

EPECTM-O

Education In **P**alliative And **E**nd-Of-Life **C**are For **O**ncology

Plenary 1:

Gaps in Oncology

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Abstract

This plenary provides background for the EPEC™-O Curriculum. It presents a profile of the gaps between current and desired comprehensive cancer care. The principal message is that gaps between current and desired practice need to be filled so that palliative care becomes an essential and inextricable part of comprehensive cancer care from the day of diagnosis.

Objectives

After studying this module, oncologists and other members of the cancer care team will be able to:

- Describe current cancer incidence, prevalence, and mortality.
- Describe the modern experience of living with cancer.
- Define palliative care.
- Identify gaps in cancer care.
- Introduce the EPEC™-O Curriculum.

Cancer Care in the 21st Century

During the second half of the 20th century, the age of science, technology, and communication has shifted the values and focus of North American society on many levels. Many authorities have suggested that we have become a "death-denying" society. Americans value productivity, youth, and independence and devalue age, family, and interdependent caring for one another. (Ref. 1)

There is no better symbol for this than the "War on Cancer" that began in 1971 with the passage of the National Cancer Act. (Ref. 2) The model was clear: with the investment of money and intelligence, cancer would be eliminated like polio had been eliminated in the 1950s. The language of "war" and "aggression" continues to be used as part of cancer care, with the unintended consequence that clinicians perceive that they have "failed" when a patient dies.

There have been mixed results in the 30 years since the war began. While there have been a few notable successes (i.e., Hodgkin's lymphoma, testicular carcinoma,

childhood leukemias), observed changes in mortality due to cancer primarily reflect changing incidence and early detection. The effect of new treatments for cancer on mortality has not been as great as was hoped. (Ref. 3) (Ref. 4) Data have emerged to illustrate the effects of cancer and its treatment on the whole patient and his or her family. Clearly, approaches to care for the patient undergoing cancer therapy, including the patient with cancer that will not be cured, must be an important part of comprehensive cancer care.

Cancer incidence/prevalence/mortality

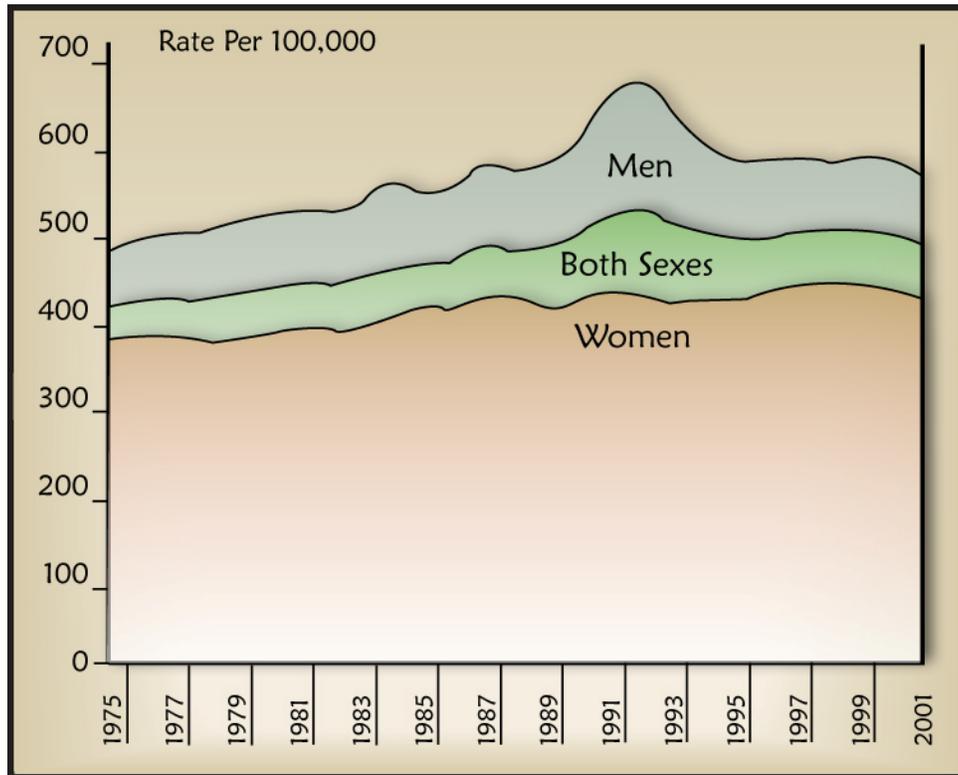
Incidence: Every year more than 2.4 million Americans are diagnosed with cancer. After excluding the 1 million people who have basal and squamous cell cancers of the skin and the in situ cancers (like breast and melanoma), about 1.3 million cases of “serious” cancer remain. About two-thirds of these 1.3 million are cured of their cancer—usually surgically. The remaining one-third eventually die of cancer (Ref. 5) (Figure 1).

Prevalence: As of 2001, there were 9.8 million people living with cancer in the United States. As a result of the success of anticancer therapy, more people are living longer with cancer, particularly with metastatic disease (e.g., median survival with metastatic cancer of the breast \approx 2 years).

For a breakdown of prevalence by cancer site, see Figure 2. For an estimate of the number of survivors, see Figure 3. For an estimate of length of survival by gender, see Figure 4.

Mortality: In 2002, 557,271 people died of cancer in the United States, representing 22.8% of the 2,443,387 deaths from all causes. (Ref. 6) Mortality rates for each year, by gender, are presented in Figure 5. Mortality rates for selected cancer sites for males are presented in Figure 6 and for females in Figure 7.

