Palliative care and Mainstream Medicine: An Overdue Collaboration

During the early stages of a serious illness, treatment is generally aggressive and the major goal of treatment is cure. As the illness progresses, the burdens of traditional medical therapies may begin to outweigh their benefits. The patient and/or physician may then emphasize different treatment goals. The transition period from traditional curative care to palliative care can be one of the most difficult phases of caring for patients with life-limiting illnesses. Nevertheless, when cure is not possible, treatment goals appropriately change from emphasizing life prolongation to emphasizing symptom control and quality of life. With this palliative care approach, patients may remain as comfortable as possible throughout the entire illness trajectory.

Palliative medicine is the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is quality of life. This discipline recognizes the multidimensional nature of suffering and responds with care that addresses all aspects of suffering. Palliative care originally referred to the care of patients with terminal illnesses, but now it refers to the care of patients with life-limiting illnesses, whether or not they are imminently dying. Philosophically, the relief of suffering and the enhancement of a patient’s quality of life are 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 incurable diseases, hospice care is generally provided during the latter segments of the continuum due to the current reimbursement system in the United States.

Despite increased societal concern about end-of-life care issues, there is no clear indication that care for most patients with advanced life-limiting illnesses has recently improved. Increased attention has been given to hospice and palliative medical education; however, in practice, the majority of physicians, residents, and medical students have received sporadic and nonstandardized training in the principles and practice of caring for patients with advanced life-limiting illnesses.

As our population continues to age, we will be faced with greater numbers of patients with advanced life-limiting illnesses. Health care professionals will see an increasing need to provide optimal care for these patients. The Institute of Medicine recently provided several recommendations regarding end-of-life care. Some of these recommendations include the following: (1) People with advanced potentially fatal illnesses and those close to them should be able to expect and receive reliable, skillful, and supportive care. (2) Health professionals must commit themselves to improving care for dying patients and to use existing knowledge effectively to prevent and relieve pain and other symptoms. (3) Educators and other health professionals should initiate changes in undergraduate, graduate, and continuing education to ensure that practitioners have relevant attitudes, knowledge, and skills to provide appropriate care for dying patients. (4) Palliative care should become, if not a medical specialty, at least a defined area of expertise, education, and research.

To begin or advance the education for those involved in or interested in end-of-life and palliative care, the University of South Florida College of Medicine, LifePath Hospice, and the H. Lee Moffitt Cancer Center & Research Institute sponsored a major palliative care conference in Tampa, Florida, on November 20, 1998. The success of this conference clearly demonstrated health professionals’ interest in and the need for ongoing education in this very important yet young field. The conference was endorsed by the Florida Chapter of the American Academy of Hospice & Palliative Medicine, Florida Hospice, Inc, and the Florida Cancer Pain Initiative.

This issue of Cancer Control contains some of the proceedings from this palliative care conference. Highlights from the conference have been selected that are thought to be of interest to the readers of this journal. Joanne Lynn, MD, MA, MS, reviews the current state of death and dying and end-of-life care in the United States from a societal and research perspective, including highlights from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). The challenges presented by our current health care system and the methods of addressing reform for this system to provide the highest quality palliative and end-of-life care are discussed. We are now beginning to see major efforts to improve the care of patients with advanced chronic diseases near the end of life.

Unrelieved pain is a common cause of suffering. Control of pain and other physical symptoms is one of the major goals of palliative care. Significant pain may be reported by 70% to 90% of cancer patients with advanced disease. Many patients experience severe pain because they do not receive adequate therapy. Pauline Lesage, MD, and Russell Portenoy, MD, present specific recommendations for the assessment and management of pain in patients with cancer. They emphasize that successful treatment of cancer pain requires therapies that address the etiology of pain, the patient’s medical status, and the goals of care. Utilization of pharmacologic and nonpharmacologic approaches, as well as disease-oriented interventions, are discussed as important parts of overall pain management.

This issue includes two additional articles on the physical aspects of palliative care. Sebastiano Mercadante, MD, reviews the efficacy of the World Health Organization’s analgesic ladder approach to cancer pain management. Although there may be some limitations in the clinical application of this approach in a small number of patients, the importance of utilizing this tool educationally in an attempt to raise the overall standard of cancer pain management cannot be overestimated. The use of opiate analgesics is associated with several potential side effects, one of which is constipation. This subject is addressed by Susan McMillian, PhD, RN, who reviews the prevalence, etiology, assessment, and management of constipation. If not well managed, constipation can negatively affect the quality of life of many patients.

The potential sources of suffering experienced by patients with advanced incurable diseases are not limited to pain and physical symptoms. Multiple psychosocial and spiritual issues can affect a patient’s quality of life near the end of life and need to be appropriately addressed. Our society is now facing a critical discussion on the application of physician-assisted suicide. Current research suggests that in addition to addressing physical pain and symptom control, attending to issues of depression, social support, and other psychosocial issues can reduce suffering and perhaps requests for assistance with suicide in patients near the end of life. William Breitbart, MD, and Barry Rosenfeld, PhD, critically review the area of physician-assisted suicide, particularly from a psychosocial and psychiatric perspective. Recommendations for clinicians of patients who express suicidal ideations or a desire for hastened death are presented.

Robert Walker, MD, presents many ethical issues that surface and are well intertwined in the care of patients near the end of life. The effect of advanced technology on the provision of compassionate medical care for these patients is discussed. Issues of shared decision making, futility, the right to refuse medical treatment, and the removal of patients from life-sustaining treatment are also discussed.

The current health care reimbursement system in the United States generally limits the provision of comprehensive multidisciplinary care for patients near the end of life to those receiving hospice care who have “a life expectancy of less than six months, should the disease take its normal course.” In cancer patients, and even more so in noncancer patients, health professionals may use the term “advanced disease” or “advanced noncancer disease” to signify prognosis by typically underestimating life expectancy, thus limiting the access to good care for many patients with advanced noncurable diseases. Brad Stuart, MD, presents guidelines that have been developed to assist health professionals with assessing prognosis in advanced disease in both cancer and noncancer patients. Although not yet validated, these guidelines can be a useful adjunct to reasonable clinical judgment as they have been incorporated into policy by many of Medicare’s fiscal intermediaries (particularly the noncancer guidelines) as requirements for reimbursement by Medicare for hospice services. Therapeutic approaches for patients with advanced noncancer primary illnesses or noncancer comorbid illnesses are also discussed.

Presenting several important and timely topics in palliative care, this issue of Cancer Control was developed to enlighten and educate its readers about this relatively young and exciting field. Major efforts are underway to provide education and awareness about this expanding field. As our society continues to age, health professionals will see increasing numbers of patients with advanced life-limiting illnesses and should be prepared to offer all reasonable options available to them. Patients should have opportunities to receive high-quality palliative care throughout their entire illness trajectory. In addition to traditional treatment goals, relieving patients’ suffering and optimizing their quality of life should remain high priorities for all health care professionals.

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References


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Back to Cancer Control Journal Volume 6 Number 2