath. That combined with dealing with financial concerns, the medical and insurance communities is just too much....Transportation is also a barrier; just getting the sick person to appointments is physically demanding, and visiting in the hospital is wearying. Parking is a big expense. Pushing a wheelchair is physically demanding.\**

\*Quotation from a response submitted through the online public testimony questionnaire for this study. See Appendix C.

Caregiving also takes a financial toll when families face high out-of-pocket costs for services and equipment or when family income decreases because family caregivers must reduce their work hours or leave their jobs altogether (Evercare and National Alliance for Caregiving, 2007; Feinberg et al., 2011; National Alliance for Caregiving, 2009). Employer support may therefore be crucial for employed family caregivers. Aware of caregiver absenteeism and lost productivity, some employers offer greater flexibility in working hours and location or other special assistance (Coalition to Transform Advanced Care, 2013).

*It took all of our savings to keep my husband at home. And it took five of us to give him the round-the-clock care he needed.\**

\*Quotation from a response submitted through the online public testimony questionnaire for this study. See Appendix C.

Given an explicit choice, most people would prefer to spend their last weeks and days in their own home, free of pain, clean and comfortable, and in control—not in emergency departments, hospitals, and critical care units away from family and familiar surroundings (see Chapter 3). As discussed earlier in this chapter, new models of home and community health care delivery and improved communication technologies are making that choice increasingly possible; however, adequate support for family caregivers remains an unmet need.

In previous generations, caregiving was a widely expected role of women in families, and caregiving responsibilities often lasted only briefly, as people died at younger ages or sooner after the onset of a serious illness. Today's families are smaller, and many women work outside the home. Moreover, not only may caregiving be needed for lengthy periods, but it is also becoming more complex, requiring management of medical equipment and medication regimens, wound care, nutrition, mental health care, use of community resources, and so on—for the most part with no formal training (Feinberg, 2013; Reinhard et al., 2012). Some key information about family caregivers appears in Table 2-4.

*We share the care of my mother-in-law with worsening dementia. The fragmentation of care is challenging, even for professional healthcare providers. Home support is almost non-existent, and we tremble regarding the limited options when/if her needs exceed what we can provide in our homes.\**

\*Quotation from a response submitted through the online public testimony questionnaire for this study. See Appendix C.

**TABLE 2-4** Some Key Facts about U.S. Family Caregivers

Subject	Figure	Descriptor
Supply of family caregivers	4:1	Projected ratio of potential caregivers (aged 45-64) to people potentially in need (over 80) in 2030 (Redfoot et al., 2013)
Medication management	78%	Of caregivers that perform medical/nursing tasks, the proportion regularly administering drugs (average 5-9 medications per day) (Reinhard et al., 2012)
No home visits	69%	Proportion of caregivers not assisted with home visits by a health professional (Reinhard et al., 2012)
Caregivers who are employed	73 %	Proportion of caregivers employed at some time while caregiving (National Alliance for Caregiving, 2009)
Caregiving for parents	72%	Proportion of employed workers serving as caregivers who care for a parent or parent-in-law (Mendes, 2011)
Caregiving for elderly people	67%	Proportion of employed workers serving as caregivers who care for someone over age 75 (Mendes, 2011)
Duration of caregiving	55%	Proportion of employed workers serving as caregivers who have been doing so for 3 years or longer (Mendes, 2011)
Worker absenteeism	6.6 days	Employed family caregivers' average annual number of days of employed work lost as a result of caregiving (Witters, 2011)
Lost productivity	\$25.2 billion	Annual cost of lost productivity due to absenteeism caused by family caregiving (Witters, 2011)
Economic impact	\$450 billion	Value of family caregiving services in 2009 (Feinberg et al., 2011)

Meanwhile, the demand for family caregiving is growing with the rising prevalence of chronic diseases (Feinberg, 2013), as well as the long-term care trends that encourage more care at home and fewer nursing home placements (see Chapter 5). And the ratio of potential caregivers (people aged 45 to 64) to people 80 and older is expected to fall from 7:1 in 2010 to 4:1 by 2030 (Redfoot et al., 2013).