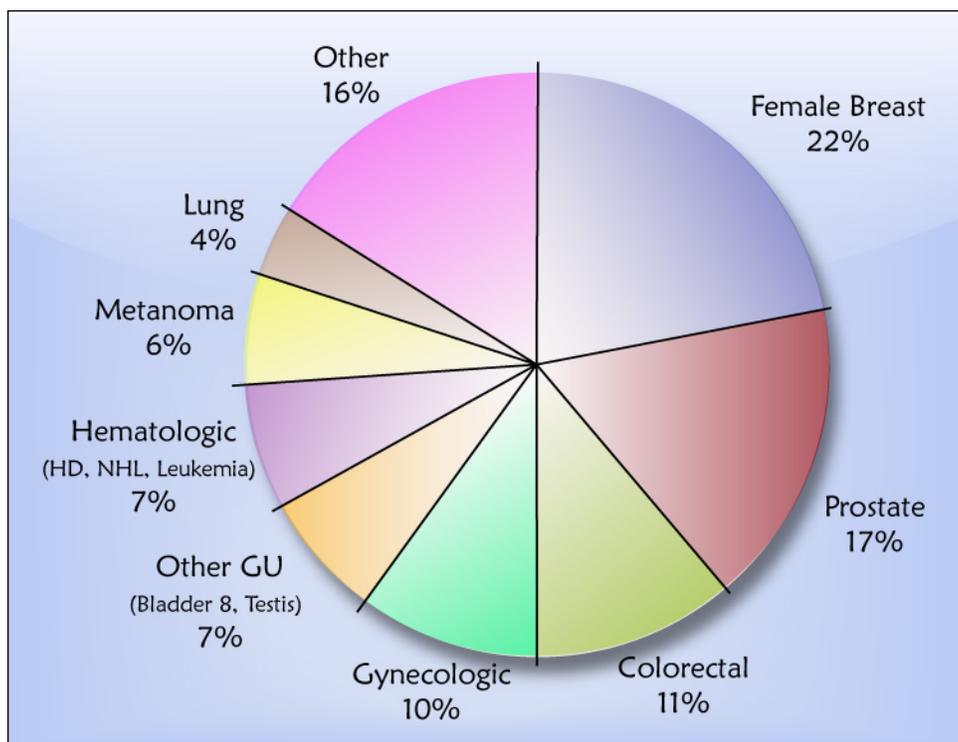
Figure 1: Cancer Incidence: Annual, Age-adjusted, for All Sites, by Sex, US, 1975-2001



* Rates are age-adjusted to the 2000 US standard population.

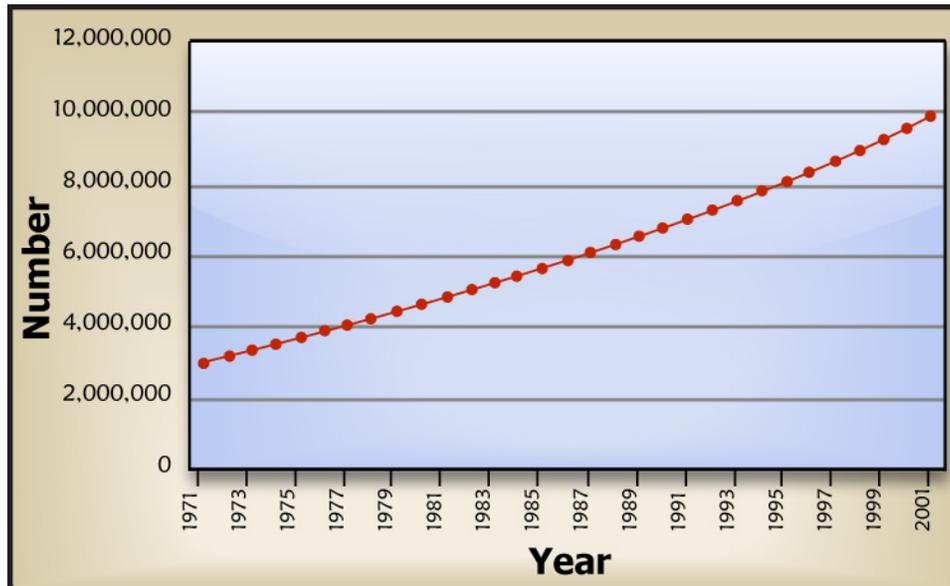
Source: Incidence data from Surveillance, Epidemiology, and End Results (SEER) program, nine oldest registries, 1975 to 2001, Division of Cancer Control and Population Sciences, National Cancer Institute, 2004. Mortality data from US Mortality Public Use Data Tapes, 1960 to 2001, National Center for Health Statistics, Centers for Disease Control and Prevention, 2004. (Ref. 5)

Figure 2: Cancer Prevalence: Estimated Number of Persons Alive in the US Diagnosed with Cancer by Site (N=9.8 million)



