

INSTITUTE OF MEDICINE

Shaping the Future for Health

IMPROVING PALLIATIVE CARE FOR CANCER

It is innately human to comfort and provide care to those suffering from cancer, particularly those close to death. Yet what seems self-evident at an individual, personal level has, by and large, not guided policy at the level of institutions in this country. There is no argument that palliative care *should* be integrated into cancer care from diagnosis to death, but significant barriers—attitudinal, behavioral, economic, educational, and legal—still limit this needed care for a large proportion of people with cancer. We have also ignored palliative care in cancer research: in accepting a single-minded focus on research toward cure, we have inadvertently devalued the critical need to care for and support patients with advanced disease.

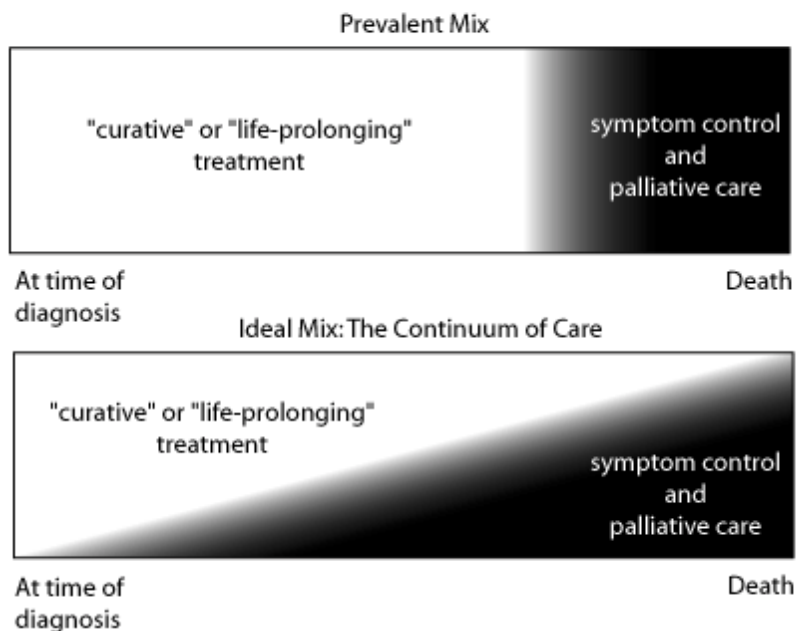
Until the early part of the twentieth century, most Americans died of infectious diseases, many in childhood and middle age. Then, virtually every serious illness spelled a fairly rapid course to death. Malignancies were identified only when large or in a critical location, and most often, no treatments were available that substantially altered the course. Now, many patients with cancer live much longer, with periods of adaptation to cancer as a chronic debilitating disease. However, improvements in the development and delivery of symptom control and other aspects of palliative care have not kept pace with the medical advances that have allowed people to live longer with cancer.

The majority of people who get cancer eventually do die from it. Dying from cancer has become synonymous with a spectrum of symptoms—pain, labored breathing, distress, nausea, confusion, other physi-



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Relationship of "curative" or "life-prolonging" treatment to symptom control and palliative care for cancer



Dying from cancer has become synonymous with a spectrum of symptoms...that go untreated or undertreated...

cal and psychological conditions—that go untreated or undertreated and vastly diminish the quality of those lives. Patients, their families, and caregivers all suffer from the inadequate care available to patients in pain and distress, although the magnitude of these burdens is only now being described.

The National Cancer Policy Board undertook this study to identify the barriers and challenges that limit palliative care and to propose solutions. The report identifies the special needs of cancer patients and the importance of the clinical and research establishment involved in cancer care to take a leadership role in modeling the best quality care from diagnosis to death for all Americans.

Even with the current advances in treatment, more than half of all patients diagnosed with cancer will die of their disease.

WHAT ARE THE PROBLEMS WITH PALLIATIVE CARE FOR CANCER?

