

Palliative care: an essential aspect of quality cancer care

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Advances in palliative care

The past 2 decades in the United States have witnessed major developments in palliative care. It is timely that this issue of *Surgical Oncology Clinics* is devoted to the role of surgery in the care of patients with advanced disease. Despite major advances in the early detection and treatment of cancer, more than 550,000 people in the United States die each year from cancer [1]. For most of these patients, the last months of life are focused on attempts to achieve comfort rather than on treatment aimed at cure of disease.

Combined with the continued mortality of cancer is the ever-looming reality of the aging of the population. By 2030, there will be approximately 70 million older persons (over the age of 65), more than double the number in 1997 [2]. International studies, governmental agencies, professional societies, and consumer reports have documented that the health care system is ill prepared to provide adequate palliative care to an aging population or to the significant numbers of individuals who will face a diagnosis of cancer during their life time.

Despite the heightened awareness of the need for improved palliative care, even the most recent reports suggest that there is great disparity between the way people spend the final months of their life and the way they would prefer to live. Organizations such as the National Hospice and Palliative Care Organization have conducted public opinion surveys reporting that the two greatest fears associated with death are being a burden to their family and dying in pain [3]. Many individuals have come to fear the prospect of prolonged illness characterized by overtreatment in the use of life-sustaining technology and invasive, debilitating treatment. Patients and their families have reported their fear that when “nothing more can be done,” their health

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care providers will abandon them. Advances in palliative care aim to ensure patients and families that, even when cure is not possible, comfort and continued care can be assured.

Barriers to quality care at the end of life

Surgical oncology, as other cancer specialties, is faced with overcoming numerous barriers to quality care in advanced disease. Care of patients is best described as a balance in which professionals hope to achieve the maximal quality of life for patients while balancing the potential for increased suffering and morbidity caused by either overtreatment or undertreatment [4]. An additional major barrier has been the lack of adequate training of health care professionals in the field of palliative care. Fortunately, many professional societies and medical specialties have begun to address the need for increased training within the basic medical curriculum and in residency programs [5]. For example, in 2001 the American Board of Surgery adopted a requirement that all surgical residents receive training in palliative care “including counseling patients/families, management of pain, cachexia and weight loss” [6].

Another key obstacle is the challenge of how best to discuss palliative care with patients and families without taking away hope. This key principle of maintaining hope has been consistently reported in the palliative care literature [7]. A survey conducted in 2002 of members of the Society of Surgical Oncology that assessed surgeons’ perspectives of barriers to palliative care also reported that the highest-rated ethical dilemma was how surgeons could provide honest information to patients without destroying their hope [8].

Major advances have occurred in the field of palliative care in a little more than 2 decades, however. The contemporary hospice movement, credited to Dame Cicely Saunders in the United Kingdom, was developed in response to growing awareness of the needs of dying patients and their families. The principles of the hospice movement then became the foundation for the current development of palliative care [4]. Hospice began as a grassroots effort in the United States with the opening of the first hospice program in Connecticut in 1974 [9]. Hospice professionals pioneered the standards of end-of-life care, and the widest adoption of these principles has been in the field of cancer. Hospice care is now used by approximately half of all dying Medicare-eligible cancer patients and by approximately 19% of dying Medicare recipients overall [10].

The emergence of palliative care

In more recent years, the basic principles of hospice focusing on comfort and quality of life in advanced disease have extended into nonhospice settings through the developing field of palliative care. Palliative care has been defined

by the World Health Organization as “an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief from suffering, by the means of early identification, impeccable assessment, treatment of pain and other problems including physical and spiritual” [11]. The definition provided by the Institute of Medicine (IOM) in its national report on the status of end-of-life care is that “Palliative care seeks to prevent, relieve, reduce or soothe the symptoms of disease or disorder without effecting a cure” [12]. The IOM, World Health Organization, and other national and international voices have challenged professionals in cancer care to integrate the basic philosophy of palliative care into comprehensive cancer care. **Box 1** [13] summarizes the basic philosophy of palliative care.

