



# Enabling the Transition to Hospice through Effective Palliative Care

CEU

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**T**he end of life has changed dramatically in recent years as life expectancies have increased, chronic disease rates have risen, and families, health care systems, and society have changed. As technology has advanced, death too often has become viewed by society as “failure” and even “optional.” Too often, referral to hospice has come too late to be sufficiently effective. While expertise in palliation of pain and symptoms at the end of life has been developed, palliative care has not been well integrated with management of chronic diseases or incorporated into the continuum of medical management from health and wellness to the end of life. We can, and must, do better.

To achieve improved clinical outcomes in end-of-life care (EOLC), it is critical to recognize, to respect, and to integrate the expertise of many professional disciplines and to foster collaboration between physicians and case managers. Ensuring the clinical competency of all health care professionals in the key principles and evidence base of palliative care is essential, because these principles can be applied not only at the end of life but across the disease trajectory. Thus, palliative care becomes a core clinical competency for case managers. Consultative expertise from palliative care experts can be sought when needed for more difficult cases.

## Demographics of Aging

At the turn of the twentieth century, life expectancy for the average American

was 47. By the turn of the twenty-first century, life expectancy had improved to approximately 77 years old.<sup>1</sup> This increase is primarily a result of improved public health, sanitation, and health care. By 2030, 20% of the American population, or 70 million people, will be older than 65.<sup>2</sup> As the U.S. population continues to age, the number of patients requiring appropriate EOLC increases. Currently, 75% of people who die each year are over 65.<sup>2</sup>

At this point, 78 million baby boomers (people now 39 to 57) represent 27.5% of the total population. By 2030, the baby boomers will be 66 to 84 and are projected to compose 20% of the total population. The senior population reached approximately 30 million in 1998 and will

reach almost 40 million by 2011 and 50 million by 2019.<sup>3</sup> The fastest growing segment of the population is the segment of those who are 85+, a cohort with the highest prevalence rates of dementia. Because most of the 2.4 million Americans who die each year are at least 65 and death is an inevitable part of aging, the demand for EOLC can be expected to increase as demographics shift.

## Chronic Diseases

With this improved life expectancy, the incidence of chronic disease has increased. Chronic diseases are among the most prevalent, costly, and potentially preventable of all health problems. Approximately 80% of people 65 or older have at least one chronic condition, and 50% have at least two. In addi-

tion, an increasing prevalence of chronic disease is expected to rise with time.<sup>4</sup>

Although clinical advances have reduced the effects of many chronic diseases, our society has been unsuccessful in changing the behaviors that cause or exacerbate these diseases. Obesity, a preventable risk factor for such chronic diseases as diabetes and cardiovascular disease, is now epidemic. Nationally, almost 75% of adults 55 to 64 years old are overweight or obese.<sup>5,6</sup>

### Variations in Trajectory of Chronic Diseases

Advances in medicine and technology have allowed more and more Americans to live longer with chronic and advanced chronic illness. Patients with chronic disease often suffer from pain and depression, further complicating their management. Furthermore, variation occurs in the decline in function and health status, as well as progression of the expected course of different chronic diseases.<sup>7</sup> Multiple chronic diseases often coexist, particularly in the elderly, adding to the complexity of disease and case management.

While variability exists based on the specific type of cancer, patients typically experience a steady decline over a few years and a short terminal phase, often lasting less than 2 months. Currently human immunodeficiency virus behaves in this way. Patients with "organ system failure," such as patients with congestive heart failure and chronic obstructive lung disease, experience a slow decline over 2 to 5 years, punctuated by periodic crises that lead to progressive loss of function and health status. Often, an acute illness results in sudden unpredictable death. Patients with dementia or frailty of old age have associated deficits in activities of daily living, speech, and ambulation, and they experience a variable course that lasts up to 6 to 8 years. As illustrated in Figure 1, the presence of multiple chronic diseases adds to the complexity of prognostication, particularly with variable disease trajectories, as often seen in frail elders.

