

REVIEW ARTICLE

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Palliative Care for the Seriously Ill

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PALLIATIVE CARE IS THE INTERDISCIPLINARY SPECIALTY FOCUSED ON IMPROVING quality of life for persons with serious illness and their families. Over the past decade,¹ the field has undergone substantial growth and change, including an expanded evidence base, new care-delivery models, innovative payment mechanisms, and increasing public and professional awareness.

CORE CONCEPTS

In the United States and increasingly in most countries, palliative care and hospice have distinct meanings. Palliative care is interdisciplinary care (medicine, nursing, social work, chaplaincy, and other specialties when appropriate) that focuses on improving quality of life for persons of any age who are living with any serious illness and for their families.² By treating pain, other symptoms, and psychological and spiritual distress, by using advanced communication skills to establish goals of care and help match treatments to those individualized goals, and by providing sophisticated care coordination, palliative care provides an added layer of support to patients, their loved ones, and treating clinicians. Ideally, palliative care is initiated at the time of diagnosis and is provided concordantly with all other disease-directed or curative treatments (Fig. S1 in the Supplementary Appendix, available with the full text of this article at NEJM.org).

Hospice, by contrast, is a formal system of interdisciplinary care that provides palliative care services to the dying in the last months of life. It was first developed in 1967 by Dame Cicely Saunders to provide a setting and model of care for people dying from advanced cancer. Today, the settings for hospice care and payment mechanisms vary across countries. In the United States, unlike most other countries, hospice is a relatively separate system of care for the terminally ill. Eligibility criteria are defined by insurance benefits and federal programs (Medicare, Medicaid, and Veterans Affairs), and Medicare-certified hospices are subject to strict regulatory requirements. Currently, patients qualify for hospice if they have a prognosis of survival of 6 months or less and are willing to forgo curative treatments. Under Medicare, this decision includes relinquishing Part A services.

Table 1 outlines the differences between hospice and palliative care in the United States. In this article, we use the term “hospice” to describe the U.S. health care delivery system that provides palliative care under the Medicare hospice benefit, “palliative care” to describe the interdisciplinary specialty, and “palliative medicine” to describe the formal subspecialty of the American Board of Medical Specialties.

CORE COMPONENTS OF PALLIATIVE CARE

The core components of palliative care include the assessment and treatment of physical and psychological symptoms, identification of and support for spiritual

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Characteristic	Palliative Care	Hospice
Model of care	Interdisciplinary team, including physicians, nurses, social workers, chaplains, and staff from other disciplines as needed; primary goal is improved quality of life	Interdisciplinary team, including physicians, nurses, social workers, chaplains, and volunteers, as dictated by statute; primary goals are improved quality of life and relief of suffering (physical, emotional, and spiritual)
Eligibility	Patients of all ages and with any diagnosis or stage of illness; patients may continue all life-prolonging and disease-directed treatments	Patients of all ages who have a prognosis of survival of ≤ 6 mo, if the disease follows its usual course; patients must forgo Medicare coverage for curative and other treatments related to terminal illness
Place	Hospitals (most common), hospital clinics, group practices, cancer centers, home care programs, or nursing homes	Home (most common), assisted-living facilities, nursing homes, residential hospice facilities, inpatient hospice units, or hospice-contracted inpatient beds
Payment	Physician and nurse practitioner fees covered by Medicare Part B for inpatient or outpatient care; hospital teams are included with Medicare Part A or commercial insurance payments to hospitals for care episodes; flexible bundled payments under Medicare Advantage, Managed Medicaid, ACOs, and other commercial payers	Medicare hospice benefit; standard hospice benefit from commercial payers is usually modeled after Medicare; Medicaid, although coverage varies by state; medication costs are included for illnesses related to the terminal illness

