

Palliative Care in Hospitals

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Palliative care is medical care focused on the relief of suffering and support for the best possible quality of life for patients facing serious, life-threatening illness and their families. It aims to identify and address the physical, psychological, and practical burdens of illness. Palliative care may be delivered simultaneously with all appropriate curative and life-prolonging interventions. In practice, palliative care practitioners provide assessment and treatment of pain and other symptom distress; employ communication skills with patients, families, and colleagues; support complex medical decision making and goal setting based on identifying and respecting patient wishes and goals; and promote medically informed care coordination, continuity, and practical support for patients, family caregivers, and professional colleagues across healthcare settings and through the trajectory of an illness. The field of hospital palliative care has grown rapidly in recent years in response to patient need and clinician interest in effective approaches to managing chronic life-threatening illness. The growth in the number and needs of seriously and chronically ill patients who are not clearly terminally ill has led to the development of palliative care services outside the hospice benefit provided by Medicare (and other insurers). This article reviews the clinical, educational, demographic, and financial imperatives driving this growth, describes the clinical components of palliative care and the range of service models available, defines the relation of hospital-based palliative care to hospice, summarizes the literature on palliative care outcomes, and presents practical resources for clinicians seeking knowledge and skills in the field. *Journal of Hospital Medicine* 2006;1:21–28.

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The field of palliative care has grown rapidly in recent years in response to patient need and clinician interest in effective approaches to managing chronic life-threatening illness.¹ This article reviews the clinical, educational, demographic, and financial imperatives driving this growth, describes the clinical components of palliative care and the range of service models available, defines the relationship of hospital-based palliative care to hospice, summarizes the literature on palliative care outcomes, and presents practical resources for clinicians seeking knowledge and skills in the field.

DEFINITION

Palliative care is medical care focused on the relief of suffering and support for the best possible quality of life for patients facing serious, life-threatening illness and their families. It aims to identify and address the physical, psychological, and practical burdens of illness. Palliative care in the United States grew out of the hospice movement that originated in both the United Kingdom and the United States about 30 years ago. Hospice care was

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developed specifically to address the needs of the dying and their families and was codified in the United States by the addition in 1983 of a federal Medicare benefit for hospice care. In the last 30 years the Medicare hospice benefit has enabled more than 7 million patients and their families to receive intensive palliative care for the terminally ill, primarily in the home. The growth in the number and needs of seriously and chronically ill patients who are not clearly terminally ill has led to the development of palliative care services outside the hospice benefit provided by Medicare (and other insurers). Both hospice and nonhospice professionals have participated in extending the hospice approach through development of palliative care services. Palliative care may be delivered simultaneously with all appropriate curative and life-prolonging interventions. In practice, palliative care practitioners provide assessment and treatment of pain and other symptom distress; employ communication skills with patients, families, and colleagues; support complex medical decision making and goal setting based on identifying and respecting patient wishes and goals; and promote medically informed care coordination, continuity, and practical support for patients, family caregivers, and professional colleagues across healthcare settings and through the trajectory of an illness.^{1,2}

Palliative care is both a general approach to health care and a growing practice specialty for professionals committing most or all of their time to the delivery of palliative care services.³ The term *palliative medicine* refers to the physician discipline within the larger field of palliative care. As of 2005, more than 1890 physicians have received specialty certification through a palliative care credentialing exam given by the American Board of Hospice and Palliative Medicine.⁴ Formal recognition of the subspecialty is currently being sought in collaboration with the American Board of Medical Specialties.⁵ As of August 2005, there were more than 50 postgraduate palliative care subspecialty fellowship programs in the United States.⁶ Between 2000 and 2003, the American Hospital Association (AHA) annual survey recorded a 67% growth in the number of hospital-based palliative care programs reported, from 632 to 1027, for a total of 25% of responding AHA member hospitals.⁷

REASONS FOR GROWTH IN PALLIATIVE CARE

A primary justification for the rapid growth in palliative care programs in institutional settings is the