### Regional Variations in Medicare Spending

As the population ages, modern tech-

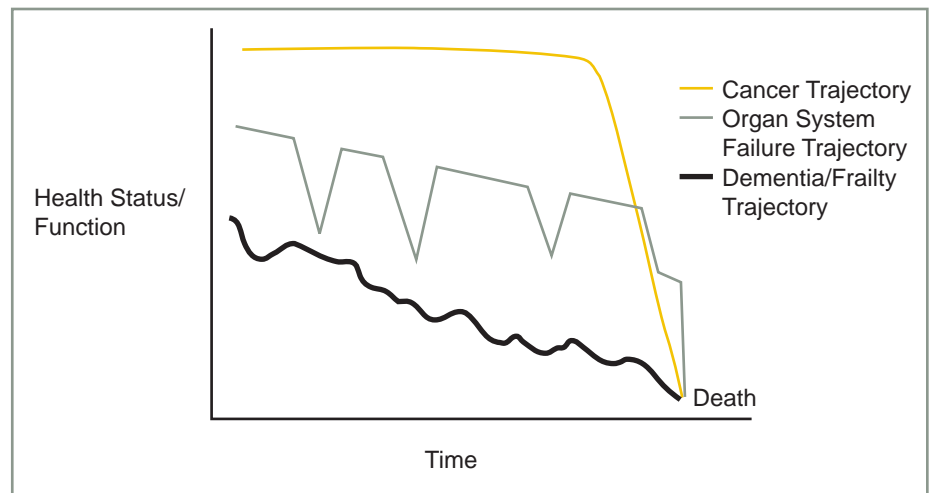


Figure 1. Chronic Illness Complicates Prognostication

nology increasingly extends the ability to intervene, particularly when life itself is threatened. In many cases, the improved technology has not improved prognosis but only prolonged dying. More than a fourth of Medicare patients spent time in the intensive care unit in the 6 months before their deaths.<sup>8</sup> The Dartmouth Atlas reports large regional variations in the portions of deaths occurring in hospitals.<sup>9</sup> Patients seeking aggressive treatment, physicians accustomed to aggressively treating dying patients, and patients not adequately prepared for the dying process all contribute to a big portion of hospitalizations during the dying process.

Regional differences in Medicare spending are largely explained by the more inpatient-based and specialist-oriented pattern of practice observed in high-spending regions. Neither quality of care nor access to care appear to be better for Medicare enrollees in higher-spending regions.<sup>10</sup> Enrollees in higher-spending regions receive more care than those in lower-spending regions but do not have better health outcomes or satisfaction with care.<sup>11</sup>

### Dying in America

Research has confirmed that too many Americans die badly. Despite the best options in medical science and technology, many patients with advanced, life-limiting illnesses suffer needlessly in the final stages of their lives. Major educational, cultural, social, and financial gaps exist. Humane care for those approach-

ing death is a social obligation that is not being met in our communities.

Too often, death is viewed as a medical failure rather than the final chapter of life. As a result, people have come to fear a technologically overtreated and protracted death, abandonment, and profound suffering for themselves and their family. Conversation about death is avoided in families and with providers until a crisis occurs, resulting in inadequate advance care planning and patient preferences that are not honored. Hospice care is introduced late, and inadequate palliation is provided. We must do better.

Death should not be seen as a defeat but simply as a part of the natural order; it is the natural outcome in 100% of those being treated with any therapy. Even when no further chance for recovery exists, hope remains for a moment without suffering, an hour of dignity, a day without pain, a week of bonding with family and friends, and a good death.

Stemming from the realization that much work needs to be done within the medical profession, the Institute of Medicine (IOM) published a report in 1997 titled "Approaching Death, Improving Care at the End of Life."<sup>12</sup> The aim was to improve the quality of care at patients' end of life by strengthening popular and professional understanding of the definition of good EOLC and by encouraging a wider societal commitment to caring well for people as they die. The IOM recognized site of death,

honored patient preferences, pain management, and hospice utilization as four quality indicators that can and should be measured as markers for excellence in EOLC.