Goals of care

Quality of life at the end of life emphasizes the possibility of positive experiences in the face of advanced disease. Patients are able to find meaning and reach personal goals before death when pain and their symptoms are well controlled [9]. Professional caregivers support and aggressively advocate for the needs of the patient and their families so that people can live out

Box 1. Philosophy of palliative care

1. Palliative care provides support and care for persons facing life-threatening illnesses across settings.
2. Palliative care is based on the understanding that dying is a part of the normal life cycle.
3. The process of dying is recognized as a profound individual and family experience.
4. Care is focused on enhancing the quality of remaining life by integrating physical, psychological, social, and spiritual aspects of care.
5. Use of an interdisciplinary team is the key to addressing the many needs of the dying and their families.
6. Interventions affirm life and neither hasten nor postpone death.
7. Through appropriate care and the promotion of a caring community, patients and families may be free to realize a degree of satisfaction and closure in preparing for death.

From: Last Acts Task Force. Precepts of palliative care. Princeton NJ: Robert Wood Johnson Foundation, 1992; with permission.

their lives with dignity and die in the manner that is meaningful to them. Goals of care change frequently as the patient declines; thus it is essential that the physician frequently reassess and clarify the patient's goals. Goals of cure, significantly prolonged survival, or extended disease-free interval may be replaced by simple goals such as maintaining bowel function, relief from pain, ability to ambulate, or control of symptoms so the patient can interact with the family or spiritual community. Palliative care interventions function as independent endpoints and should coexist with active treatment. A major issue in advancing the field of palliative care has been the need to institute palliative care earlier, at the time of cancer diagnosis and not just in the weeks or months preceding death. Major cancer centers are attempting to provide patients with palliative-focused care simultaneously with traditional treatments or participation in clinical trials. The best oncology care is not "either/or" but rather is care that combines the best of disease-oriented care and comfort-focused care.

Assessment of quality of life in advanced cancer

Quality of life encompasses physical, psychologic, social, and existential/spiritual dimensions. Advanced cancer affects all dimensions of quality of life, and its effects differ tremendously among individuals. Quality is best described by the patient based on the patient's own life experiences and goals. Dimensions of quality are highly interrelated. For example, the presence of unrelieved symptoms such as pain, nausea, or gastrointestinal disturbances has a profound influence on psychologic aspects such as anxiety and depression. Certainly, the patient's quality of life affects family caregivers' quality of life, and unrelieved symptoms or distress in patients results in significant burden for family caregivers.

A more in-depth explanation of these dimensions of quality of life sheds light on the relevance of surgical oncology to the goals of palliative care. Within the domain of physical well-being are multiple symptoms caused by disease progression, debility, and changes that affect the physical well-being of the patient. Pain is one of the primary concerns of terminally ill patients and their family members. The distressing symptoms common in advanced disease include dyspnea, fatigue, dysphagia, and anorexia/cachexia. Other common physical aspects affecting quality of life are functionality, sleep, rest, and disturbance of appetite [14].

In the realm of psychologic well-being, patients facing cancer in all stages of the disease experience a wide range of emotions and psychologic concerns. Communication is a key component of the psychologic domain. One of the greatest challenges of surgeons is "breaking bad news" and offering honest but supportive communication in relation to the patient's goals and progress of treatment. Long-term cancer survivors have consistently reported that the way the initial diagnosis and prognosis were communicated had a lasting impact on their illness and survivorship [15,16]. Teaching effective commu-

nication skills has become a key component of medical education to improve palliative care [17,18]. Even individuals with tremendous family support, high cognitive function, and effective coping strategies experience a usual course of emotional response to illness including anxiety, sadness, fear, depression, distress, grief, anger, and hope.