abundant data demonstrating the high prevalence of pain and symptom distress in hospitals,⁸⁻¹¹ nursing homes,^{12,13} and community settings.¹⁴ Virtually all persons with serious illness spend at least some time in a hospital, usually on multiple occasions, in the course of their disease or condition.¹⁵ Despite the finding that when polled more than 90% of Americans say they would prefer to die at home, more than 75% of adult deaths occur in institutional settings (hospital or nursing homes)—more than 50% in hospitals and 25% in nursing homes—and 85% of pediatric deaths occur in hospitals.^{16,17} Further, more than half of persons older than age 85 die in a nursing home and 43% of persons older than age 65 reside in a long-term care facility at some time before they die,¹⁸⁻²¹ a figure projected to rise substantially over the next several decades. The much larger number of patients who are not dying but are living with chronic, debilitating, and life-threatening illness also need expert symptom management, communication and decision-making support, and coordination of care across settings. In one national survey, physicians reported that poor care coordination resulted in patient communication problems, lack of emotional support for patients, adverse drug reactions, unnecessary hospitalization, patients not functioning to potential, and unnecessary pain.²² In addition to studies demonstrating high degrees of symptom distress across all age groups in hospitalized and nursing home patients,⁸⁻¹⁴ other works have shown high use of burdensome, nonbeneficial technologies among the seriously ill,²³⁻²⁷ caregiver burden on families,²⁸⁻³¹ and communication problems between these patients, their families, and their treating physicians about the goals of care and the medical decisions that should follow.^{32,33} Other studies have reported broad dissatisfaction with the general quality of care for the seriously ill and dying in hospitals and nursing homes,^{18,34} specifically, perceptions of impersonal and indifferent care. Several studies of patients and their families have identified relief of suffering, practical support needs, open communication, and opportunities to relieve burdens on and strengthen relationships with family as the top-priority needs from the healthcare system.³⁴⁻⁴⁰

The growth in the number and needs of the elderly with multiple chronic conditions who will turn to the healthcare system in coming years underscores the need to create a delivery system in the United States that can be responsive to these pri-

orities. By 2030 the number of persons with chronic conditions will exceed 157 million.^{41–44} With the possible exception of advanced cancer conditions (accounting for 24% of adult deaths), in which prognosis is somewhat more reliably linked to performance status,^{42–43} prognostication of outcome is a highly inexact science for the chronically ill of all ages and in a range of diagnostic categories, including stroke, dementia, and end-stage cardiac, renal, hepatic, and pulmonary diseases. This has been a major part of the impetus for the growth in palliative care services not predicated on a link to terminal prognoses.^{41–43} Hospitals and nursing homes are under increasing pressure to structure care processes in a manner fitted to the needs of the seriously ill because of studies demonstrating poor quality of care, demands from patients and families, accreditation requirements, and the costs of care for this patient population. More than 95% of Medicare spending goes to the 63% of Medicare patients with two or more chronic conditions, and three quarters of Medicare dollars go to hospitals.⁴⁴ Hospital costs have risen nearly 10% per year in each of the last 2 years, because of both the increasing numbers of patients turning to them for care and the growth in the number and expense of effective life-prolonging therapies. These forces have stimulated the development of new models for the efficient and effective care of patients with serious and complex illness.^{22–27,44}

CLINICAL COMPONENTS

The three primary domains of palliative care clinical practice are assessment and treatment of pain and other symptom distress, including psychiatric symptoms⁶⁴; communication about goals of care and support for complex medical decision making; and provision of practical and psychosocial support, care coordination, and continuity, as well as bereavement services if death occurs.^{1,2,65} Palliative care specialists work to support primary and specialist physicians in the care of complex and seriously ill patients by providing intensive bedside treatment and reassessment of multiple-symptom distress, by helping with time-consuming and difficult interactions with distressed patients and family members, and by attempting to ensure a seamless, safe, and well-communicated discharge and follow-up process after the patient leaves the hospital.⁶⁶ Resources for physicians seeking more knowledge or training in the treatment of symptom

TABLE 1
Palliative Care Internet Resources for Clinicians

Palliative care clinical competencies

- Education on Palliative and End of Life Care (www.epec.net): comprehensive curriculum covering fundamentals of palliative medicine; free downloadable teaching guides in PowerPoint format.
 - End of Life/Palliative Education Resource Center (www.eperc.mcw.edu): medical educator resources for peer-reviewed palliative care teaching materials.
 - Department of Pain Medicine and Palliative Medicine at Beth Israel Medical Center (www.StopPain.org): clinical, educational, professional, and public resources.
 - www.Palliativedrugs.com: extensive information on pharmacological symptom management.
 - American Academy of Hospice and Palliative Medicine (www.aahpm.org): physician membership organization providing board review courses, publications.
 - American Board of Hospice and Palliative Medicine (www.abhpm.org): physician board certification.
 - Center for Palliative Care at Harvard Medical School (www.hms.harvard.edu/cdi/pallcare): faculty development courses, other educational programs.
 - National Consensus Project on Quality Palliative Care (www.nationalconsensusproject.org): clinical practice guidelines.
 - American Geriatrics Society (www.americangeriatrics.org/products/positionpapers/persistent_pain_guide.shtml): clinical guidelines on pain management in the elderly.
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Palliative care program development