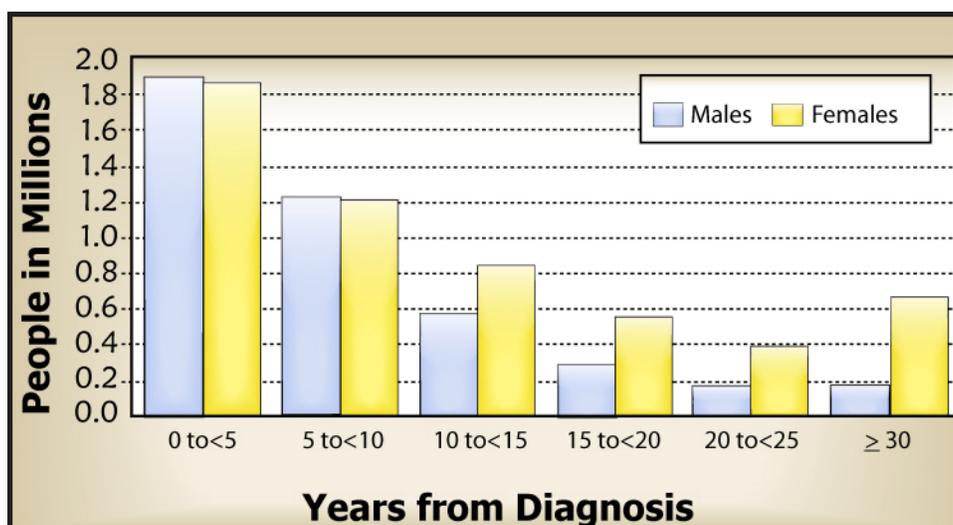
Source: November 2003 Submission: Populations from January 2001 were based on the average of the July 2000 and July 2001 population estimates from the US Bureau of the Census. Complete prevalence is estimated using the completeness index method. US Estimated Prevalence counts were estimated by applying US populations to SEER 9 Limited Duration Prevalence proportions. (Ref. 7)

Figure 3: Cancer Prevalence: Estimated Number of Cancer Survivors in the US from 1971-2001



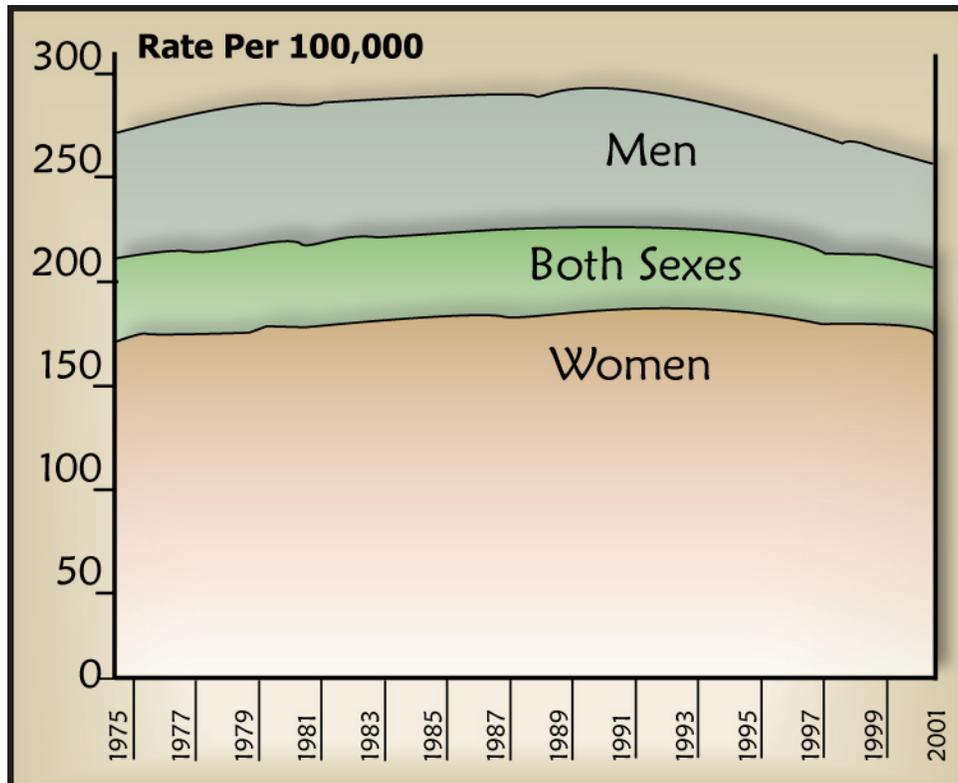
Source: November 2003 Submission: Populations from January 2001 were based on the average of the July 2000 and July 2001 population estimates from the US Bureau of the Census. Complete prevalence is estimated using the completeness index method. US Estimated Prevalence counts were estimated by applying US populations to SEER 9 Limited Duration Prevalence proportions. (Ref. 7)

Figure 4: Cancer Prevalence: Estimated Number of Persons Alive in the US Diagnosed with Cancer on January 1, 2001 by time From Diagnosis and Gender (N=9.8 million survivors). Invasive/1st Primary Cases Only



Source: November 2003 Submission: Populations from January 2001 were based on the average of the July 2000 and July 2001 population estimates from the US Bureau of the Census. Complete prevalence is estimated using the completeness index method. US Estimated Prevalence counts were estimated by applying US populations to SEER 9 Limited Duration Prevalence proportions. (Ref. 7)