The social dimension of quality of life involves the integrity of personal relationships. Physical and psychologic symptoms greatly affect the patient's ability to maintain relationships and participate in the family. Another major impact of serious illness is altered sexuality. The ability to maintain intimacy and expressions of sexuality change throughout the course of illness but remain important aspects of quality of life for patients and their families. Financial concerns are also paramount for the patient and family amid the usual demands of a chronic illness (eg, lost wages, out-of-pocket medical costs, transportation costs) and the ever-increasing indirect costs to patients and families in a burdened health care system [10].

The fourth dimension of quality of life is spiritual/existential well being. Although somewhat more elusive than the other dimensions, the patient's sense of spirituality is enormously affected by a life-threatening illness such as cancer. Religious or cultural rituals and activities are important means of support [19]. The presence of unrelieved systems such as pain often invoke questions of "why me," and patients struggle with difficult decisions regarding prolongation of life and maintaining hope and faith as treatments fail. Sources of suffering commonly cited in cancer include physical distress, concerns of family and relationships, questioning the meaning of illness, past life experiences, and the sense of unfairness of a diagnosis such as cancer. These dimensions of quality of life are depicted in Fig. 1.

The quality-of-life model has been applied to research related to palliative surgery in cancer by researchers at the City of Hope National Medical Center [8,20–22]. Decisions made by patients, family caregivers, and surgeons regarding treatment options such as surgery can affect each of the dimensions of quality of life as illustrated in Fig. 2.

Assessment of spiritual concerns can be facilitated by collaboration with social workers, nurses, or chaplains. Tools to assess spiritual needs [23] are available as an efficient means of identifying spiritual beliefs so these beliefs can be incorporated into the plan of care. Spirituality is a component of the patient's culture and may involve issues such as use of native healers, belief in miracles, and religious traditions [24,25].

Continuity of care

A guiding principle of palliative care is that palliative care be integrated across the continuum of care. The World Health Organization has recognized that health care has traditionally been focused predominantly on cure, with palliative care provided only in the last days or weeks of an individual's life. As an alternate model, the World Health Organization suggests that palliative