- Center to Advance Palliative Care (www.capc.org): technical assistance for clinicians and hospitals seeking to establish or strengthen a palliative care program.
 - Palliative Care Leadership Centers (www.capc.org/pclc): six exemplary palliative care programs providing site visits, hands-on training, and technical assistance to support new palliative care clinicians and programs nationwide.
 - Promoting Excellence in End of Life Care (www.promotingexcellence.org): organization and Web site supporting innovative approaches to delivery of palliative care, plus comprehensive Web-based resources.
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All Web sites accessed August 10, 2005.

distress and other aspects of palliative care are given in Table 1.

The core components of symptom management^{67,68} include: 1) Routine and repeated formal assessment, without which most symptoms will be neither identified nor addressed; 2) Expertise in prescribing, including the safe use of opioid analgesics, adjuvant approaches to pain management, and management of a wide range of other common and distressing symptoms and syndromes including, for example, delirium, dyspnea, fatigue, nausea, bowel obstruction, and depression⁶⁹; and 3) Skillful management of treatment side effects, which is required to successfully control symptoms.

Communication skills and effective support for making decisions about clinical care goals include

not only fundamental physician responsibilities such as communicating bad news and elucidating patient wishes for future care, but also the ability to promote communication and consensus about care goals among multiple specialist consultants, to address and resolve disagreements and conflicts among patients, families, and providers about goals of care, and to assist in the evolving process of balancing the benefits with the burdens of various medical interventions.^{32,70-73}

The great majority of care for an illness is provided at home by family members neither trained nor emotionally prepared for these responsibilities.^{51,74} The burden on family caregivers is one of the top concerns of seriously ill patients.³⁵ Patients and families often struggle with anxieties about doing the wrong thing, difficulty traveling to physicians' offices, social isolation, and a high prevalence of preventable suffering of all types.³⁴⁻⁴⁰ Palliative care clinicians attempt to improve the success and sustainability of the discharge plan by providing medically informed and therefore more appropriate care management recommendations and by mobilizing a range of community resources to increase the likelihood that families will be able to manage the care at home with the necessary supports and backups in place, including appropriate screening and referrals for complicated grief and bereavement.^{51,75,76} Several small prospective studies of palliative care have suggested that palliative care has resulted in reduction in the number of emergency department visits and hospitalizations and in the length of hospital stays, presumably because of the efficacy and comprehensiveness of care coordination in averting crises.^{54,55,61,97-98}

CLINICAL MODELS

Given the multifaceted approach needed to support patient quality of life throughout advanced illness, one profession or individual cannot be expected to provide all aspects of palliative care. As described in the recently completed National Consensus Project Guidelines for Quality Palliative Care,² specialty-level palliative care is optimally delivered through an interdisciplinary team consisting of appropriately trained and credentialed physicians, nurses, and social workers with additional support and contributions from chaplains, rehabilitative experts, psychiatrists, and other professionals as indicated. Clearly, however, the staffing of a palliative care program will depend critically on the needs and capacities of the setting. A full interdisciplinary

team is needed for a large tertiary-care teaching hospital, whereas a part-time advance-practice nurse with backup from colleagues as needed may suffice for a small rural hospital or long-term care setting. Specialist-level palliative care is delivered through a range of clinical models and settings, including inpatient consultation services, dedicated inpatient units, and outpatient practices, among others.^{77,78} Programs within the United States are housed in a range of clinical subspecialties including oncology, geriatrics, nursing, case management, hospitalist, and other programs, depending on the locus of leadership and administrative support.^{77,78} Most programs are supported by utilizing diverse sources,⁷⁷ including physician and nurse-practitioner billing through insurers such as Medicare Part B,^{53,81} as well as hospital support typically predicated on cost avoidance analyses, foundation and other grants, and philanthropy. Detailed guidance on appropriate documentation and billing for palliative care physician services may be found in Schapiro et al.,⁵³ von Gunten,⁷⁹ and on the Web site of the Center to Advance Palliative Care (www.cap-c.org).⁷⁷