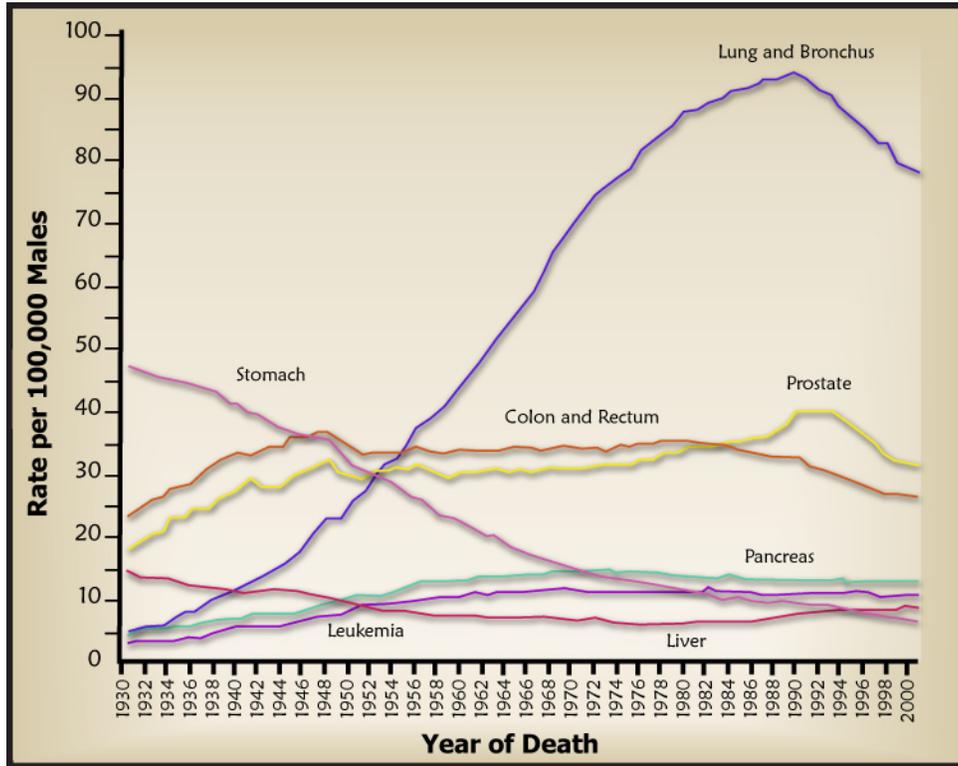
Figure 5: Cancer Death Rates: Annual, Age-adjusted, for All Sites, by Sex, US, 1975-2001



* Rates are age-adjusted to the 2000 US standard population.

Source: Incidence data from Surveillance, Epidemiology, and End Results (SEER) program, nine oldest registries, 1975 to 2001, Division of Cancer Control and Population Sciences, National Cancer Institute, 2004. Mortality data from US Mortality Public Use Data Tapes, 1960 to 2001, National Center for Health Statistics, Centers for Disease Control and Prevention, 2004. (Ref. 5)

Figure 6: Cancer Mortality: Annual, Age-adjusted, Among Males for Selected Cancer Types, US, 1930-2001

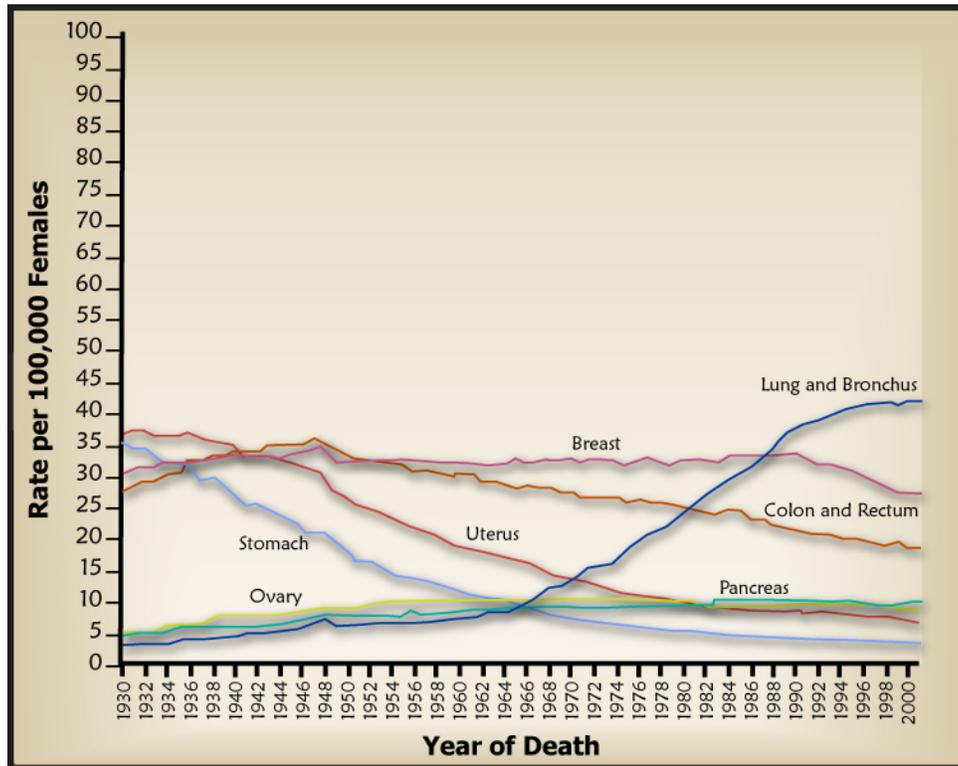


* Rates are age-adjusted to the 2000 US standard population.

Note: Due to changes in ICD coding, numerator information has changed over time. Rates for cancers of the lung and bronchus, colon and rectum, and liver are affected by these coding changes.

Source: Surveillance, Epidemiology, and End Results (SEER) program, nine oldest registries, 1975 to 2001, Division of Cancer Control and Population Sciences, National Cancer Institute, 2004. (Ref. 5)

Figure 7: Cancer Mortality: Annual, Age-adjusted, Among Females for Selected Cancer Types, US, 1930-2001



* Rates are age-adjusted to the 2000 US standard population.