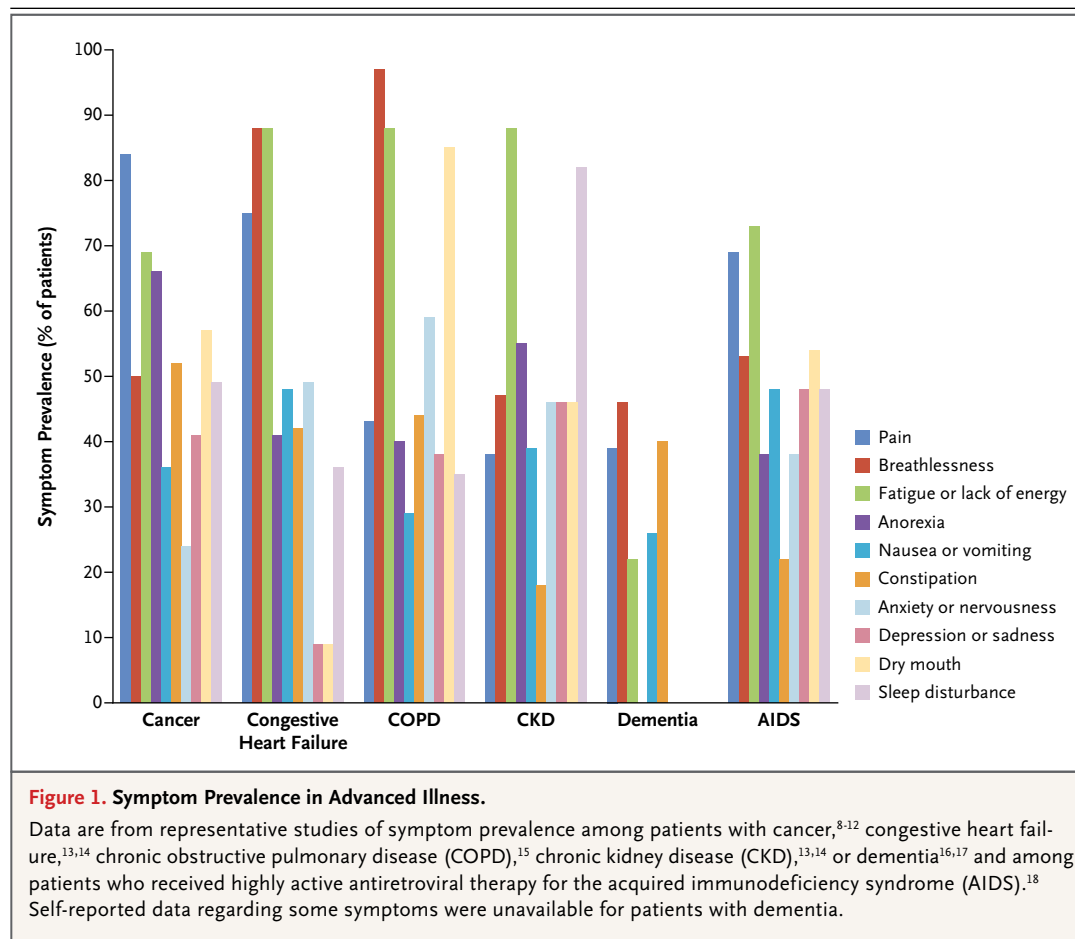
* ACO denotes accountable care organization.

Domain	Key Recommendations
Structure and processes of care	Interdisciplinary team, comprehensive interdisciplinary assessment, education and training; relationship with hospice program
Physical aspects of care	Pain and other symptoms are managed with the use of best practices
Psychological and psychiatric aspects of care	Psychological and psychiatric issues are assessed and managed; grief and bereavement program is available to patients and families
Social aspects of care	Interdisciplinary social assessment with appropriate care plan; referral to appropriate services
Spiritual, religious, and existential aspects of care	Spiritual concerns are assessed and addressed; linkages to community and spiritual or religious resources are provided as appropriate
Cultural aspects of care	Culture-specific needs of patients and families are assessed and addressed; recruitment and hiring practices reflect the cultural diversity of the community
Care of the imminently dying patient	Signs and symptoms of impending death are recognized and communicated; hospice referral is recommended when patient is eligible
Ethical and legal aspects of care	Patient's goals, preferences, and choices form basis for plan of care; the team is knowledgeable about relevant federal and state statutes and regulations