### **Describing Death in America: What We Need to Know**

As noted earlier, about 2.4 million Americans die each year, most from or accompanied by chronic diseases. It is also now well known that more and more dollars are spent on medical care the nearer someone is to death. Although death is largely a phenomenon of old age, death among younger people is significant, adding up to half a million infants, children, and young adults. We know relatively little about the quality, appropriateness, or costs of care they receive or the burdens on caregivers and survivors. Even less is known about the deaths of young people than about deaths among middle-aged and elderly people. We have much to learn about the quality of care provided and the quality of life achieved by the dying in relation to that care during the final period of life.

No uniform standards have been set for technology utilization or appropriate hospitalization of dying patients. Avoidance of hospital costs during the final dying phase would likely reflect significant cost savings. As the baby boomers age, the demand for EOLC services and benefits coverage will increase. There is an urgent need to improve and to measure the quality, effectiveness, and standards of EOLC.<sup>13</sup>

### **Site of Death**

According to bioethicist George Annas, "If dying patients want to retain some control over their dying process, they must get out of the hospital they are in and stay out of the hospital if they are

out." To achieve high-quality EOLC at home, we must identify and provide for an individual's unmet needs. Comparison of state and national site of death statistics highlight the variation noted in Oregon. In 1980, 50% of Oregon deaths occurred in the hospital, compared with 35% in 1993 when the national average was 56%. In 1999, 31% of deaths were in a hospital, which represented the lowest rate in the country.

### **National Models of End-of-life Care Current Model: Hospice**

Unparalleled palliative care at the end of life has largely been provided by hospice and financed with the Medicare hospice benefit. Hospice delivers care that neither hastens nor postpones death; its focus is on maintaining quality of life, including relief from pain and other distressing symptoms, while integrating medical, psychologic, and spiritual aspects of care. Support systems are offered for patients to live as actively as possible, and for families during the patient's illness and in bereavement.

Hospice offers comprehensive care in the last months of life. Services are provided by a coordinated team of doctors, nurses, social workers, grief counselors, spiritual counselors, physical therapists, home health aides, and volunteers. All services are provided in the home, if at all possible. Otherwise, inpatient care is available in hospice facilities, special hospital units, and nursing homes.

Medicare beneficiaries are entitled to the benefit without additional premiums. The following hospice services are covered in full:

- Skilled nursing services
- Volunteer services
- Physician visits
- Skilled therapy
- Home health aide visits

- Medical social services
- Spiritual counseling
- Nutrition counseling
- Bereavement support for the family

The Medicare hospice benefit also covers 95% of the cost of drugs for pain and other symptoms and for inpatient respite care to relieve the caregiving responsibilities of the family, and most hospices do not collect the 5% copayment. For services related to the terminal illness, there are virtually no out-of-pocket expenses, even for drugs, equipment, and other expensive items that are often needed in the last months of life. No other Medicare benefit offers such financial protection. While the benefit does not cover 24-hour care, continuous nursing and short-term inpatient services are available during a medical crisis. The benefit also does not cover personal services.

Medicare beneficiaries are provided maximum choice and are permitted to choose any Medicare-certified hospice in the country. If patients prefer to be cared for by their own doctor rather than the hospice physician, most hospices will accommodate their preference.

The family's burden is reduced by the financial relief that the Medicare benefit provides and by the volunteers that hospices offer in addition to the hospice staff. Volunteers may do household chores, may keep the patient company, and generally may respond to the family's need for support. Bereavement services for families are available for about a year after death, so hospice patients are reassured that support will continue after they are gone. After hospice admission, there is virtually no paperwork, no bills, no claims, and no financial surprises.

To best serve their patients, case managers must know the eligibility criteria for the Medicare hospice benefit, which includes:

- Patient must have Medicare Part A
- Patient's doctor and the hospice medical director must confirm that the patient has a life expectancy of less than 6 months
- Patient must agree in writing not to pursue treatments for curing the illness

## **Self-Study Course on Coordinating Hospice**

Among the significant barriers to hospice care are lack of awareness and understanding of hospice and a reluctance of health professionals to discuss end-of-life options with their patients. To address these barriers, the American Hospice Foundation has produced "Coordinating Care at the End-of-life: The Role of Hospice," a new self-study course available on CD-ROM. The course focuses on communication skills to initiate advance care planning and reach consensus on end-of-life decisions with patients, families, and physicians. For further details, go to [www.americanhospice.org/news/SelfStudy.htm](http://www.americanhospice.org/news/SelfStudy.htm) or call (202) 223-0204.