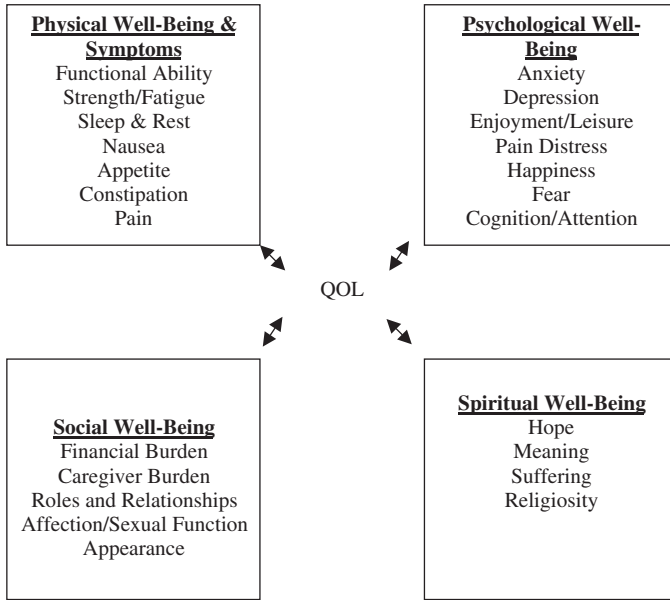


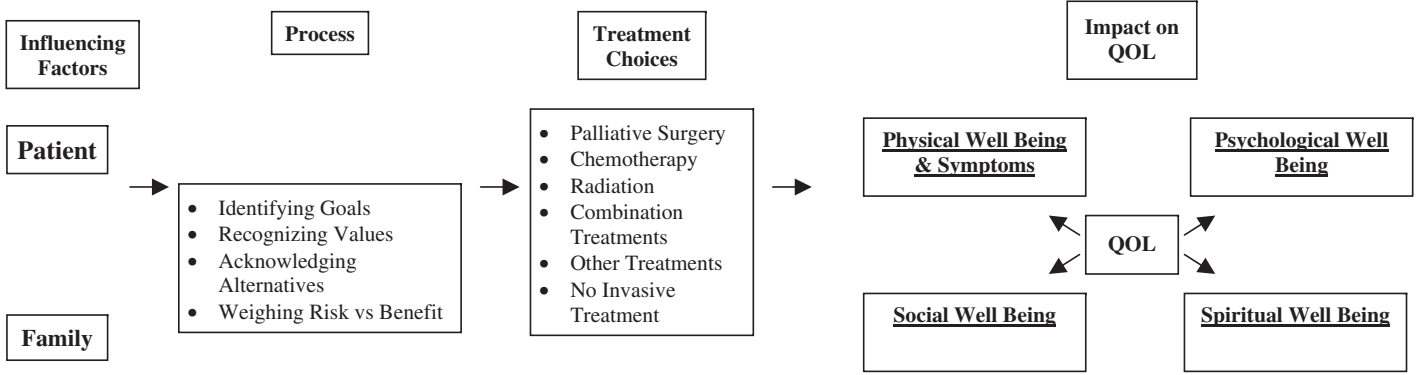
Fig. 1. Quality-of-life model. (From Ferrell BR, Grant M. Quality of life model. Duarte (CA): City of Hope National Medical Center; 2000; with permission.)

care be integrated from the time of diagnosis [26]. Fig. 3 illustrates a paradigm in which palliative care is initiated during the course of curative treatment or disease-specific care, although the focus may be predominantly on cure or the prolongation of life. If the patient’s disease progresses, comfort care becomes far more predominant. The World Health Organization also emphasizes that care is extended to the family members during the period of bereavement following the time of death.

The need to reform systems of cancer care in the United States has been cited by authorities at all levels, from individual treatment centers to the National Cancer Institute and other national organizations [5,12,13]. In 1997, the IOM issued a report entitled “Approaching Death: Improving Care at the End of Life” [12]. Key recommendations from the IOM Committee on the End of Life Care are given in Box 2.

Following the release of this initial report, the IOM issued a report specific to reforms needed in cancer care in conjunction with the National Cancer Policy Board [27]. In a complementary report, several medical

Fig. 2. Clinical decision-making in palliative surgery. (Adapted from Ferrell B, Chu D, Wagman L, et al. (2003). Patient and surgeon decision making regarding surgery for advanced cancer. *Oncol Nurs Forum* 2003;30(6):E106–14; with permission.)



- Surgeon**
- estimated difficulty of the palliative procedure
 - duration of hospitalization required
 - recovery time at home required
 - % chance of achieving the palliative goal in the short term
 - anticipated durability of the intervention
 - anticipated malignant disease progression

- Additional Outcomes**
- Low Morbidity
 - Durable Palliation
 - Patient Satisfaction with Treatment
 - Survival
 - Family Caregiver Satisfaction/QOL/ Burden
 - Health System Outcomes (Cost)

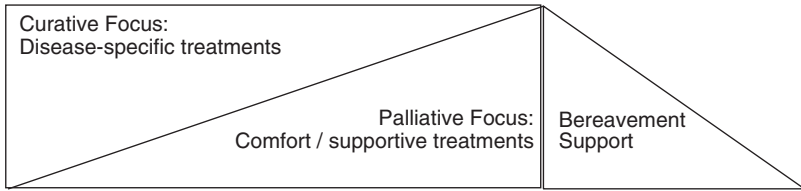


Fig. 3. Continuum of care. (From *Cancer pain relief and palliative care*. Technical report series 804. Geneva (Switzerland): World Health Organization; 1990; with permission.)

specialty groups collaborated to develop and issue principles of care for patients at the end of life (Box 3) [28]. These key principles illustrate the opportunities for surgical oncology to contribute to the evolving field of palliative care. Principles such as respecting the dignity of the patient, encompassing alleviation of pain and other physical symptoms, offering continuity of care, and promoting evidence-based research are hallmarks of quality cancer care.

