

Palliative Care Across the Continuum of Cancer Care

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Key Words

Palliative care, integrated care

Abstract

Optimal oncology care requires the integration of palliative medicine into oncology care across the disease trajectory. All patients require screening for palliative care services at the initial oncologic visit and reassessment throughout the continuum of care. As a result of the increasing attention focused on palliative care nationally and internationally, the domains of palliative cancer care have been elucidated and have fostered the development of guidelines for quality palliative care. The recent recognition of palliative medicine as a subspecialty in the United States, the growing number of hospital-based palliative care programs, and the accreditation of palliative medicine fellowship programs by the Accreditation Council for Graduate Medical Education highlight the increased visibility of palliative medicine. This provides hope for the future of oncologic care. The palliative approach is subsumed in cancer care—it provides assistance with decision-making, symptom management, and access to financial, emotional, and spiritual services. A fully integrated program of oncology and palliative care provides the greatest opportunity for care and cure. (*JNCCN* 2009;7:481–487)

The term *palliative care* was originally coined by Dr. Balfour Mount, a urologic surgeon and leader of the palliative care movement in oncology. Although multiple definitions of palliative care have been proposed, they all share

common themes, including a multidisciplinary approach to the relief of suffering, improvement in quality of life, and a focus on patient and family defined goals of care.

Palliative care as an essential component of best oncology care was proposed almost 20 years ago by the WHO and was defined as “the active total care of patients whose disease is not responsive to curative treatment” and emphasized that “many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment.”¹ The WHO mandates all national cancer control programs to address the palliative care needs of patients. Palliative care is now recognized as an integral part of optimal oncologic care, regardless of disease stage. It can be delivered concurrently with life-prolonging care or as the primary focus of care.

The integration of palliative care into the field of oncology has been slow to develop. In 1998, ASCO published a special article entitled “Cancer care during the last phase of life.”² In the executive summary, it stated: “ASCO believes that it is the oncologist’s responsibility to care for their patients in a continuum that extends from the moment of diagnosis throughout the course of the illness,” including symptom control and psychosocial support during all phases of care. Identified obstacles to delivering high-quality, integrated care include the attitudes of health care professionals and patients toward palliative and end-of-life care, lack of availability or insurance coverage for this care, inadequate physician training and education, and a lack of appropriate role models.^{3–6}

The traditional approach to cancer care was based on the dogma that adequate treatment of the cancer improves symptoms. Although this is true to some extent, the emerging focus on survivorship has clarified the fact that some cancer-related symptoms and treatment-related morbidity may negatively impact quality of life indefinitely, regardless of whether cure is achieved. Fur-

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thermore, for a significant minority of patients, cure is not an option.

The number of patients living with cancer is increasing. In 2004, the number of cancer survivors was estimated to be 10.8 million.^{7,8} Of these, 63% were considered long-term survivors (> 5 years beyond the time of their original diagnosis), with 39% surviving 10 years or more. Longitudinal, population-based studies showed that, compared with patients without a history of cancer, those with a history are more likely to have significant functional limitations, including fatigue, lack of stamina, and decreased ability to participate in usual life activities (e.g., walking, shopping, social events).^{9,10} Some long-term symptoms are more frequently associated with a particular primary cancer site. For instance, Ganz et al.¹¹ found a higher incidence of general aches and pains (70%), muscle stiffness (64%), and joint pain (62%) in breast cancer survivors compared with healthy cohorts.

Awareness of palliative care is expanding rapidly, in both medical practice and the medical literature. The number of palliative care programs and fellowships in the United States has increased dramatically,¹²⁻¹⁴ and a few joint fellowship programs in oncology and palliative care now exist (Jamie H. Von Roenn, MD, unpublished data). As of January 2009, 47 palliative medicine fellowship programs received accreditation from the Accreditation Council for Graduate Medical Education (ACGME).