Note: Due to changes in ICD coding, numerator information has changed over time. Rates for cancers of the uterus, ovary, lung and bronchus, and colon and rectum are affected by these coding changes. Uterus cancers are for uterine cervix and uterine corpus combined.

Source: Surveillance, Epidemiology, and End Results (SEER) program, nine oldest registries, 1975 to 2001, Division of Cancer Control and Population Sciences, National Cancer Institute, 2004. (Ref. 5)

Plenary 1 - Video 1

Suffering Associated with Cancer

Today, when people discover that they have cancer, their lives change dramatically. They have to learn to cope with the disease as well as a wide range of issues that are frequently manifestations of their illness experience (Figure 9). (Ref. 8) (Ref. 9) (Ref. 10)

(Ref. 11) (Ref. 12) (Ref. 13) People living with cancer experience multiple symptoms, functional decline, and possible physical disfigurement; they experience multiple psychological, social, spiritual, practical, and end-of-life issues; and they are affected by grief and loss. All of these experiences affect their work and family and make situational adaptation challenging.

While a disease affects an individual (the patient), the resulting illness also affects the patient's family (i.e., everyone close in knowledge, care, and affection) and anyone who lives or works with the patient or provides care.

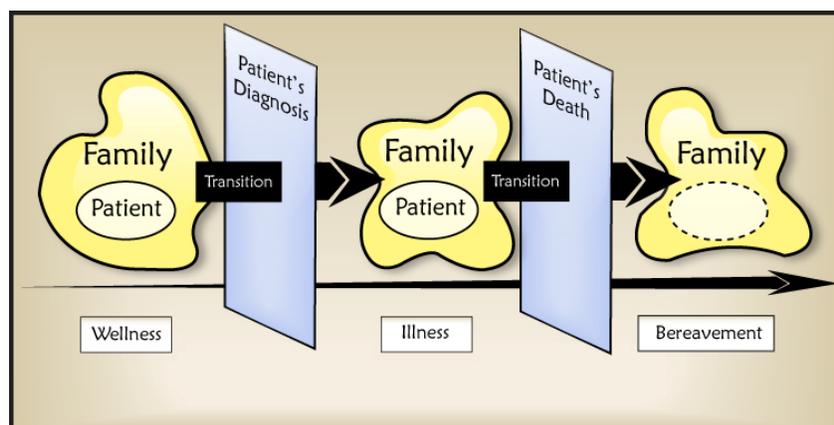
As patients and families imagine their future with cancer, fears and fantasies driven by past experiences and media dramatization frequently heighten anxiety about the events that may occur. Patients and families worry that symptoms won't be managed, that they will lose function and control, and that they will be abandoned. They wonder who will provide care, how they will pay for it, what dying will be like, and what comes after death. (Ref. 14) (Ref. 15) (Ref. 16)

Family transitions

A diagnosis of cancer changes patients and families forever. As they move from a state of wellness to a state of illness with treatment, there may be a number of losses, including self-esteem, opportunity, income, financial security, and the potential for a rewarding future (Figure 8). The illness can interfere with experiences that bring meaning and value and add quality to their lives. It can cause suffering and lead everyone to question what the future holds in both life and death.

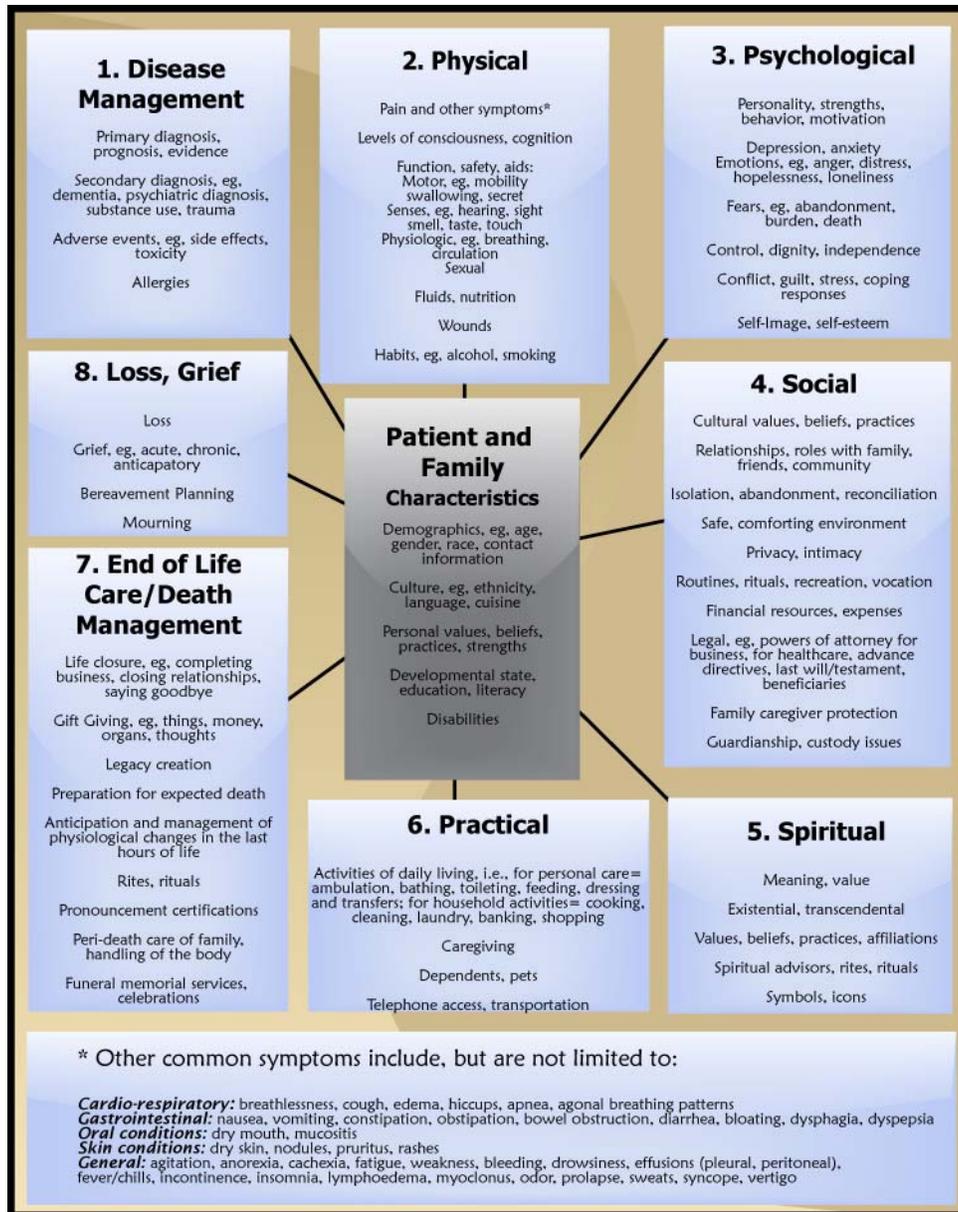
Cancer and its treatment often change family roles and relationships. Leadership and group dynamics are challenged and even changed. As an advanced life-threatening illness evolves and the patient dies, the existing family group adjourns and a new group forms that has different membership, roles, leadership, and group dynamics. While the patient is no longer present in person, his or her memories and legacies live on and affect those who remain.