Future opportunities

This issue of *Surgical Oncology Clinics* is timely, because the broad field of palliative care has increasingly recognized the important role of surgical intervention within a multidisciplinary approach to palliative cancer care. A recent issue of the *Journal of Palliative Medicine* included an editorial titled “Surgery and Palliative Care” emphasizing major advances in the field [29]. This journal recognized the pioneering work of surgeons Geoffery Dunn and Robert Milch in providing leadership for the American College of Surgeons Task Force on Palliative Care. The mission of this task force is to facilitate introduction of the precepts and techniques of palliative care into surgical practice and education in the United States and Canada. Highlights of their activities include establishing a requirement that residents receive training in palliative care and increasing palliative care content for the Surgical Education and Self Assessment Program (SESAP), the American College of Surgeons’ continuing education course used as a study guide for general surgery certification and recertification.

Palliative care has been recognized as an essential component of quality cancer care. The National Comprehensive Cancer Network [30] has developed guidelines for palliative care, and projects such as the Center to Advanced Palliative Care [31] have focused efforts of integration of palliative care in acute care settings. In March 2004 national guidelines for palliative care were released that probably will improve the quality of palliative care programs [32]. Surgical oncology has much to contribute to the goal articulated by pioneers of hospice and palliative care, “to comfort always.”

Box 2. Recommendations from the Institute of Medicine Committee on Care at the End of Life

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. Physicians, nurses, social workers, and other health professionals must commit themselves to improving care for dying patients and to using existing knowledge effectively to prevent and relieve pain and other symptoms.
3. Because many deficiencies in care reflect system problems, policy makers, consumer groups, and purchasers of health care should work with health care providers and researchers to
 - a. Strengthen methods for measuring the quality of life and other outcomes of care for dying patients and those close to them
 - b. Develop better tools and strategies for improving the quality of care and holding health care organizations accountable for care at the end of life
 - c. Revise mechanisms for financing care so that they encourage rather than impede good end-of-life care and sustain rather than frustrate coordinated systems of excellent care
 - d. Reform drug prescription laws, burdensome regulations, and state medical board policies and practices that impede effective use of opioids to relieve pain and suffering
4. Educators and other health professionals should initiate changes in undergraduate, graduate, and continuing education to ensure that practitioners have the relevant attitudes, knowledge, and skills to care well for dying patients.
5. Palliative care should become, if not a medical specialty, at least a defined area of expertise, education, and research.
6. The nation's research establishment should define and implement priorities for strengthening the knowledge base for end-of-life care.
7. A continuing public discussion is essential to develop a better understanding of the modern experience of dying, the options available to dying patients and families, and the obligations of communities to those approaching death.

From: Field MJ, Cassel CK. Approaching death: improving care at the end of life (report of the Institute of Medicine Task Force). Washington DC: National Academy Press, 1997; with permission.

Box 3. Core principles for care of patients

1. Respecting the dignity of both patient and caregivers
2. Being sensitive to and respectful of the patient's and family's wishes
3. Using the most appropriate measures that are consistent with patient choices
4. Encompassing alleviation of pain and other physical symptoms
5. Assessing and managing psychological, social, and spiritual/religious problems
6. Offering continuity (if the patient desires, care should continue to be given by the patient's primary care and specialist providers)
7. Providing access to any therapy that may realistically be expected to improve the patient's quality of life, including alternative or nontraditional treatments
8. Providing access to palliative care and hospice care
9. Respecting the right to refuse treatment
10. Respecting the physician's professional responsibility to discontinue some treatments when appropriate, with consideration for both patient and family preferences
11. Promoting clinical evidence-based research on providing care at the end of life.

From: Cassel CK, Foley KM. Principles of care of patients at the end of life: an emerging consensus among the specialites of medicine. New York NY: Milbank Memorial Fund. <http://www.milbank.org/enoflife/index.html>; with permission.

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