- Some, but not all, hospices require patients to have a primary caregiver.

Despite the fact that hospice is widely available, its services are underused. The average length of treatment in hospice has dropped from 70 days in 1983 to approximately 36 days currently. To adequately address physical, emotional, psychosocial, and spiritual needs, experts estimate a dying patient needs at least 60 days of care from hospice.<sup>2</sup> Medicare benefits cover up to 180 days of hospice care. Extended care (more than 180 days) can be provided if justifiable.

### Enhanced Model

#### Addition of Palliative Care to Ease Transition to Hospice

In our current model of care, shown in Figure 2, patients choose to continue with life-sustaining treatments until they are able to accept death, and then they enter a hospice program. In making this choice, patients must be certified to have an incurable terminal illness and a life expectancy of 6 months or less. Palliative care experts observe that the current financing model forces individuals to choose between “curative” therapy and hospice care.

In 1990, the World Health Organization<sup>14</sup> defined *palliative care* as “an approach that improves the quality of life of patients and families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.”

“Palliative care:

- 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 patient’s illness and in their own bereavement
- Uses a team approach to address

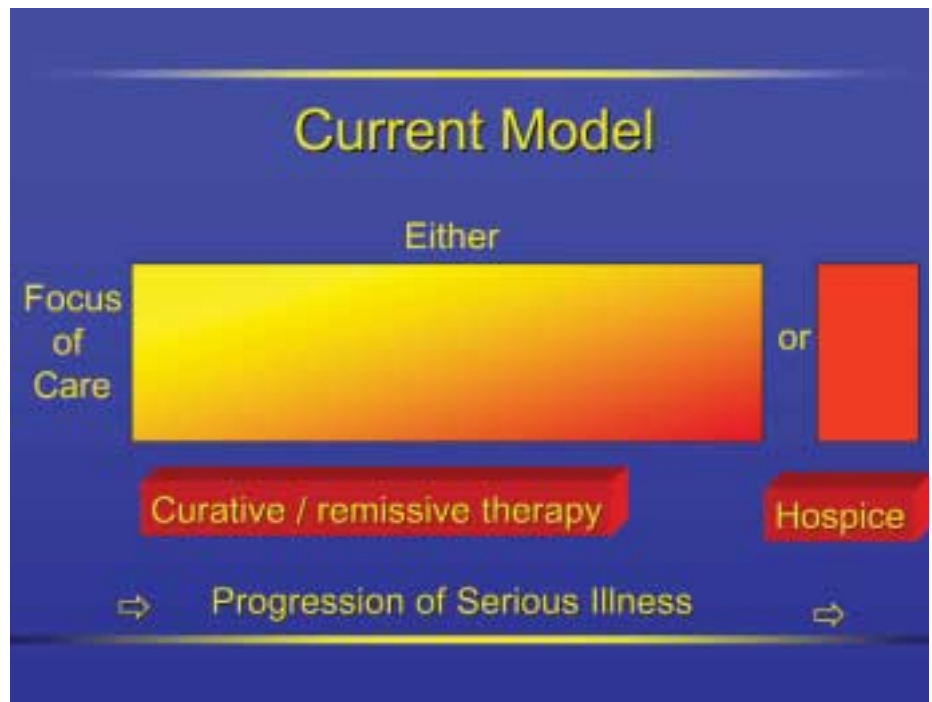


Figure 2. Hospice’s Place in Current Model of Health Care  
Adapted from *Education for Physicians on End-of-life Care*, 1999

the needs of patients and their families, including bereavement counseling, if indicated

- Enhances quality of life and also may 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 complication.”

As defined by the IOM in 1997, “Palliative care seeks to prevent, relieve, reduce, or soothe the symptoms of disease or disorder without effecting a cure. Palliative care in this broad sense is not restricted to those dying or those enrolled in a hospice program. It attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them.”<sup>12</sup> Essentially, palliative care embraces the philosophy of hospice care.