RELATIONSHIP TO HOSPICE

Although new clinical specialties in palliative medicine and nursing are emerging, in the United States palliative care for those in the terminal stages of illness has been delivered through hospice programs for more than 30 years. Under current regulatory and payment guidelines hospice care is delivered to patients who are certified by their physicians as likely to die within 6 months if the disease follows its usual course and who are willing to give up insurance coverage for medical treatment primarily focused on cure or prolongation of life. It is noteworthy that there is great variability among United States hospices, with some able to support continued disease-modifying treatments such as chemotherapy and radiation if a patient so desires.² Hospice programs aim to create increased opportunity for death at home, focusing on symptom control and the psychological and spiritual issues that are paramount to persons in the terminal phases of illness. Once the hospice benefit has been accessed, patients and families receive comprehensive case-managed services across all settings of care (although the great majority of hospice care is delivered at home) from an interdisciplinary team, coverage for medications and equipment related to the terminal illness, and practical, psycho-

social, respite, and bereavement support for caregivers.^{80,81} Several recent studies have confirmed the findings of an earlier work⁸² in demonstrating the beneficial outcomes of hospice care including reduced mortality in spouses and high levels of family satisfaction.^{18,83} Palliative care programs based in both hospital and community settings have led to increases in hospice referral rates and hospice length of stay, promoting continuity of palliative care and the intensive palliation and family support needed as death approaches.⁵⁵ Coordination and partnerships between palliative care and hospice programs are critical to achieving continuity of palliative care throughout the full course of an illness and across the continuum of care settings.²

IMPACT OF PALLIATIVE CARE ON QUALITY OF CARE

Reports on palliative care specialist services utilizing diverse models and approaches have suggested a range of benefits from palliative care, including reduced pain⁴⁵⁻⁴⁷ and other symptom distress,^{45,48,49} improved health-related quality of life,⁹⁵ high patient and family satisfaction^{18,49-51,96} with care and with physician communication, and increased likelihood of the location of death being outside a hospital.^{33,49,52,97-99}

Because it can help to demonstrate care structures, processes, and outcomes associated with improved quality (such as routine assessment of pain in the hospital), a palliative care program may help hospitals measure and meet Joint Commission for Accreditation of Healthcare Organizations (JCAHO) requirements in the domains of pain management, communication, family and patient education, and continuity of care, among others.⁵³ Several groups have reported marked increases in hospice referral rate and hospice length of stay as a result of hospital- and nursing-home-based palliative care programs, presumably as a result of enhanced case identification, counseling, and referral processes.^{54,55} Case control and observational studies of palliative care and ethics consultation services have demonstrated reductions in costs per day and in hospital and ICU lengths of stay, presumably because of enhanced support for discussions about the goals of care and the resulting facilitation of patient and family decisions about the types and settings of future care.^{50,55-61} Hospitals have begun to invest in palliative care services, both to enhance quality of care and because of their measurable impact on reducing ICU and total bed days and

their efficacy in supporting transitions from high-intensity, high-cost hospital settings to more appropriate and desired care settings, such as the home.^{55-63,97-98} Observational studies have yielded no differences in mortality between patients receiving palliative care and controls receiving the usual care.^{48,55,56}

EDUCATION IN PALLIATIVE CARE

Curricular content on palliative care has been noticeably lacking from medical and nursing education curricula, textbooks, and certifying examinations, although this is beginning to change.⁸⁴⁻⁹¹ Both the Liaison Committee for Medical Education (LCME) and the Accreditation Council for Graduate Medical Education (ACGME) now require or strongly encourage programs to provide under- and postgraduate training in palliative care in order to be accredited.^{89,90} As of 2005, more than 50% of teaching hospitals had established palliative care clinical services,⁹² which constitute the necessary platform for clinical training. The rapid growth in the availability of postgraduate fellowship training in palliative medicine will produce the faculty leaders needed for these educational and research programs in medical school and residency training programs.^{93,94} Physicians in practice may gain knowledge and skills through a range of national courses and Web-based resources and through preparation for the certifying exam given annually by the American Board of Hospice and Palliative Medicine⁴ (Table 1).

CONCLUSIONS

The growth in palliative care specialists and programs in hospitals in the United States represents a grass roots professional response to the needs of a patient population with chronic advanced illnesses and family care burdens within a healthcare system structured to provide care for acute intercurrent illness. Rapid increases in the number of new hospital programs, as well as early studies indicating improved clinical, satisfaction, and utilization outcomes, suggest that palliative care services are likely to become a routine and well-integrated part of the healthcare continuum in the United States over the next several years. A number of resources are available to healthcare professionals seeking more training as well as to hospitals or nursing homes wishing to establish their own clinical or educational programs. Such programs have provided a platform for both newly graduated and sea-

soned professionals to continue to serve the needs of their patients through the assessment and relief of suffering, provided simultaneously with efforts to cure or mitigate disease.

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