In theory, family caregivers should be in an ideal position to foster patient-centered care, starting with an understanding of the patient's health status, helping to identify care goals, and participating in the development of the plan of care (Gillick, 2013). But such participation requires support from the health care team. Although palliative care tends to provide such support, even families involved in palliative care often feel unprepared to perform the caregiving role (Abernethy et al., 2008; Kilbourn et al., 2011; Payne et al., 1999). And patients and families not receiving palliative care may lack any systematic caregiver support.



Personal attributes that help in the caregiver role include adaptability and resilience, and caregivers benefit from the constructive involvement of other family members. But they are at risk of loss of control, loss of identity, and loss of relationships, as well as exhaustion and eventual bereavement (Sourkes, 2013). In addition,

Caregivers are at increased risk of disease because of the burden and difficulties associated with caregiving. A lot don't sleep or eat right. They neglect themselves, so they're at higher risk of depression and anxiety, coronary types of problems and are more prone to getting sick (Vuong, 2013, quoting Dr. Linda Ercoli, Assistant Professor of Psychiatry, University of California Los Angeles).

Results of a systematic review of 19 studies from six countries (the United States, Canada, the United Kingdom, Norway, Israel, and Saudi Arabia) were inconclusive as to whether gender, age, and relationship to the patient affect caregiver stress. In 8 of the studies, however, stress was found to increase as the patient's condition worsened and death approached (Williams and McCorkle, 2011).

Family caregivers receive services as well as provide them. Those services may include respite care (temporary custodial care of the patient) and bereavement services—counseling, assistance with arrangements, and other supports for as long as a year after a death—which are a component of quality palliative care. Both respite and bereavement services are covered under the Medicare Hospice Benefit (CMS, 2012).

AARP, the National Alliance for Caregiving, and other groups have helped call attention to the extent of and challenges entailed in family caregiving. However, research on family caregivers' roles, needs, behavior, health risks, success in performance, interaction with professional members of the health care team, and use of respite care and other support services is not highly developed. Research on family caregiving remains sparse, perhaps reflecting its lack of visibility as compared with the services offered by health care professionals.

Family caregivers have received some protections from the federal government. The Family and Medical Leave Act of 1993 guarantees up to 12 weeks of job-protected unpaid leave for attending to the care needs of a spouse, child, or parent, but not other family members (DOL, 2013). The National Family Caregiver Support Program, established by the Older Americans Act, as amended in 2000, has helped increase awareness of the importance of family caregivers by establishing the caregiver as a client and providing family counseling, support groups, training, and respite care (Feinberg, 2013; AoA, 2012). The Affordable Care Act includes multiple references to caregivers and may help them by promoting models of care that prevent or facilitate transitions between care settings (Feinberg, 2013). Medicaid's Cash & Counseling program, available in about 15 states, permits beneficiaries to pay family members modest sums for home care services in some cases (National Resource Center for Participant-Directed Services, 2013). And family caregivers of seriously injured veterans (who served after September 11, 2001) may receive a stipend, comprehensive training, medical services, and other services under the VA Program of Comprehensive Assistance to Family Caregivers (VA, 2013).

An IOM committee investigating health care workforce needs for an aging America took note of the importance of integrating family caregivers into health care teams and providing them with better training. One recommendation of that committee reads: "Public, private, and community organizations should provide funding and ensure that adequate training opportunities are available in the community for informal caregivers" (IOM, 2008, p. 255).

## RESEARCH NEEDS

A comprehensive review of studies on end-of-life care (NINR, 2013) undertaken since the publication of *Approaching Death* (IOM, 1997) identifies a shortage of research on the changing demographic characteristics of populations experiencing serious advanced illnesses or multiple chronic conditions, especially kidney and liver conditions and HIV/AIDS. According to the NINR report, “Issues related to economics, ethics, and access must be integrated into new research paradigms[,] and attention to culture, ethnicity, and minorities must be made to produce a measurable shift in the focus of research grants, the sources of funding dollars, and the dissemination of meaningful results to inform and educate the public” (NINR, 2013, pp. xi-xii). The report suggests that public-private partnerships could help fill these research gaps and improve the delivery of hospice and palliative care.