The literature reflects the growing visibility of palliative medicine. A significant rise in the proportion of Ovid MEDLINE publications related to palliative medicine and hospice between 1970 and 2005 (0.08%–0.38%) has been reported,¹⁵ underscoring the relationship between palliative care and oncology because nearly two thirds of the journals responsible for 50% of the clinical trials in palliative care were cancer-specific.¹⁶ This change corresponds with the growing recognition by health care professionals of the importance of the relief of suffering and whole-patient care to patients and their families.

In the past decade, improving the quality of life and care for people with cancer has become a national priority.¹⁷⁻²² The Institute of Medicine (IOM) published a series of documents characterizing the role of palliative cancer care within comprehensive oncology care.¹⁷⁻²² The original IOM report, published in 1997, documented numerous deficiencies in palliative care

in the United States.¹⁷ Subsequent IOM reports in 1999, 2001, and 2007 described best practices, identified areas of needed research in palliative care, and described the role of psychosocial oncology and integration of palliative care into the care of survivors.¹⁸⁻²²

The National Cancer Institute has called for the “relief of suffering” for all cancer patients by 2015. ASCO is advocating for improvements in education and training in palliative cancer care.²³ An ASCO Palliative Care Task Force convened and developed recommendations to better integrate palliative care into its educational programs and policy activities. The ASCO board of directors endorsed these recommendations and is committed to facilitating their implementation.

Models of Care

The continuum of cancer care begins at diagnosis and extends to treatment, survivorship care, and end-of-life care. Early models of cancer care offered palliative care as an alternative to anticancer care: the “cure-or-care” model (Figure 1). As depicted, time is on the x axis in these early models. Anticancer therapy is the initial focus of care from diagnosis, with cure as the goal. An abrupt crossover to palliative and end-of-life care occurs when cure is no longer an option. However, this either/or approach has no rational basis.

Recognition of this led to the development of a more integrated approach. As portrayed in Figure 2, palliative care interventions increased, but usually in correlation with decreasing treatment options and interventions over time.¹⁶ As time progresses on the x axis, the role of palliative care increases and anticancer therapy decreases until eventually the entire focus is on palliative care. When the expected prognosis is less than 6 months, a transition to hospice may occur. However, in reality, the transition to hospice care often occurs late in the course of cancer care, when the prognosis is days to weeks.²⁴

Optimal cancer care recognizes that a defined role for palliative care exists in every stage of cancer care. At diagnosis, symptoms requiring treatment may bring patients to medical attention. The intensity of palliative care interventions fluctuates over time, portrayed as spikes that may occur with treatment changes or recurrences (Figure 3A).

Not infrequently, it is the presentation of new symptoms that heralds the recognition of tumor re-

currence. With a change in therapy or initiation of new treatment, prevention and treatment of symptoms are nearly always required. This model of integrated care is ideal because it includes the period of survivorship; recognizing that symptom management and quality-of-life issues for this growing population continue to require attention, impeccable assessment, and aggressive management (Figure 3B).

The NCCN publishes expert consensus guidelines for the diagnosis and treatment of numerous tumor types and for the integration of palliative care into cancer care.²⁵ Using these guidelines as a framework, this article focuses on the integration of palliative care across the cancer continuum, including initial screening, assessment throughout anticancer therapy, and the role of palliative care posttreatment.

Initial Screening for Palliative Care Services

The initial visit to an oncologist's office includes a thorough assessment of palliative care needs. The initial screening, performed by the physician and/or other health care professionals, determines the presence and severity of symptoms, patient and family distress, the presence of comorbid conditions, patient/family concerns about the anticipated course of the disease, and the impact of treatment on the patient and family unit.

Based on the physician's estimate of life expectancy, the intensity of needed palliative care services can be estimated. A patient who presents with significant nausea, psychological distress, dyspnea, or pain may require intensive palliative services from the outset. If the initial screen fails to identify significant physical symptoms or psychosocial concerns, information about available palliative care services may

be provided and the anticipation and/or prevention of treatment-related symptoms are discussed.