Figure 8: Patient/Family Transitions During Illness and Bereavement



Patients and families face multiple issues during illness and bereavement that cause suffering. These issues can be grouped into eight domains.

Figure 9: Domains & Issues Associated with Illness and Bereavement



Symptoms and suffering

In one study of patients with cancer, inpatients averaged 13.5 symptoms while outpatients averaged 9.7 symptoms. (Ref. 17) While some of these symptoms are related to the primary illness, some are adverse effects of medications or therapy, and others result from intercurrent illness.

Psychological distress

In addition to physical symptoms, many patients and families also experience considerable psychological distress, including anxiety, depression, worry, fear, sadness, hopelessness, etc. In one study that examined fears expressed by patients, 40% of patients with advanced illness where death was expected were afraid of being a burden to their family and friends. (Ref. 18)

Social isolation

Today, in contrast to our past, many Americans live alone or only with one other adult. Often both need to work, and if they are older at least one of them may be frail or ill. Other family members—brothers, sisters, children, and parents—often live far away and have lives of their own. Friends have their own obligations and priorities. Although many Americans live in urban areas, there is considerable social isolation in this society that is built on independence and self-reliance.

While 90% of Americans believe it is a family's responsibility to provide care for someone who is seriously ill, this social isolation creates a very different situation from the one that existed in the past. Today, when a patient needs assistance, the burden of caregiving frequently falls to a small number of people, often women, who may be unskilled and without the resources they need to provide that care.

Financial pressures

In addition to the issue of who will provide care, financial issues associated with caregiving have a significant impact on the family. In one study, 20% of family members had to quit work or make another major life change in order to provide care for a loved one. (Ref. 18) Even when they had medical insurance, a significant number of patients and families suffered financial devastation. In the same study, 31% of families lost most of their savings caring for their loved one; 40% of families became impoverished providing care. For some families, the financial implications may prohibit any thought of caring for a loved one at home.

Coping strategies

Particularly in the face of prolonged suffering and unmanaged symptoms, strategies for coping with illness, disability, loss of control, lack of ability to do things that are meaningful, etc., are varied. If suffering is not relieved, distress may be so significant that some patients may become destructive, planning suicide or seeking assistance to die prematurely by physician-assisted suicide or euthanasia.

Place of death

While a 1996 Gallup survey commissioned by the National Hospice Organization (NHO) reported that 90% of respondents desired to die at home, the technological

development of medicine has historically moved death out of the home and into institutions. (Ref. 19) People have died shielded from the family's and community's sight, usually behind hospital doors. By 1949, 50% of deaths in America occurred in institutions; by 1958, this number had increased to 61%. Since 1980 it has remained at around 74% (in 1992, 57% of Americans died in hospitals, 17% died in nursing homes, and only 20% died in their own homes). (Ref. 20) (Ref. 21)

Given the strongly expressed desire to die at home, the pattern of death in the United States is paradoxical. Although there is some regional variation, the majority of patients dying in hospitals and nursing homes are dying with illnesses for which the expected outcome is death. These patients could be managed at home. (Ref. 22) It is also clear that institutionalization does not yield better outcomes in terms of meeting patient and family needs. (Ref. 23)

As care for patients with life-threatening illnesses has shifted into institutions, a generalized lack of familiarity with the dying process and death has evolved. Only a minority of people, including physicians, have ever watched someone die. Most nonprofessionals have never seen a dead body except, perhaps, at a funeral parlor. Fantasy about what death is like is fueled by media dramatization and rarely by reality. (Ref. 24)

Plenary 1 - Video 2

Gaps

When the current status of care for the dying is summarized, the large gap becomes apparent between the way Americans currently live and die with cancer, and the way they would like to experience the end of their lives at home. With the shift to fight death—the enemy—at all cost, treatments have frequently become excessively aggressive, symptoms have not been controlled, and patients have lost their independence. Many families have not coped with caring for acutely ill patients at home, and death far too frequently has occurred in institutions. While generalizations may be misleading for individual patients and families, they do help illustrate the general culture of dying in the United States and how far it is from what most Americans desire.

