



A comprehensive approach to treating patients with cancer includes cancer treatment, supportive interventions, and palliative care.

Route 43, Hancock, Massachusetts, 2000.
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Integrating Palliative Care in Oncology

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Background: *Cancer is the second leading cause of death among Americans. The World Health Organization has mandated an integrated approach to palliative care in the treatment of patients with cancer. However, medical decision making in the setting of life-threatening disease remains complicated.*

Methods: *An integrated palliative care approach depends on the skillful blend of antineoplastic, supportive, and palliative interventions. For standardizing care plans, documenting palliative interventions, and tracking and improving outcomes, palliative care elements are defined. At our institute, medical symptom management, psychosocial support, and advance care planning are incorporated into routine cancer care.*

Results: *Although progress is being made toward integrating palliative care in the field of oncology, further efforts are needed to ensure that cancer patients and their families who need palliative care receive it.*

Conclusions: *If fully implemented, the integrated palliative care approach will result in quaternary prevention, ie, the prevention of suffering.*

Introduction

Cancer exacts a toll of suffering well beyond that which can be easily measured. One in three Americans will develop cancer within his or her lifetime, and one in five will die of cancer. It is estimated that cancer rates will continue to rise, with more than 1.5 million new patients being diagnosed in the United States this year. Cancer is currently the second leading cause of death in the United States, and it is a prevalent problem worldwide.

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tion (WHO) has stated that pain and symptom control should be of high priority in cancer care, and it has recommended greater allocation of resources to palliative interventions. The WHO defines palliative care as "active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families."¹ Palliative care is far from standardized, and it is not widely applied. Much work remains to fulfill the WHO's directive that palliative interventions be integrated throughout the continuum of cancer care.

Barriers to Palliative Care

In the United States, professional education in care for the dying is limited, and the communication skills needed by oncology health care providers are rarely taught. Physician training, the "professionalization" process, emphasizes a medical model, not a biopsychosocial or holistic model of care.^{2,3} Health care providers are not educated in methods to integrate primary and palliative goals of treatment. They are not formally prepared to manage suffering, and this is compounded by a societal reinforcement of stoicism. Profound confusion in our culture about the use of opioid (narcotic) drugs as analgesics and poor assessment of pain and other symptoms add to the problem.⁴ In a multicultural society, patients and care providers often need to bridge a gap of widely differing ethical, moral, and religious belief systems. Other challenges to palliative care delivery include finding mechanisms for ensuring continuity of care, preventing abandonment, and respecting patient/family values, especially for those who are not strong care advocates and coordinators in our fragmented health care system. A lack of advance care planning increases the risk that patient preferences will not be respected, may lead to more medically futile care, and places an unexpected burden of care on families. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) suggests the need for more practical strategies to reduce futile care while respecting the wishes of patients and families and simultaneously achieving our research goals.⁵ There is a marked and growing interest in examining resource allocation to achieve the best quality survival from cancer.

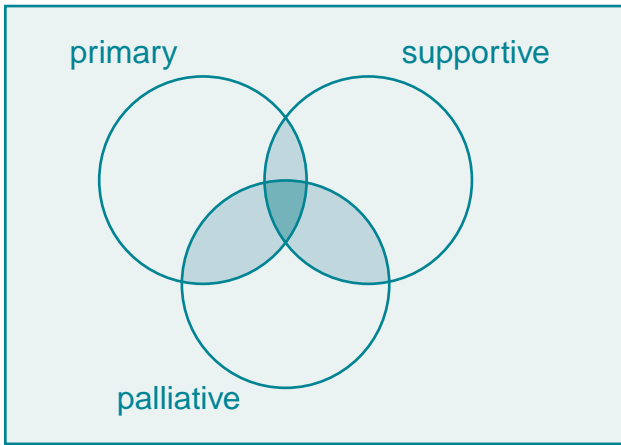
The current societal trend to legalize physician-assisted suicide also asks us to work harder to establish palliative care as the norm. Intensive symptom control, with psychological and spiritual support, should be available to dying patients and their families as the preferable alternative to accelerated or deliberate death.

Decision-Making Issues

In clinical oncology practice, there is a wide variation in medical decision making regarding choices of antineoplastic and palliative treatments, especially in the advanced stages of cancer. Often, decisions are not based solely on medical information, due partly to a paucity of scientific data on which to base them. Therapeutic choices may be limited by economic factors and reimbursement policies. Clinicians in a tertiary care center may be further affected by conflicts between clinical and research issues. The personal values of the patient and family, as well as the professionals caring for them, often are overriding. How all of these factors interrelate remains unknown.