Assessment Throughout Anticancer Therapy

The National Consensus Project for Quality Palliative Care recognizes 8 domains of quality hospice and palliative care.²⁶ Guidelines for palliative care assessments during anticancer treatment, outlined by NCCN, incorporate the major National Quality Forum (NQF) preferred practices within each domain.²⁶ Based on these domains and the associated guidelines for best practice, the palliative care assessments and interventions focus on the following: 1) physical symptoms, 2) psychologic and psychiatric aspects of care, 3) spiritual, religious, and existential aspects of care, 4) care of the imminently dying patient, 5) legal and ethical concerns, 6) social aspects of care, 7) cultural factors that may affect care, 8) communication and understanding of patient/family goals, and 9) patient and family education.

Because the suffering, in the broadest sense, of patients and families often intensifies in the setting of advanced disease, the emphasis placed on the various components of the palliative care assessment will vary depending on the prognosis. Unfortunately, distinguishing prognosis for individual patients with cancer is a difficult task that physicians of all specialties are unable to do with accuracy. Multiple tools exist to assist with formulating prognosis, but none is predictive for an individual patient.²⁷

Performance status is one useful prognostic factor, regardless of the underlying disease. Two performance scales are widely used: the ECOG scale (a 0–5 scale where 0 is normal and 5 is dead) and the

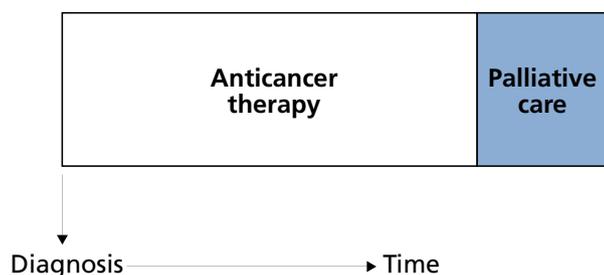


Figure 1 Early integration of palliative care.

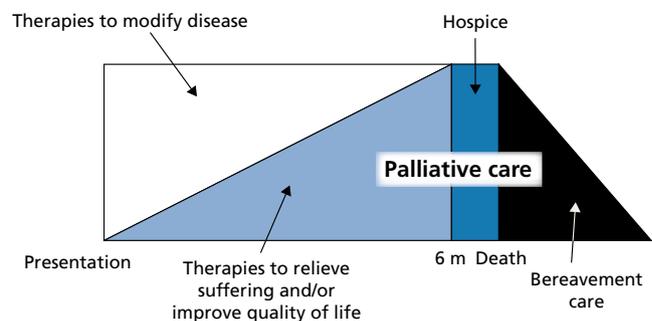


Figure 2 Survivorship with active cancer.

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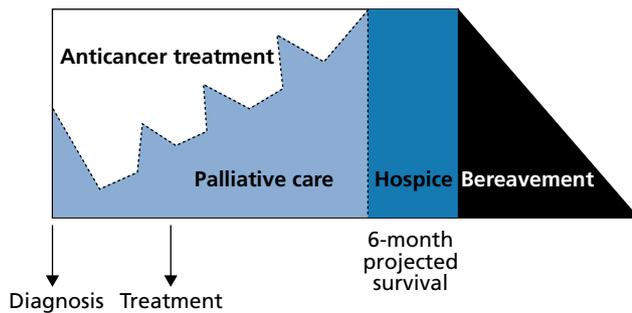


Figure 3A Survivorship and continued palliative care.

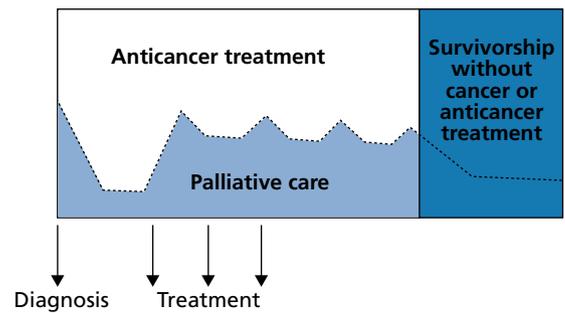


Figure 3B Survivorship and continued palliative care.