This chapter has identified numerous important areas for further research, including

- the prevalence and nature of care that is neither beneficial nor wanted, and practical ways to avoid it;
- the effect of palliative care on longevity;
- the elements of palliative care likely to offer the greatest improvements in quality of life;
- evidence-based measures of quality end-of-life care, beyond those identified to date by NQF and including aspects of the proposed core components listed in Table 2-2;
- family caregivers’ roles, needs, behavior, health risks, success in performance, interaction with other members of the health care team, and use of respite care and other support services;
- reliable approaches to prognosis that start earlier in the disease trajectory, and assessment of whether more accurate prognoses lead to improvements in quality of life and other outcomes of care; and
- the effects and value of specific types of clinical innovations in delivering end-of-life care.

Pediatric-related research needs may be especially pressing. Appendix F suggests the need for research in the following areas for children near the end of life:

- comparative effectiveness studies of different approaches to symptom management and bereavement support;
- analyses of care received in emergency departments, outpatient settings, and hospices and through home health agencies;
- cohort studies examining the effect of palliative care on outcomes and on the patient experience; and
- studies of how best to staff, manage, and finance hospital-based pediatric palliative and community-based pediatric hospice services.

A general lack of investment in research on palliative care is identified in a review of the palliative care landscape referenced earlier in this chapter (Meier, 2011). That review suggests that the National Institutes of Health (NIH), in particular, can make important contributions in

this field. In 2006-2010, NIH funded 240 percent more palliative care projects than it did in 2001-2005, but palliative care still accounted for only a fraction of 1 percent of all NIH grants (Gelfman et al., 2010).

Given that palliative care is inherently patient-centered, the Patient-Centered Outcomes Research Institute (PCORI) may be a potential funding source for research in this field going forward. PCORI was established under the Affordable Care Act, and its research “is intended to give patients a better understanding of the prevention, treatment, and care options available, and the science that supports those options”<sup>18</sup> (PCORI, 2014). In developing its research priorities, PCORI reviewed previous comparative effectiveness prioritization efforts and found 10 common priority areas for comparative effectiveness research; palliative care was one of these areas (PCORI, 2012). While its own national priorities and research agenda do not specifically call for research on palliative care, many of the topics highlighted are relevant to this field, including prognostication, shared decision making, health care teams, and differences in patient preferences.

Besides concerns about the *quantity* of research on topics related to end-of-life care, there are concerns about the *quality* of such research. One concern is that an emphasis on developing quantifiable results through such traditional methods as randomized controlled trials tends to omit key questions, such as why a treatment was effective, how patients viewed their experience, and what mechanisms caused the outcomes observed (Fleurence et al., 2013; Steinhauser and Barroso, 2009; see also IOM, 2009, p. 31).<sup>19</sup> Efforts to broaden the types of investigations used in comparative effectiveness research and involve consumers in the design and execution of studies may help address this concern (Fleurence et al., 2013).

One potentially rich area of research involves linking major academic medical centers to community-based settings, using treatment results experienced by large numbers of patients to show which treatments work best for whom, and then disseminating that information back to clinicians and patients in useful ways (Westfall et al., 2007). This approach, typical of a “learning health care system,” would transform the nation’s clinical trials enterprise (IOM, 2012, especially p. 15, Table 2-1) and is endorsed in the recent IOM report on cancer care (IOM, 2013).

Practice-based research networks (PBRNs) are one practical way to conduct “practice-relevant” research in community-based settings. For example, PBRNs that are supported by AHRQ, link primary care practices in research relevant to community-based health care (AHRQ, 2013). Each PBRN includes at least five primary care practices; most of the research conducted by the current 131 networks has focused on underserved, low-income, and minority populations (Peterson et al., 2012). PBRNs are even collaborating to create consortia of research networks (Calmbach et al., 2012; Peterson et al., 2012).