* Adapted from the National Consensus Project for Quality Palliative Care.²

distress, expert communication to establish goals of care and assist with complex medical decision making, and coordination of care (Table 2). Ideally, many of these components can and should be provided by primary treating clinicians — much in the way that uncomplicated hypertension or

diabetes is managed by primary care physicians rather than by cardiologists or endocrinologists — with specialist-level palliative care teams providing care in the most complex and difficult clinical cases. However, in reality, most physicians and other health care professionals cur-



rently in practice have had limited or no formal training in these areas.³

The following sections highlight key concepts and recent developments in palliative care practice. Evidence is drawn largely from observational studies, with an increasing number of recent randomized, controlled trials. Interested readers may find additional details regarding specific domains of palliative care research in other recently published reviews.⁴⁻⁷

PHYSICAL AND PSYCHOLOGICAL SYMPTOMS

Whereas pain is the most studied and publicized symptom experienced by persons with common serious illnesses, observational prevalence studies suggest that pain is only one of many distressing symptoms (Fig. 1).⁸⁻¹⁸ Routine comprehensive symptom assessment with the use of validated instruments is indicated in the context of advanced disease. As compared with routine care, which includes standard clinical histories

and review of systems, formal symptom assessment with the use of validated instruments can improve the identification of distressing symptoms and lead to enhanced comfort and better outcomes.¹⁹ Table S1 in the Supplementary Appendix summarizes standard approaches to managing the common symptoms, such as anorexia, anxiety, constipation, depression, delirium, dyspnea, nausea, and fatigue, that occur in patients with serious illness.

SPIRITUALITY

Data suggest that spiritual concerns are common in persons with serious illness and that the majority want to discuss their spirituality with their physicians.²⁰ Nevertheless, less than 50% of physicians believe that it is their role to address such concerns, and only a minority of patients report having their spiritual needs addressed.^{20,21} Widespread consensus holds that health care chaplains should provide spiritual care,² yet there

are insufficient numbers of health care chaplains and very few are certified in palliative care. Thus, most seriously ill patients depend on other members of the health care team to address spiritual concerns.

Various studies highlight the importance of spirituality and religious practice with respect to outcomes in seriously ill patients. An observational study by Winkelman et al. showed that patients with cancer who had unmet spiritual concerns were more likely to have significantly worse psychological quality of life than those whose spiritual concerns were addressed.²² In addition, a multisite cohort study involving 343 patients with advanced cancer showed that the patients whose spiritual needs were supported received more hospice care and were less likely to have burdensome nonbeneficial interventions near the end of life than those whose needs were not met and, furthermore, that spiritual support from the medical team or chaplain was associated with higher quality-of-life scores.^{23,24} In the same cohort, patients who relied highly on religious faith to cope with cancer were more likely than those with a low level of religious coping to receive mechanical intubation and intensive care unit (ICU) care near the end of life.²⁵ Whereas consensus supports referral to a chaplain when spiritual concerns are identified, the efficacy of spiritual interventions has not been studied. Similarly, the mechanisms by which spiritual distress affects outcomes and whether these mechanisms are modifiable remain unknown.