Public expectations of physicians

Despite having concerns, the public has an optimistic attitude toward end-of-life care and the role of physicians. In 1997, an AMA Public Opinion Survey asked, “Do you feel your doctor is open and able to help you discuss and plan for care in case of life-threatening illness?” The results showed that the majority of Americans (74%) expect their physicians to be confident and competent to provide them with care if they develop a life-threatening illness. (Ref. 25)

Palliative Care

Palliative care aims to relieve suffering and improve quality of life. (Ref. 26)

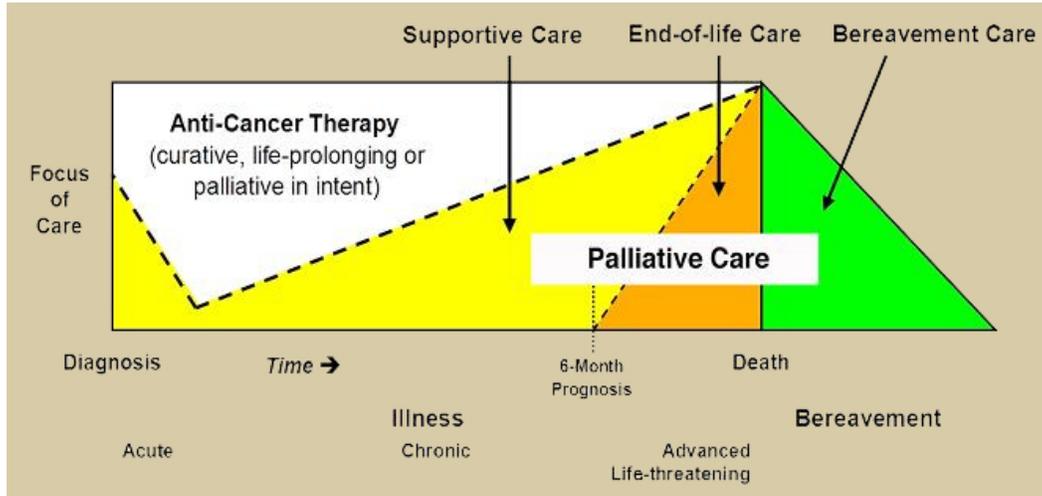
Initial concepts of hospice as end-of-life care developed from the prolonged experience of illness and dying in cancer patients recognized by Dame Cicely Saunders in the 1960s (Ref. 27) The concept of palliative care has evolved from hospice over time. Today, the knowledge base and approaches to relieving suffering are too powerful and too important to save until the end-of-life, and there is no argument against integrating palliative care into cancer care from diagnosis to death. (Ref. 28)

Palliative care includes therapies to help patients and families manage the physical, psychological, social, spiritual, and practical issues they face throughout their illness experience. (Ref. 28) For oncologists and members of the cancer care team, palliative care also includes the important skills of communication and decision making that help them facilitate the process of providing care.

Palliative care is appropriate for any patient and/or family living with or at risk for developing cancer, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs and are prepared to accept care. (Ref. 29) Palliative care may be combined with anticancer care or it may become the total focus of care. Palliative care is most effectively delivered by an interdisciplinary team of health care providers, (i.e., chaplains, nurses, occupational therapists, pharmacists, physicians, physiotherapists, social workers, speech therapists, volunteers) who are both knowledgeable and skilled in all aspects of the caring process related to their discipline of practice. In this definition, the terms supportive care, end-of-life care and bereavement care are part of this larger domain of palliative care (Figure 10). It is less important that clinical services use the name palliative care than that they reliably deliver the care that is needed.

Plenary 1 - Video 3

Figure 10: Palliative Care



This model of combining palliative care with standard cancer care is not just an assertion of this Curriculum. It is included in reports from the leading oncology policy organizations. In 1999, the National Cancer Policy Board called for “the management of cancer-related pain and timely referral to palliative and hospice care” as part of its report entitled *Ensuring Quality Cancer Care*. This was followed in 2001 by a subsequent report entitled *Improving Palliative Care for Cancer* advocating that “cancer centers should play a central role ... in advancing palliative care research and clinical practice....” (Ref. 28) In support, the National Comprehensive Cancer Network has developed clinical practice guidelines for palliative care, distress, pain, practical and psychosocial issues, fatigue, delirium, and depression.

Gaps in Cancer Care

The American Society for Clinical Oncology (ASCO) represents 19,000 physicians who practice medical, radiation, surgical, and pediatric oncology. In 1998, ASCO stated that it is the oncologists’ responsibility to care for their patients along a continuum that extends from the moment of diagnosis throughout the course of the illness. In addition to appropriate anticancer treatment, this includes symptom control and psychosocial support during all phases of care, including those during the last phase of life. (Ref. 30)

Oncologist training

In 1998, the American Society of Clinical Oncology conducted the first and only large-scale survey of US oncologists about their experiences in providing palliative care. The survey questionnaire consisted of 118 questions. (Ref. 31) A total of 3,227 oncologists responded. There were no significant differences in the percentages of medical, radiation, surgical, or pediatric oncologists who responded as a proportion of their

representation in ASCO. The most frequent sources of palliative care education were as follows:

- Ninety percent said they learned from trial and error during clinical practice.
- Seventy-three percent learned from colleagues during clinical practice.
- Seventy-one percent learned from a role model during oncology fellowship training.
- Interestingly, 38% said a significant source of education was a traumatic experience with a patient.

