

The Emergence of Palliative Care

The goals of care need to be identified and discussed throughout a patient's illness. During the early stages of a life-limiting illness, treatment is generally aggressive, and the major goal of treatment is often cure. As the illness progresses, the burdens of traditional medical therapies may begin to outweigh the benefits, and treatment goals may change. This transition period from traditional curative care to palliative care can be difficult for both patients and health care professionals. When cure is not possible, the emphasis of treatment may appropriately change from prolonging life to controlling symptoms and enhancing quality of life. A palliative care approach allows patients to remain as comfortable as possible throughout the illness trajectory.

Palliative care originally referred to the care of patients with terminal illnesses, but it now refers to the care of patients with chronic illness, whether or not they are imminently dying. Philosophically, the relief of suffering and the enhancement of quality of life are the primary objectives of both hospice and palliative care. Although general hospice and palliative care approaches are similar and may be provided along the illness trajectory for patients with advanced noncurable diseases, hospice care is generally provided during the latter segments of the continuum due to the current reimbursement system in the United States.

While a variety of palliative care definitions exist, a comprehensive definition has been adopted by the Last Acts Campaign's Task Force on Palliative Care¹: Palliative care refers to the comprehensive management of physical, social, spiritual, and existential needs of patients, particularly those with incurable, progressive illnesses. Palliative care affirms life and regards dying as a natural process that is a profoundly personal experience for the individual and family. The goal of palliative care is to achieve the best possible quality of life through the relief of suffering, control of symptoms, and restoration of functional capacity while remaining sensitive to personal, cultural, and religious values, beliefs, and practices.

The Last Acts Campaign's Task Force further identified precepts of palliative care: (1) respecting patient goals, preferences, and choices, (2) providing comprehensive caring, (3) utilizing the strengths of interdisciplinary resources, (4) acknowledging and addressing caregiver concerns, and (5) building systems and mechanisms of support.

Palliative care complements other therapies that are available and appropriate to the identified goals of care early in the course of a chronic illness. The intensity and range of palliative interventions may increase as the illness progresses and the complexity of the care and needs of patients and their families increases. The priority of care frequently shifts

during this time to focus on end-of-life decision making and care that supports comfort and is consistent with the values and expressed desires of the patient. Palliative care guides the patients and their families as they make the transition through the changing goals of care. It also helps the patient who wishes to address issues of life completion and life closure.

For many people desiring ongoing traditional curative care, hospice is not an attractive option. Patients who are averse to the word or concept of hospice or who have difficulty acknowledging that they are facing a terminal illness may benefit from and should be able to receive palliative services. In order to best prepare patients and families physically, emotionally, and spiritually and to ensure the highest quality of life, "palliative discussions" should begin earlier in the disease trajectory. The unpredictability of outcomes of patients with chronic diseases substantiates the need to begin discussion of treatment options early after diagnosis.

Palliative care should be considered not as an "alternative" to other types of medical treatment but as an adjunct type of care to allow comprehensive, whole-patient-directed, high-quality management. Palliative care services should be provided along the continuum of care from acute care to ambulatory care to long-term care and should include hospice care.

Palliative care discussions should occur at the time of diagnosis of a chronic, progressive disease, providing the patient with full informed consent for all treatment options. If the disease progresses, the focus on curative treatments may decrease as an emphasis on palliative care and relief of suffering (physical, emotional, and spiritual) increases. The patient and family are informed partners in decision making from the beginning and have time to prepare for and respond to physical, psychosocial, and spiritual issues.

Despite increased international concern about end-of-life care issues, there is no clear indication that care for most patients with advanced chronic illness has improved. Increased attention has been given to hospice and palliative medical education; however, in practice, a majority of health care professionals have received only sporadic training in the principles and practice of caring for patients with advanced life-limiting illnesses.²

In the United States, medical conferences generally devote minimal time to palliative medicine, and only five of 126 medical schools surveyed in 1994 offered a separate course on end-of-life care.³ Many physicians, nurses, and students acknowledge a lack of confidence and skill in the area of palliative medicine, and they desire more education and training on symptom control and management of psychosocial and spiritual concerns.

Recently, palliative care programs have begun to emerge in the United States. They closely resemble hospice programs in their approach but involve patients earlier in their disease course. Palliative care can be considered appropriate for any patient with a chronic progressive or life-limiting illness and

for the patient's family. Symptom management, psychosocial and spiritual support, and multidisciplinary care are key factors in the provision of palliative care services.

Palliative care training programs for physicians have recently been developing over the last few years in the United States, with close to 20 programs now available for such training. These programs typically provide residents with additional training and experience in the palliative care of patients with life-limiting illnesses so that the residents can generally focus their careers in these areas.