Significant resources to facilitate the conduct of high-quality palliative care and end-of-life research have emerged since *Approaching Death* (IOM, 1997) was published. The National Palliative Care Research Center, acting in partnership with the Center to Advance Palliative

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<sup>18</sup>*Patient Protection and Affordable Care Act of 2010*, Public Law 111-148, 111th Cong., 2d Sess. (January 5, 2010), §6301.

<sup>19</sup>Randomized controlled trials also may exclude patients with multiple chronic conditions or chronic conditions combined with disabilities (Fleurence et al., 2013). This exclusion can leave out many people nearing the end of life. Trials also typically ignore family-related factors, including the role of family caregivers. In general, moreover, clinical trials assess only the efficacy of an intervention under carefully controlled conditions, not its effectiveness in the real world.

Care, provides a mechanism for establishing research priorities, preparing a new generation of researchers, and coordinating and supporting studies aimed at improving care (NPCRC, 2013). The Palliative Care Research Cooperative Group, established in 2010, offers a mechanism for connecting researchers and clinicians across varied clinical settings and facilitating timely completion of complex studies, including randomized controlled trials, by pooling resources and expertise across sites (Abernethy et al., 2010).

## FINDINGS, CONCLUSIONS, AND RECOMMENDATION

### Findings

This study yielded the following findings on the delivery of person-centered, family-oriented end-of-life care.

#### *Burdensome Transitions*

People nearing the end of life often experience multiple transitions between health care settings, including high rates of apparently preventable hospitalizations. These transitions can fragment the delivery of care and create burdens for patients and families (Coleman et al., 2006; Jencks et al., 2009; Naylor et al., 2013; Teno et al., 2013).

#### *Growth of Hospice*

The role of hospice in end-of-life care has been increasing in the last two decades. Hospice grew from being the locus of 17 percent of all U.S. deaths in 1995 to 45 percent in 2011 (IOM, 1997, p. 40; NHPCO, 2012a).

#### *Growth of Specialty Palliative Care*

The years since *Approaching Death* (IOM, 1997) was published also have seen the emergence and growth of specialty palliative care. By 2011, fully 85 percent of all hospitals with 300 or more beds reported having palliative care services (CAPC, 2011, 2013; see also Chapter 4 for information about the number of board-certified hospice and palliative physicians and certified nurses).

#### *Provision of Palliative Care*

The guidelines and expert advice of professional associations encourage oncologists, cardiologists, and other disease-oriented specialists to counsel patients about palliative care. Nevertheless, widespread adoption of the practice of timely referral to palliative care appears to be slow, despite support for integrating and improving the basic level of knowledge of palliative care among all clinicians who treat patients with serious advanced illness (Cheng et al., 2013; Goodlin, 2009; IOM, 2013; Matlock et al., 2010; Molony, 2013; Quill and Abernethy, 2013; Shaw, 2010; Smith et al., 2012).

#### *Interdisciplinary Teams for Palliative Care*

Besides physician specialists in hospice and palliative medicine, members of palliative care interdisciplinary teams often include specialty advanced practice nurses and registered

nurses, social workers, chaplains, pharmacists, rehabilitation therapists, direct care workers, and family members (Adams et al., 2011; American Occupational Therapy Association, 2011; American Society of Health System Pharmacists, 2002; Brumley and Hillary, 2002; Cruz, 2013; Hebert et al., 2011; Meier, 2011; NASW, 2013, 2014; NQF, 2006; Pollens, 2004; Puchalski et al., 2009; Vitello, 2008).

### *Impact of Hospice and Palliative Care on Longevity*

Some evidence suggests that on average, palliative care patients (including hospice patients) may live longer than similarly ill patients receiving usual care (Connor et al., 2007; Saito et al., 2011; Temel et al., 2010).