The Center for the Advancement of Palliative Care gave this definition in 2002: “Palliative care is interdisciplinary care that aims to relieve suffering and improve quality of life for patients with

advanced illness and their families. It is offered simultaneously with all other appropriate medical treatment.”<sup>15</sup>

On a national level, various models have been tried in an attempt to integrate palliative care into mainstream medicine. Educational initiatives, such as the Robert Wood Johnson Foundation-sponsored and the American Medical Association-developed “Education for Physicians on End-of-life Care,”<sup>7</sup> have been launched. Community coalitions have sprung up around the country. Hospital/hospice collaborations have launched palliative care inpatient teams and units. Data from Cedars–Mt. Sinai Medical Center have been shared at national symposia to build the business case for expansion of palliative care; this information is housed at their Web site.<sup>15</sup>

According to the 2001 IOM report “Crossing the Quality Chasm,”<sup>16</sup> the new model for care for the twenty-first century should be safe, effective, patient-centered, timely, efficient, and equitable. In this new model of care, patients and families set realistic goals, share in decisions, and develop plans of care. Services are reliable, accessible, culturally sensitive, and chosen based on informed, shared decision making. Palliative care

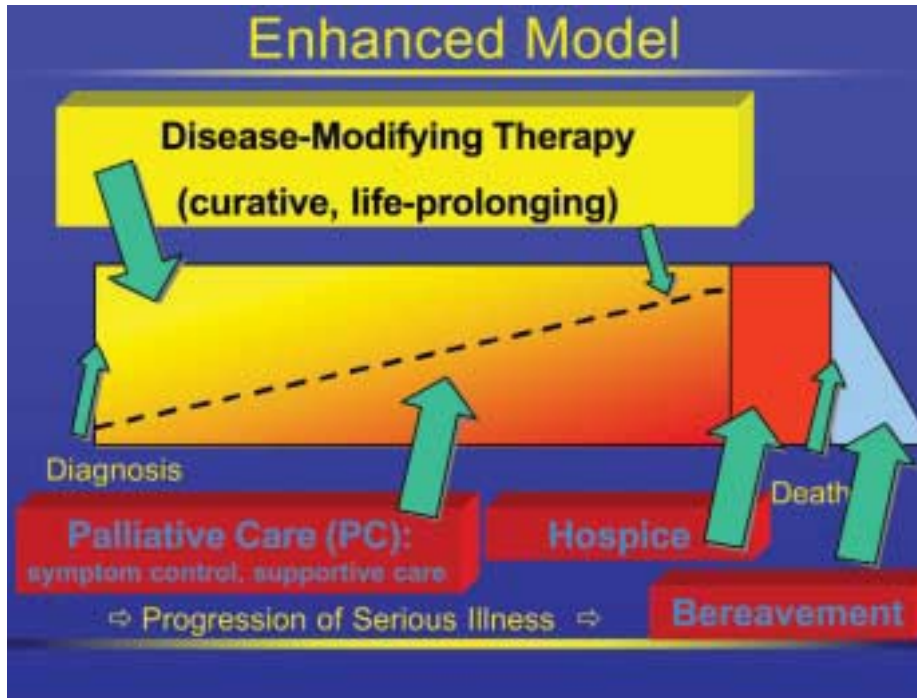


Figure 3. Palliative Care and Hospice Integrated in an Enhanced Model of Health Care  
Adapted from *Education for Physicians on End-of-life Care*, 1999

is an integral component of this model.

In this enhanced model (Figure 3), case managers play a pivotal role in integrating the management of chronic diseases by means of disease-modifying treatment with palliative care services and with easing the transition to hospice care. This approach is particularly true for patients with advancing chronic illness who, indeed, are appropriate candidates for hospice care and who can take advantage of the Medicare benefit. To better define the cohort of patients who potentially are eligible for hospice and would benefit from a palliative approach, a critical question for case managers to ask is, "Would it surprise me if this patient died in the next year?"

Case managers serve a vital role in the lives of patients facing the end of their lives. Careful, comprehensive, and compassionate care coordination should be the hallmark of case management with this population. □

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