- Even with the current advances in treatment, more than half of all patients diagnosed with cancer will die of their disease. We do not have in place appropriate palliative care for symptom management throughout the course of treatment and advancing disease, or at the end of life, when symptoms are most severe.
- The Medicare hospice benefit is used by a large proportion of elderly cancer patients as they near death, but requires changes in eligibility and benefits to remedy serious deficiencies.
- Palliative care services for children dying of cancer are poorly defined and very poorly reimbursed by insurers.
- It is difficult, if not impossible, for patients and their families to get basic information explaining the content and availability of palliative care throughout the course of disease, or about hospice options at the end of life.
- A broad range of initiatives in professional education, public education, organization of palliative care, and reimbursement policy have been funded by foundations and are maturing. The federal government has not yet begun to apply these findings in publicly-funded programs.
- In biomedical research, where government funding dictates the agenda, little has been spent on palliative care: NCI spends less than 1% of its budget on research and training in palliative or end-of-life care. Yet advancements in basic and clinical science have opened the door to a wide array of opportunities for developing new interventions and for better use of existing interventions for cancer and end-of-life symptom control.
- Within the National Cancer Institute, there has never been an institutional locus for palliative or end-of-life care, and its national advisory boards include few or no experts in, or advocates for, palliative care.

HOW CAN PALLIATIVE CARE BE IMPROVED?

NCI-designated cancer centers should play a central role as agents of national policy in advancing palliative care research and clinical practice, with initiatives that address many of the barriers identified in this report.

Recommendation 1: *NCI should designate certain cancer centers, as well as some community cancer centers, as centers of excellence in symptom control and palliative care for both adults and children. The centers will deliver the best available care, as well as carrying out research, training, and treatment aimed at developing portable model programs that can be adopted by other cancer centers and hospitals. Activities should include, but not be limited to the following:*

- *formal testing and evaluation of new and existing practice guidelines for palliative and end-of-life care;*
- *pilot testing “quality indicators” for assessing end-of-life care at the level of the patient and the institution;*
- *incorporating the best palliative care into NCI-sponsored clinical trials;*
- *innovating in the delivery of palliative and end-of-life care, including collaboration with local hospice organizations;*
- *disseminating information about how to improve end-of-life care to other cancer centers and hospitals through a variety of media;*
- *uncovering the determinants of disparities in access to care by minority populations that should be served by the center, and developing specific programs and initiatives to increase access; these might include educational activities for health care providers and the community, setting up outreach programs, etc.;*
- *providing clinical and research training fellowships in medical and surgical oncology in end-of-life care for adult and pediatric patients; and*
- *creating faculty development programs in oncology, nursing, and social work; and*
- *Providing in-service training for local hospice staff in new palliative care techniques.*

Recommendation 2: *NCI should add the requirement of research in palliative care and symptom control for recognition as a “Comprehensive Cancer Center.”*

Practices and policies that govern payment for palliative care (in both public and private sectors) hinder delivery of the most appropriate mix of services for patients who could benefit from palliative care during the course of their illness and treatments.

Recommendation 3: *The Health Care Financing Administration (HCFA) should fund demonstration projects for service delivery and reimbursement that integrate palliative care and potentially life-prolonging treatments throughout the course of disease.*

Recommendation 4: *Private insurers should provide adequate compensation for end-of-life care. The special circumstances of dying children—particularly the need for extended communication with children and parents, as well as health care team conferences—should be taken into account in setting reimbursement*

levels and in actually paying claims for these services when providers bill for them.

Information on palliative and end-of-life care is largely absent from materials developed for the public about cancer treatment. In addition, reliable information about survival from different types and stages of cancer is not routinely included with treatment information.

Recommendation 5: Organizations that provide information about cancer treatment (NCI, the American Cancer Society, and other patient-oriented organizations [e.g., disease-specific groups], health insurers and pharmaceutical companies) should revise their inventories of patient-oriented material, as appropriate, to provide comprehensive, accurate information about palliative care throughout the course of disease. Patients would also be helped by having reliable information on survival by type and stage of cancer easily accessible. Attention should be paid to cultural relevance and special populations (e.g., children).