COMMUNICATION SKILLS

Empirical research that is focused on communication in the context of serious illness has grown rapidly in the past decade. Building on consensus-based approaches to conducting difficult conversations (e.g., “breaking bad news”), a series of randomized trials and skills assessments before and after training have rigorously studied these approaches, refined frameworks for these discussions, identified core communication skills, and begun to examine the clinical outcomes associated with effective communication training.²⁶⁻²⁸ Common communication scenarios may involve communicating serious news, discussing prognostic uncertainty, establishing goals of care, and selecting treatment options.²⁹

Various efforts have honed cognitive road maps for these specific clinical scenarios, such

as SPIKES (setting up the interview, assessing the patient’s perception, obtaining the patient’s invitation, giving knowledge and information, responding to emotion, and summarizing the discussion), and have identified core skills for effective communication, such as expressing empathy with the use of NURSE (naming, understanding, respecting, supporting, and exploring) statements.²⁹ Communication skills training programs that are based on empirical research now exist — both online (www.capc.org/topics/communication-and-palliative-care) and in workshop settings (www.vitaltalk.org).

In a large, prospective cohort study involving patients with advanced cancer, those who had a goals-of-care discussion with their physician were less likely than patients who did not have such a discussion to die in an ICU or to receive mechanical ventilation and cardiopulmonary resuscitation and were more likely to be enrolled in hospice for longer than 1 week.³⁰ Another prospective cohort study involving patients in the ICU and their families showed that structured discussions about patients’ wishes for end-of-life care were associated with significantly increased overall family satisfaction with ICU care and improved family satisfaction with decision making.³¹ Considerable strides have also been made in the science of advance care planning and decision support tools.^{32,33} Particularly relevant to clinicians who are building primary palliative care skills and are aiming to engage patients in advance care planning are public-use websites that have materials from these studies (e.g., www.prepareforyourcare.org, www.agingwithdignity.org/five-wishes.php, and www.acpdecisions.org).

MODELS OF PALLIATIVE CARE DELIVERY

HOSPITALS

The most common setting for nonhospice palliative care services in the United States, and in much of the world, is the acute care hospital. Initially established within academic medical centers in North America, palliative care programs have spread to other hospital types. Indeed, over the past decade, palliative care programs have grown by more than 150%, such that almost 90% of hospitals with 300 beds or more and two thirds of hospitals with 50 beds or more now have palliative care programs.³⁴ Beginning in

2011, the Joint Commission established the Advanced Certification for Palliative Care Programs.³⁵ To date, 82 programs have received this certification.³⁵

Within hospitals, the primary model of care delivery is the interdisciplinary consultation team. Large hospitals and mature programs may also include dedicated inpatient units. In addition to these traditional models, new service-delivery models and innovations include dedicated ICU teams, comanagement models, in which a palliative care specialist joins an existing specialty team (e.g., oncology), and triggers for automatic palliative care referrals. Multiple randomized, controlled trials and a few observational studies that have compared the outcomes in seriously ill patients who were referred to hospital-based palliative care teams with the outcomes in patients who received usual care have shown reduced symptom distress,³⁶⁻³⁸ enhanced quality of life,^{37,38} and decreased spiritual distress²³ among the patients referred to palliative care. Although several quasi-experimental studies have also shown reduced costs and resource utilization,^{5,7} no formal cost-effectiveness studies (i.e., measuring both costs and a range of patient and family outcomes) have been completed to date.⁷

COMMUNITY

Historically in the United States, community-based palliative care was available only through hospice programs and, therefore, available only to patients with a prognosis of survival of 6 months or less who had decided to forgo further curative treatments. Hospice continues to provide the largest proportion of palliative care in home-based settings, but this care is provided for limited time spans and only during the final stages of disease. The overall quality of and satisfaction with hospice care has been consistently high.³⁹

In the past decade, community-based models of palliative care have been developed to serve seriously ill people who are not eligible for hospice. These programs are evolving rapidly as a result of the Affordable Care Act (ACA), which expanded cost-sharing programs (e.g., accountable care organizations), created bundled-payment programs, and encouraged the formation of commercially managed Medicare and Medicaid programs. Because of the incentives provided in these new programs, private payers and Medicare Advantage plans have been early innovators in de-

veloping palliative care programs because of the potential of these programs to reduce costs and improve quality. These programs use interdisciplinary palliative care teams to establish clear goals of care, enhance symptom management and caregiver support in the home setting, coordinate care, and provide an extra layer of support to treating physicians.^{40,41}