Karnofsky Performance Score (KPS; a 0–100 scale where 0 is dead and 100 is a normal, fully functioning person). A KPS score of 40 or an ECOG score of 3 or higher is associated with a median survival of 3 months or less.^{28,29}

The National Hospice Organization evaluated the predictive value of performance status and 14 different symptoms in patients with advanced illness. A KPS of less than 50 (patient requires physical assistance and frequent medical care) and the presence of 1 or more of 5 symptoms suggested a poor outcome. The 5 symptoms—*anorexia, weight loss, dysphagia, dry mouth, and dyspnea*—were predictive of a poor prognosis. If none of these symptoms was present, the median survival was 6 months, compared with 6 weeks if all symptoms were present.³⁰ Many prognostication tools take into account a subjective prediction of survival by a physician, whereas other tools are disease-specific.^{31–35}

Once providers determine prognosis, the palliative care approach can be determined according to 3 broad categories: 1) curable or early disease, 2) survivorship without active cancer (including surveillance for recurrent disease), and 3) advanced disease and end-of-life care. Although the palliative care assessment and needs overlap across these groups, the approach is tailored to meet the specific needs essential for comprehensive cancer care in each setting.

A determination of the benefits and risks of anticancer therapy is an individualized assessment incorporating the patient's preexisting comorbidities, patient and family goals of care, patient performance status, tumor type and stage, and treatment efficacy and its toxicity. The acceptability of treatment-related morbidity partly depends on the patient's goals of care and estimated life expectancy. The intent

of antineoplastic therapy—cure versus palliation—must be clearly communicated to effectively address patient goals and to determine what toxicity is acceptable from the patient's point of view.

If cure is a reasonable expectation from treatment, greater toxicity to achieve that goal may be acceptable. If, however, survival is measured in weeks to months, best supportive care, including hospice, may or may not be the most appropriate goal. For the patient with a very poor prognosis (weeks to days) or an imminently dying patient, intensive palliative care services focused on the relief of suffering provide the best care. Optimal palliative care provides psychosocial support for the patient and family.²⁶ Palliative care/hospice supports the patient and family and prepares them for the dying process. Regardless of the initial prognosis, the need for palliative interventions requires frequent reassessment at intervals throughout the duration of care to ensure adequate symptom control, reduction of distress, and optimal quality of life.

Symptom evaluation is a vital component of the palliative care assessment. The number and severity of symptoms vary with the cancer stage. Patients with advanced cancer experience an average of 13 symptoms while hospitalized and at least 7 in the outpatient setting.³⁶ Pain is one of the most distressing symptoms for cancer patients and their families. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments found that at least 40% of patients have moderate to severe pain more than 50% of the time during their final 3 days of life, and more than 25% experience dyspnea.³⁷ Successful approaches to pain management have been established,³⁸ but assessment and treatment of pain are often difficult; no internationally accepted

assessment tool exists,³⁹ partly because of inadequate physician training.⁴⁰

Physician attitudes and practices in cancer pain management were assessed by a survey of ECOG oncologists and found to support this contention. Only 51% of respondents believed pain control in their own practice setting was good or very good; 86% believed that most patients with pain were undermedicated. Poor pain assessment was rated by 76% of the physicians as the single most important barrier to adequate pain management.⁴¹ Unfortunately, this lack of training exists in multiple domains of palliative care. A 1998 ASCO survey of 3227 oncology physicians reported that 81% of respondents noted inadequate mentoring or coaching in discussing poor prognosis, and 65% reported inadequate education about controlling symptoms.⁵

Beyond a determination of the balance between anticancer therapy and symptom management for individual patients at a particular point in their disease course, the palliative care assessment strives to identify psychosocial distress, define personal goals and expectations, meet educational needs, address cultural factors affecting care, and assess criteria for early consultation with a palliative care specialist. Psychosocial interventions focus on a broad array of concerns. Examples include assessment and treatment of anxiety and depression; access to transportation and interpreters; and referral to financial, educational, and emotional resources. A multidisciplinary team of social workers, nurses, chaplains, and psychologists is ideal for meeting these needs. Attention to these issues provides patients and families with a sense of support and personal control, reduces distress, relieves caregiver burden, and strengthens relationships.