### *Impact of Palliative Care on Quality of Life*

Palliative care has been associated with a higher quality of life, as measured by indicators that include information and communication, access to home care, emotional and spiritual support, well-being and dignity, care at time of death, and a lighter symptom burden (Casarett et al., 2008; Gomes et al., 2013; Rabow et al., 2013; Temel et al., 2010).

### *Prognosis*

Since *Approaching Death* was published in 1997, new predictive models have emerged that enhance clinicians' ability to make valid and reliable medical prognoses. Lack of adequate prognostication may prevent some patients from receiving appropriate hospice care because of the 6-month prognosis rule in the Medicare Hospice Benefit (described in Chapter 5) (Fischer et al., 2006; Gwilliam et al., 2011; Krishman et al., 2013; Pirovano et al., 1999; Tax Equity and Fiscal Responsibility Act of 1982<sup>20</sup>; IOM, 1997, Appendix D. For commentary on the 6-month rule, see, e.g., Groninger, 2012).

### *Family Caregiving*

With an aging population, demand for family caregiving is increasing. At the same time, the types of tasks being performed by family caregivers are expanding from personal care and household tasks to include medical/nursing tasks, such as medication management and other services for those near the end of life. Three in 10 U.S. adults are family caregivers (National Alliance for Caregiving, 2009; Redfoot et al., 2013; Reinhard et al., 2012). Information about the number and responsibilities of caregivers specifically for those nearing the end of life is not available.

## **Conclusions**

Care near the end of life can be complex. People with serious advanced illness and their families could benefit from all clinicians having a basic level of competence in addressing the palliative care needs of this population. Such patients and their families may further require the involvement of interdisciplinary teams of professionals specifically trained in palliative care. Such care teams—whether available in hospitals, long term acute care facilities, nursing homes, hospices, clinics, or patients' homes—combine services and expertise to meet the broad needs of patients and families. However, palliative care currently is unavailable in many geographic areas

<sup>20</sup>Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA), P.L. 97-248, section 122.

and in many settings where people with advanced serious illness receive care. Transformational change is required, building on evidence about high-quality, compassionate, and cost-effective care that is person-centered and family-oriented and available wherever patients nearing the end of life may be. A further need is to continue to build and strengthen that evidence base while responding to challenges posed by new communication and biomedical technologies, growing demands on caregivers, and demographic change.

*Approaching Death* (IOM, 1997) was published 17 years ago. Then, hospice was well on its way to achieving mainstream status, and palliative care was in the early stages of development. Now, hospice is in the mainstream, and palliative care is well established in hospitals and in the professions of medicine, nursing, social work, and chaplaincy. Yet many clinicians and families still appear to not regard palliative care as an essential component of high-quality care. The needed shift among the public and health care providers toward recognizing all that hospice and palliative care can achieve remains incomplete.

### **Recommendation**

Government health insurers and care delivery programs as well as private health insurers should cover the provision of comprehensive care for individuals with advanced serious illness who are nearing the end of life.

Comprehensive care should

- be seamless, high-quality, integrated, patient-centered, family-oriented, and consistently accessible around the clock;
- consider the evolving physical, emotional, social, and spiritual needs of individuals approaching the end of life, as well as those of their family and/or caregivers;
- be competently delivered by professionals with appropriate expertise and training;
- include coordinated, efficient, and interoperable information transfer across all providers and all settings; and
- be consistent with individuals' values, goals, and informed preferences.

Health care delivery organizations should take the following steps to provide comprehensive care:

- All people with advanced serious illness should have access to skilled palliative care or, when appropriate, hospice care in all settings where they receive care (including health care facilities, the home, and the community).
- Palliative care should encompass access to an interdisciplinary palliative care team, including board-certified hospice and palliative medicine physicians, nurses, social workers, and chaplains, together with other health professionals as needed (including geriatricians). Depending on local resources, access to this team may be on site, via virtual consultation, or by transfer to a setting with these resources and this expertise.
- The full range of care that is delivered should be characterized by transparency and accountability through public reporting of aggregate quality and cost measures for all aspects of the health care system related to end-of-life care. The committee believes that informed

individual choices should be honored, including the right to decline medical or social services.

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