Unlike traditional programs for managing chronic disease, these new programs serve a highly complex population and are designed to include the core domains of palliative care (Table 2). Although robust data on their cost-effectiveness are still needed, preliminary observational data from community-based programs and evidence from randomized trials of other programs of outpatient palliative care have shown enhanced symptom management, improved patient and family satisfaction scores, and significant reductions in hospitalization rates, emergency department visits, days in the ICU, and physician office visits.^{4,40,41} Furthermore, in two randomized trials involving certain subpopulations, persons receiving palliative care in community settings have had longer survival than community-dwelling persons with the same diagnosis who are not receiving palliative care.^{37,42} Further study is needed to replicate this observed survival benefit and elucidate the mechanisms, because survival was not the primary outcome in either of the studies cited. Community-based palliative care services are more well developed in Canada, Western Europe, and Australia than they are in the United States.^{6,42-44}

LONG-TERM CARE

Approximately 1.8 million U.S. residents live in nursing homes, and this number is expected to more than double by 2030.^{45,46} The palliative care needs of this population are vast. More than 25% of elderly persons die in nursing homes, 67% of persons with advanced dementia live their final days in this setting,¹⁶ and more than half of nursing home residents require extensive or complete assistance with activities of daily living.⁴⁵

Currently, there are three models for delivering palliative care in nursing homes. The most established model is hospice. Many nursing homes contract with a hospice agency for services, and the percentage of persons in nursing homes who received hospice services before they died increased from 14% in 1999 to 33% in 2006.⁴⁷ As

compared with nursing home care that does not include hospice, hospice use in nursing homes is associated with lower rates of invasive therapies and hospitalizations, improved management of pain and symptoms, and higher family satisfaction with care.⁴⁷ The 6-month prognostic requirement for hospice eligibility greatly limits access, however, given the duration of need and the unpredictable prognoses of most nursing home residents.

Another model is palliative care consultation, in which an external palliative care physician or nurse practitioner provides recommendations to the nursing home clinicians and bills services under Medicare Part B. Difficulties related to this model include a lack of reimbursement mechanisms for nonphysician members of the palliative care team and a reliance on the nursing home staff — who may not have palliative care training — to implement and follow through on recommendations. Finally, some nursing homes have developed internal palliative care teams or specialized units, which are focused primarily on residents with advanced dementia.

EXPANDING ACCESS TO PALLIATIVE CARE AND BARRIERS TO DELIVERY

Although palliative care was focused initially on patients dying from cancer, the patient population that may benefit from palliative care has expanded considerably. Many randomized, controlled trials and case-control studies of palliative care interventions to date have shown reductions in patients' symptoms and health care utilization and improvements in quality of life and family satisfaction across a wide spectrum of populations, including patients with advanced cancer,³⁷ neurologic disease,⁴⁸ or lung disease⁴² and older adults with multiple coexisting conditions and frailty.^{6,49} The patient population that benefits most from referral to specialist-level palliative care and the appropriate timing of such referral are still being defined by empirical research, yet consensus recommendations support referral at the time of diagnosis for patients with advanced cancer, neurologic disease, or organ damage; those with multiple coexisting conditions, frailty, or advanced cognitive impairment; those with a high symptom or iatrogenic-treatment burden (e.g., those who have received a bone marrow transplant for acute leukemia);

and those who have onerous family or caregiver needs regardless of prognosis.^{2,36}

Considerable barriers may prevent many persons from accessing or using palliative care services. First, the number of palliative care specialists falls far short of what is necessary to serve the population in need. A 2010 study estimated that 6000 to 18,000 additional physicians are needed to meet the current demand in the inpatient setting alone.⁵⁰ Similar shortages are also anticipated across other disciplines. The demand for the expansion of palliative care services in new care settings that was created by incentives under the ACA and the Joint Commission Advanced Certification for Palliative Care, as described above, is further straining the limited specialist-level palliative care workforce.