Culturally sensitive delivery of care in this increasingly diverse society is a growing priority in today's health care system. This may be particularly important in the setting of life-threatening illness. The Coping with Cancer study is a federally funded, multisite, prospective study examining racial and ethnic disparities in end-of-life care.⁴² Dedicated studies like this will help identify differences in beliefs and treatment preferences among racial and ethnic groups. Added understanding of why significant differences in preferences for care exist and what these differences are will serve as the basis for future guidelines. Culturally sensitive communication may

clarify the patient's wishes for care, enhance family involvement in care, and address cultural customs and beliefs. A cultural liaison may provide invaluable assistance in understanding personal priorities and facilitate advance care planning, although current literature does not include dedicated studies supporting this recommendation.

Criteria for early consultation with a palliative care specialist can be divided into patient characteristics and social circumstances, including anticipatory bereavement issues. Patient characteristics that may signal the need for early intervention include significant comorbidities that exacerbate symptoms, multiple "allergies" or adverse reactions to common symptom-directed therapies, limited treatment options, or patients at high risk for poor pain or symptom control (e.g., patients with a history of chronic pain, drug or alcohol abuse, psychiatric diagnoses, or cognitive impairment).

The NCCN Clinical Practice Guidelines in Oncology: Distress Management (to view the most recent version of these guidelines, visit the NCCN Web site at www.nccn.org) suggest referral to mental health providers, social workers, or pastoral care services for all patients with a high distress score. The basis for the distress identifies the appropriate referral. The NCCN Distress Management tool is a self-report measure consisting of a global distress measure and 5 distress domains: practical concerns (e.g., housing, insurance, physical symptoms), family problems, and emotional and spiritual/religious concerns.⁴³⁻⁴⁵ Throughout the cancer continuum, patient and family distress and social circumstances are addressed continuously, because patient/family needs are fluid across the cancer experience. At least some of the appropriate personnel resources are present at most sites of cancer care. The growing number of palliative care programs across the country will hopefully increase the availability of these service providers.⁴⁶

The need for palliative care intensifies as patients approach death. During the last days or hours of life, interventions that may be provided by a palliative care team include aggressive symptom management, discussion and support of discontinuation of diagnostic tests and nonessential medications, provision of comfort, and care of the patient and family unit.

In addition to aggressive pharmacologic treatment of symptoms, the medical team can ease the patient and family concerns about death by ensur-

ing that they understand the signs and symptoms of imminent death, provide support during the dying process, facilitate closure, and offer anticipatory bereavement support. The goal is for a “good death,” a death that is consistent with the patient’s and family’s wishes, free from avoidable distress and suffering, culturally sensitive, and consistent with clinical and ethical standards.

Bereavement support for the family may be provided by formally expressing condolences, offering specific bereavement services, addressing family questions about organ donation and autopsy, and offering to inform other health care providers about the patient’s death. Although formal services are underused, a bereaved caregiver often turns to informal resources in the medical community for support. A recent retrospective study found that fewer than half (46%) of bereaved caregivers used at least one type of specialized professional bereavement intervention, defined as a support group, bereavement counseling, or psychologist or psychiatrist services.⁴⁷ Many more (88.5%) reported use of some form of bereavement care, including a physician, clergy member, social worker, or nursing service. Future studies may help refine services to better address the needs of bereaved caregivers.

Conclusions

Optimal oncology care requires the integration of palliative practices and principles throughout the continuum of cancer care. All patients require screening for palliative care services at the initial oncologic visit and reassessment throughout the duration of care. Multiple oncology organizations throughout the world, and the WHO, support this contention. To achieve this goal, oncologists require improved training in palliative medicine.

The increased visibility of palliative medicine in the United States, as a result of the growing number of hospital-based palliative care services and the new recognition of palliative medicine as a subspecialty, should increase the availability of education and training opportunities. This, coupled with a commitment from ASCO to integrate palliative medicine into oncology care, will hopefully advance this goal.

Palliative care provides assistance with decision-making, symptom management, recognition of patient/family goals of care, and access to financial, emotional, and spiritual services. A fully integrated

program of oncology and palliative care provides the greatest opportunity for care and cure.

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