Practice guidelines for palliative care and for other end-of-life issues are in comparatively early stages of development, and quality indicators are even more embryonic. Progress toward their further development and implementation requires continued encouragement by professional societies, funding bodies, and payers of care.

Recommendation 6: Best available practice guidelines should dictate the standard of care for both physical and psychosocial symptoms. Care systems, payers, and standard-setting and accreditation bodies should strongly encourage their expedited development, validation, and use. Professional societies, particularly the American Society of Clinical Oncology, the Oncology Nursing Society, and the Society for Social Work Oncology, should encourage their members to facilitate the development and testing of guidelines and their eventual implementation, and should provide leadership and training for nonspecialists, who provide most of the care for cancer patients.

Recommendation 7: The recommendations in the NCPB report, *Enhancing Data Systems to Improve the Quality of Cancer Care* (see Appendix B) should be applied equally to palliative and end-of-life care as to other aspects of cancer treatment. These recommendations include

- developing a core set of cancer care quality measures;
- increasing public and private support for cancer registries;
- supporting research and demonstration projects to identify new mechanisms to organize and finance the collection of data for cancer care quality studies;
- supporting the development of technologies, including computer-based patient record systems and intranet-based communication systems, to

improve the availability, quality, and timeliness of clinical data relevant to assessing quality of cancer care;

- *expanding support for training in health services research and other disciplines needed to measure quality of care;*
- *increasing support for health services research aimed toward improved quality of cancer care measures;*
- *developing models for linkage studies and the release of confidential data for research purposes that protect the confidentiality and privacy of health care information; and*
- *funding demonstration projects to assess the impact of quality monitoring programs within health care systems.*

Research on palliative care for cancer patients has had a low priority at NCI and as a result, few researchers have been attracted to the field and very few relevant studies have been funded over the past decades. NCI should continue to collaborate with the National Institute of Nursing Research on end-of-life research (the lead NIH institute for this topic), but cannot discharge its major responsibilities in cancer research through that mechanism.

Recommendation 8: *NCI should convene a State of the Science Meeting on palliative care and symptom control. It should invite other National Institutes of Health and other government research agencies with shared interests should be invited to collaborate. The meeting should result in a high-profile strategic research agenda that can be pursued by NCI and its research partners over the short and long terms.*

Recommendation 9: *NCI should establish the most appropriate institutional locus (or more than one) for palliative care, symptom control, and other end-of-life research, possibly within the Division of Cancer Treatment and Diagnosis.*

Recommendation 10: *NCI should review the membership of its advisory bodies to ensure representation of experts in cancer pain, symptom management, and palliative care.*

**Estimated New Cancer Cases and Deaths by Sex for All Sites
United States, 2000**

	Estimated New Cases			Estimated Deaths		
	Both Sexes	Male	Female	Both Sexes	Male	Female
All types of cancer	1,220,100	619,700	600,400	552,200	284,100	268,100

Excludes basal and squamous cell skin cancers and in situ carcinomas except urinary bladder, which are rarely fatal. Estimates of new cases are based on incidence rates from the NCI SEER program 1979-1996. ©2000, American Cancer Society, Inc., Surveillance Research



More Information...

Please visit the National Academy Press Web site at www.nap.edu for the background papers that comprise part 2 of the full report, *Improving Palliative Care for Cancer* (to be published in summer 2001).

The National Cancer Policy Board was established in 1997 at the Institute of Medicine and National Research Council to address broad policy issues that affect cancer in the United States and to recommend ways to advance the Nation's effort against cancer. The board, of about 20 members drawn from outside the federal government, includes health care consumers, providers, and researchers in a variety of disciplines in the sciences and humanities. Please visit the National Cancer Policy Board home page:

www.iom.edu/iom/iomhome.nsf/Pages/National+Cancer+Policy+Board

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This summary and the recommendations presented in this report are based on the work of the experts listed below. The background papers they wrote comprise Part 2 of the full report, which will be available from the National Academy Press in summer 2001.

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