Finally, regional, socioeconomic, and racial and ethnic-group determinants influence access to palliative care.^{51,52} The factors associated with increased availability of hospital-based palliative care include not-for-profit status, geographic locations outside the southern United States, teaching hospitals, and faith-based hospitals.⁵² In addition, persons of minority races and ethnic groups access palliative care and hospice services far less frequently than do whites.⁵¹ This situation is particularly worrisome given evidence that, as compared with whites, these groups have higher rates of inadequately treated pain, preference-discordant medical treatments, and low satisfaction with care and provider communication.⁵¹

EVIDENCE GAPS AND FUTURE DIRECTIONS

Key research needs to be funded and performed if palliative care is going to achieve its potential to enhance value throughout the health care system. First, as noted above, important gaps in clinical evidence need to be addressed so that persons with serious illness can receive the best available care. For example, the biologic bases of nonpain symptoms are poorly understood, and treatments for symptoms such as breathlessness, fatigue, pruritus, delirium, and even pain are suboptimal, and randomized, controlled trials of interventions are needed to identify ways to improve care for patients with those symptoms.

Second, the needs of older adults with serious illness and their caregivers and the longitudinal nature of those needs have yet to be well de-

scribed.⁵³ In particular, the complex care needs of patients with multiple coexisting conditions must be investigated. The population at risk must be defined beyond traditional disease-specific or prognosis-based definitions, and a better understanding of the multiyear needs of these persons and their caregivers is required in order to develop targeted care models and, given an inadequate workforce, to deploy the workforce efficiently.⁵³ Third, data to guide care for seriously ill children and for adults with end-stage dementia are needed. Finally, the development and evaluation of palliative care–delivery models outside hospitals is essential. If this research is to be undertaken, research funding for palliative care will need to be increased beyond the 0.01% of the National Institutes of Health budget that currently supports research on palliative care.⁵⁴

Knowledge of palliative care and the skills of non–palliative medicine physicians also need to be improved to meet patients' needs. Expanding the primary palliative care skills of all clinicians will be a key step toward resolving the shortage in the palliative care workforce. The core palliative care competencies of communication, pain and symptom management, and psychosocial assessment remain, at best, a small part of most medical school and residency training programs. The vast majority of practicing physicians and trainees has rudimentary skills in these areas, which negatively affects patient and family outcomes.³ Conversely, an increasing body of evidence suggests that these skills (particularly communication skills) can be effectively learned and developed and are associated with improved outcomes.^{26–28} Strategies to expand specialist-level palliative care training and generalist training in core palliative care knowledge and skills are needed.

Major issues impeding the access to palliative care are the perceptions among doctors that palliative care is appropriate only at the end of life, that palliative care is synonymous with hospice, and that patients will react negatively and lose all hope if palliative care referral is discussed.^{55,56} In contrast to the perceptions of physicians, a recent survey showed that almost 90% of adults in the United States had either no knowledge or limited knowledge of palliative care. When read a definition, more than 90% of the respondents stated that they would want palliative care for themselves or their family member and that it should be universally available.⁵⁷ Targeted social marketing and educational efforts must be directed both to the public and to medical professionals.

Palliative care is now a rapidly growing medical specialty in the United States, and a mounting body of evidence shows that palliative care teams enhance the quality of health care for persons living with serious illness and for their families, while reducing medical expenditures. Palliative care teams are well established in most U.S. hospitals, although penetration is varied, and most of the patients and families who could benefit from palliative care services still do not receive them. New models of community-based palliative care are emerging, although data on their cost-effectiveness are not yet available. Gaps in research, workforce deficits, and deficiencies in public and professional knowledge need to be addressed if care for persons with serious illness and their families is to be further improved.

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Disclosure forms provided by the authors are available with the full text of this article at NEJM.org.

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