When patients first receive a cancer diagnosis, most will opt for curative treatment. A critical decision point occurs when it is realized that disease is progressing, that active antineoplastic treatment will most likely fail to achieve cure, and that death from cancer is predictable (although the clinical course is highly variable). This critical decision point represents a psychologically hard "corner," stressing the patient to accept premature death. Caregivers are also stressed by the anticipated burden of care and eventual loss of the patient. Medical treatment options to stall the disease process may be offered. Alternatively, the patient may be presented with the concept of "comfort care only" and told that "there is nothing more to be done," which leaves many questions regarding the duration and quality of life the patient may expect as she or he nears death. This decision point has historically been considered the transition from curative to palliative treatment.

Another decision point occurs when referral to hospice is made. At this time, the patient and family generally accept a prognosis of less than 6 months. The actual burdens of care (the patient's physical symptom burden and family caregiver burden) increase as disease and debility progress. The prospect of imminent death accentuates anticipatory grieving. Emotional exhaustion of the patient and caregivers may impair their ability to select among therapeutic choices. Patients and their families are stressed to establish consistent goals of care that can be maintained across care settings. The patient, family, and professional staff have difficulty with this transition from oncologic care to hospice. The patient may prefer to remain under the care of their oncologist, although that may not ensure comprehensive terminal care. After a patient's death, the survivors' bereavement depends in part on the psychological residuum of the preterminal experience, including guilt and self-blame for the outcome of choices made.



Integrated approach to palliative care.

Complex clinical decisions at the end of life must be individualized, yet we have no general guidelines from which we can structure the process and thus assist the patient and family to make the best use of available resources. To improve the care of the dying and their families, clarification of this decision-making process is essential.⁶ Deferring palliative interventions until near the end of life deprives patients and families of services that can greatly help them. From the time of cancer diagnosis through the treatment to cure, in relapse or in disease progression to terminal phase, patients require interventions that are directed against the disease (antineoplastic or cancer treatment), medically supportive of the cancer treatment (supportive care), and aimed at relief of symptoms (palliative care). This integrated approach, which is independent of prognosis and primary treatment goals, is conceptualized in the Figure. The balance of antineoplastic, supportive, and palliative interventions is determined by the individual patient's clinical condition and family circumstances, which change over time.

Integrating Palliative Care

The elements of palliative care are medical symptom management; psychosocial and spiritual support for patient and family; and advance care planning (Table). These elements can be incorporated into actual care plans for care planning, documentation, quality improvement efforts, and outcomes tracking, as is being done at our institute. Consistency in the application of these elements of palliative care in the oncology setting is needed, as is regular outcomes monitoring.

Although the study of quality-of-life issues is growing,⁷ most research in cancer has been focused on the toxicity of antineoplastic treatments and survival rates. A clear definition of palliation is needed as a foundation for future examination of the value of specific palliative

approaches in cancer therapy and by broadening clinical endpoints, to improve studies of antineoplastic interventions.

Challenges to integrating palliative care in oncology include the reorganization of health care delivery and uncertain financing of palliative care. The central assumption of integrated palliative care is that the treatment of suffering associated with life-threatening illness is compassionate care, expressed through individualized choices of palliative medical interventions. The Institute of Medicine's Committee on Care at the End of Life concluded in its recent study that dying patients "should be able to expect the health care system to assure reliable, effective, and humane caregiving."⁸ The Committee made specific recommendations for professional education, health system reform, and ongoing public discussion of end-of-life care issues.

Improving End-of-Life Care

Through organizations such as the Open Society Institute's Project on Death in America, Community-State Partnerships to Improve End of Life Care funded by the Robert Wood Johnson Foundation, and the American Alliance of Cancer Pain Initiatives, many projects are underway to improve end-of-life care. Definition of a "good death" is being explored. Ongoing research is directed to better understand patient and caregiver needs. Professional curricula are being revamped. Health systems research is evaluating deficiencies that result from public, professional, and system-related barriers to excellent end-of-life care. Health care policy makers are increasingly attentive to the needs of the dying. These massive efforts in patient advocacy, professional education, research, and public dialogue promise the continuing transformation of American medicine that has already begun.

Palliative Care Elements

Medical symptom management:	Treating physical symptoms (pain, nausea, etc) Addressing psychiatric symptoms (depression, delirium, etc)
Psychosocial Support:	Assisting patients Assisting families
Advance Care Planning:	Discussing anticipated course, including prognosis Eliciting patient/family values and preferences Evaluating resources Establishing advance directives

Although certain changes may be difficult to measure, it is imperative that the value of excellent care for patients with life-threatening illness and their families be further demonstrated. When fully realized, incorporating palliative interventions throughout the continuum of cancer and other serious illness will achieve quaternary prevention, ie, the prevention of suffering.

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