Home-based and inpatient palliative care services have also developed in the last few years in multiple settings. Palliative care home care programs are generally "bridge-like" programs that provide multidisciplinary palliative care to homebound patients with life-limiting illnesses who do not meet admission criteria for hospice services. Reimbursement is generally limited to those who are eligible for Medicare home care services. Studies are now attempting to determine if this approach to care is cost effective while providing high-quality services to patients in their home setting. Palliative care inpatient units or consultation services, typically provided by an interdisciplinary team of health care professionals, have also developed recently to provide a palliative care approach for patients in the inpatient setting. A palliative care consultation service has recently opened at our institute. The goals of these services are similar to hospice services but are provided to patients earlier in the disease course. The emphasis remains on managing symptoms, enhancing quality of life, and providing psychosocial and spiritual support rather than curing the patient's disease. This emphasis is

exemplified by the articles in this issue of *Cancer Control*.

A second palliative care conference, "End of Life Care in the 21st Century: Exploring the Controversies of Palliative Medicine," sponsored by the University of South Florida College of Medicine, the H. Lee Moffitt Cancer Center & Research Institute, and LifePath Hospice, was held on April 14-15, 2000, and drew audiences from much of the United States and other countries as well. Manuscripts of several of the presenters from this conference comprise the majority of this issue of *Cancer Control*. This conference attempted to increase the knowledge of health care professionals concerning palliative care.

Pain continues to be a major problem among patients in multiple settings. This issue emphasizes the importance of good pain management among patients in a palliative care or end-of-life setting. An article coauthored by Vincent Perron, MD, and myself describes an approach to the assessment and management of pain in palliative care patients and stresses the importance of this issue. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has demanded attention to this subject by requiring all JCAHO-accredited institutions to assess pain as a fifth vital sign to be documented routinely. This manuscript describes some of the important steps in assessing and managing pain.

Physician-assisted suicide has been legal in the state of Oregon since 1995. In his article, Robert M. Walker, MD, explains why it is possible that physician-assisted suicide may extend to include incapacitated patients, and he describes the concept of extending this act as the "legal slippery slope." He contends

that physician-assisted suicide could potentially extend to become voluntary euthanasia and ultimately nonvoluntary euthanasia. He highlights this possibility so those who are advocates of true patient choice will realize the potential for future legal decisions that will end life based not on patient choice but on the choice of others.

Sharon M. Weinstein, MD, describes the implementation of a palliative care program into a tertiary oncology center. This type of program includes medical symptom management, psychosocial support, and advance care planning in addition to the traditional medical care patients receive. She describes the difficulties with the decision making that occur throughout the trajectory of the disease and the need for ongoing communication and informed consent. She emphasizes the importance of implementing this type of care in order to achieve quaternary prevention — the prevention of suffering associated with the disease.

Caregivers of patients with advanced disease are being required to provide increasing amounts of care to their relatives. They have been more extensively studied recently in light of an increased morbidity and mortality among this group as a result of multiple caregiver issues. Ruth McCorkle, PhD, FAAN, and Jeannie V. Pasacreta, PhD, RN, CS, describe the needs of caregivers and present some of the findings from their research on caregiver issues and interventions to improve caregiver outcomes in palliative care.

Palliative care issues are handled differently among countries, reflecting cultural differences and specific medical practices. Juan M. Núñez Olarte, MD, PhD, and D.

Gracia Guillén, MD, PhD, add an international flavor to this issue with their description of cultural issues and ethical dilemmas in palliative care and end-of-life care in Spain. It is easy to recognize the differences that occur in the practice of palliative medicine between Spain and the United States. This manuscript emphasizes the importance of recognizing each patient's cultural background and values so clinicians will understand not only the decision-making process but also how patients should be approached and how specific decisions are made. A recent article also highlighted the importance of patient individuality on what factors patients considered important to quality care near the end of life.⁴

It is easy to see palliative care's continued emergence into mainstream medicine and its importance to high-quality patient care, particularly in the oncology setting. The increasing use of palliative care services should foster a smoother transition for patients into hospice care. The patients who receive palliative care services generally would be more comfortable talking with their health care providers about death and dying since pain and symptom management, as well as quality of life, has been emphasized early in the disease course. We are likely to continue to see an expansion of palliative care services as this approach to care may also provide a cost-effective means of providing health care for patients with advanced disease who are not yet near the end of life. Patients early in the disease course should benefit from the multidisciplinary approach to care to maximize not only their comfort but also their quality of life while respecting their values and preferences for care.

Our society will be faced with the care of increasing numbers of patients with advanced progressive illnesses. Patients should have the opportunity to receive high-quality palliative care throughout the disease trajectory. Relief of patient suffering and optimizing patients' quality of life must remain high priorities for all health care professionals.

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The Palliative Care Conference was supported by unrestricted educational grants from Knoll Pharmaceutical Co., Purdue Frederick Co., the H. Lee Moffitt Cancer Center & Research Institute, St. Joseph's-Baptist Health Care, Pfizer Pharmaceuticals, Ortho Biotech, Roxane Laboratories, Inc., Aventis Pharmaceuticals, Bergen Brunswig, Eli Lilly and Co., Janssen, Mead Johnson Nutritionals, Project GRACE, and SIMS Deltec, Inc.

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