

Palliative and End-of-Life Care for Patients with Malignancy



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KEYWORDS

- Palliative care • End-of-life (EOL) • Hospice • Cancer • Life-sustaining treatments (LST)
- Symptoms • Patient-centered and family-centered outcomes

KEY POINTS

- Palliative and end-of-life (EOL) care needs for patients living with cancer and their families are substantial and include distressing symptoms, psychosocial suffering, and existential and/or spiritual suffering.
- Palliative care referral is associated with improved symptoms, decreased intensity of non-palliative EOL care, and higher family-rated satisfaction with EOL care.
- Provider attitudes and perceptions continue to be important barriers to referral to specialty palliative care.
- Disparities in referral to palliative care persist for nonwhite populations of patients with malignancy.
- Palliative care delivery may be improved by addressing attitudes and knowledge about palliative care among health care providers and patients.

INTRODUCTION

Many patients with cancer are living longer. Development of targeted, disease-specific cancer treatments has reshaped the way clinicians think about cancer.^{1–7} When patients with cancer develop life-threatening complications from their disease or its treatments, improvements in the delivery of life-sustaining treatments (LSTs), usually delivered in an intensive care unit (ICU), have been instrumental in supporting patients through decompensations and complications. LSTs have improved survival for general ICU populations.^{8–14} Although the efficacy of some LSTs has been mixed in patients with cancer, time-limited trials for many of

these therapies are reasonable to consider for appropriate patients.^{9,15–17}

Cancer remains a common and important life-limiting condition. Worldwide, cancer was responsible for 8.2 million deaths, or 13% of all deaths, in 2012. In the United States, cancer is the second most common cause of death following heart disease.¹⁸ Given the prevalence of cancer, its associated symptoms, and its impact on quality of life and life expectancy, patients and their families are at risk for unmet palliative care (PC) needs from the time of diagnosis, during active cancer treatment, and up to the time of the patient's death. This article defines palliative and

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end-of-life (EOL) care. It then reviews causes and treatments of dyspnea for patients with cancer. Models and timing for palliative and EOL care delivery are discussed, including the promising role for technology in addressing unmet PC needs. In addition, common barriers to delivery of palliative and EOL care for patients living with cancer are identified.

DEFINING PALLIATIVE AND END-OF-LIFE CARE

The World Health Organization (WHO) defines PC as:

A [team] approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.¹⁹

PC teams address domains of physical, existential, spiritual, and social suffering and facilitate complex decision making at any stage of a disease (Box 1).^{20–23} PC is an important aspect to delivering high-quality EOL care, defined as the last 6 months of life for hospice evaluation, but is not restricted to EOL care and decision making.

Clinical practice guidelines and expert opinion recommend incorporating PC into oncology practices or teams.²⁴ Patients with cancer frequently live with a high burden of physical symptoms. Existential, psychosocial, and spiritual suffering are also common and can be more difficult to identify and quantify. Weighing acceptable tradeoffs between quality of life and potential treatment options to achieve control or even cure contribute to

patients' uncertainty over their lives, their roles in their families, and their roles in society. High-quality PC can uncover priorities, preferences, and goals for patients as they consider these choices. Thus, PC plays a critical role in delivering patient-centered and family-centered care for patients living with cancer.

Inconsistent terminology is challenge in defining PC and understanding its impact on clinical and patient-centered and family-centered outcomes. In a systematic review, terms including "palliative care," "[best] supportive care," "terminal care," "end of life," "goals of care," and "transition of care" were used to discuss PC and associated interventions.²⁵ Furthermore, the type of journal also affects which terms are used, with "supportive care" more frequently used in oncology journals, whereas "palliative care" and "end of life" were more frequent in palliative medicine journals. Establishing a common language with consistent definitions for PC is necessary to better understand the impact of PC on the quality of care for patients with life-limiting conditions such as cancer.

PALLIATION OF DYSPNEA IN CANCER

Dyspnea Prevalence, Causes, and Significance

Symptom burden is substantial for patients with cancer. Fatigue, decreased appetite, pain, and dyspnea are frequently reported and are among the most bothersome symptoms to patients. Many of these symptoms worsen as patients approach the end of their lives (Fig. 1).²⁶ Although a review of all of the symptoms experienced by patients living with cancer is beyond the scope of this article, a brief review of dyspnea prevalence, its causes, and its association with outcomes is presented.

Respiratory symptoms are among the most common physical symptoms for patients living with cancer.²⁶ Moderate to severe dyspnea affects approximately 25% of patients with advanced cancer, with prevalence increasing during the last 6 months of life.^{26–29} Seventy percent of patients with cancer report intense, episodic exacerbations of dyspnea with activity during the last 6 months of life.^{26,27} Moreover, dyspnea can exacerbate other distressing symptoms such as pain and fatigue.²⁶

Like pain assessment, there is no objective measurement tool for dyspnea. Vital signs, laboratory tests, or radiographic imaging should not be used to confirm the presence of dyspnea or gauge its severity. Patients with cancer frequently report significant, distressing dyspnea without typical signs of respiratory distress such as tachypnea

Box 1

Evidence-based domains of high-quality palliative care

Symptom relief

Emotional support to patient and families

Promote shared decision making and advanced care planning

Meeting the needs of patients and their families/caregivers

Addressing grief and spirituality

Preparation for the dying process

Coordination of care

Data from Refs.^{20–23}

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