This survey provides evidence that oncologists do not get good information from their colleagues and role models despite reporting these individuals as their most frequent educational resource.

- Eighty-one percent said they had inadequate mentoring or coaching in discussing poor prognosis.
- Sixty-five percent said they received inadequate information about controlling symptoms.
- Fewer than 10% thought all of their formal training during medical school, internships, residency, and fellowship combined was “very helpful.”
- Only 33% reported hearing lectures about palliative care issues during oncology fellowship training.
- Only 10% reported completing a rotation on a palliative care service or hospice.

Barriers to palliative care

There are many other reasons why palliative care is not what it could or should be in oncology. A few that were illustrated by the ASCO survey are summarized here.

Sense of personal failure. In the ASCO survey, oncologists frequently reported having a sense of personal failure related to palliative and end-of-life care.

- Ninety percent reported feeling at least some anxiety discussing poor prognosis.
- Seventy-five percent reported feeling at least some anxiety discussing symptom control with patients and families.
- Seventy-six percent reported feeling some sense of personal failure if a patient dies of cancer.

Unrealistic expectations. Oncologists also reported that unrealistic expectations play a role in making the practice of oncology difficult.

- Twenty-nine percent said that unrealistic patient expectations made the practice of oncology difficult.
- Fifty percent reported feeling that family expectations made the work difficult.
- Twenty-seven percent reported that significant conflict arose from unrealistic expectations.

Pain management. Oncologists reported perceiving that they do not do a good job of pain management in their own practices. (Ref. 32) This is an important barrier because if pain management is ineffective, there is little chance that the other aspects of palliative care will be incorporated into practice.

Burnout. Greater than 50% of oncologists reported experiencing burnout in their own personal lives, (Ref. 33) in which the syndrome of decreased energy, apathy, and imperviousness to the needs of patients and their families prevents them from meeting those needs.

Other issues. In the ASCO survey, oncologists reported the following issues as having at least some influence on their practices related to palliative and end-of-life care:

- Ninety-seven percent reported believing that oncologists are reluctant to “give up.”
- Ninety-nine percent said that patient and/or family demands for antineoplastic therapy make it difficult.
- Eighty percent reported that the reimbursement of chemotherapy, as opposed to other aspects of cancer care, influence care.
- Eighty percent said that reluctance to talk about issues other than antineoplastic therapy affects oncologic practice.
- Ninety-one percent reported that the fact that it takes more time to do palliative care than give antineoplastic therapy influences their practice.

Taken together, these reports help explain recent data indicating that ineffective chemotherapy is administered nearly to the time of death in large numbers of cancer patients. (Ref. 34)

It is not the point of this plenary to analyze all determinants of the current state of affairs. There is enough blame to go around. However, if we are to build a health care system and ethic that cares for all of us, then palliative care as part of comprehensive cancer care must improve.

Professional satisfaction

There is reason for hope. These bleak findings need to be contrasted with the sense of professional satisfaction reported by these oncologists.

- Ninety-eight percent reported feeling some emotional satisfaction in providing palliative care.
- Ninety-two percent reported feeling some intellectual satisfaction in providing palliative care.

Clearly, there is a marked contrast between the satisfaction that can be derived from the work, and the preparation for the work. It stands to reason that if oncologists develop the core competencies and skills in palliative care, they and their patients and families will fare better.

Goals of EPEC™-O

As one contribution to help bridge the gap between patient and family expectations and the current state of palliative care in comprehensive cancer care, the National Cancer Institute, in collaboration with the American Society for Clinical Oncology and the EPEC™ Project team, want to equip oncologists with the tools to teach a core base of knowledge and skills that will help oncologists and their cancer programs improve their competence and confidence, strengthen physician-patient relationships, and enhance personal satisfaction with cancer care.

Topics

After providing an overview, EPEC™-O presents strategies to help oncologists address the multiple issues that cause patients and families suffering and facilitate the process of providing comprehensive cancer care. It also offers strategies to further develop teaching skills. EPEC™-O is not an attempt to make every oncologist an expert in palliative care.

Table 1: Topics Within EPEC™-O

<p>Overview</p> <p>Plenary 1: Gaps in Oncology</p> <p>Plenary 2: Models of Comprehensive Care</p> <p>Plenary 3: Charting the Future</p> <p>Module 1: Comprehensive Assessment</p>	<p>Developing Teaching Skills</p> <p>Teach 1: Teaching Skills 1</p> <p>Teach 2: Teaching Skills 2</p>
<p>Addressing the Multiple Issues Faced by Patients and Families</p> <p>Module 2: Cancer Pain Management</p> <p>Module 3: Symptoms, including: Anorexia/cachexia, Anxiety, Ascites, Bowel Obstruction, Constipation, Delirium, Depression, Diarrhea, Dyspnea, Fatigue, Insomnia, Malignant Pleural Effusions, Menopausal Symptoms, Mucositis, Nausea/vomiting, and Skin</p> <p>Module 4: Loss, Grief, and Bereavement</p> <p>Module 5: Survivorship</p> <p>Module 6: Last Hours of Living</p>	<p>The Process of Providing Care</p> <p>Module 7: Communicating Effectively</p> <p>Module 8: Clarifying Diagnosis and Prognosis</p> <p>Module 9: Negotiating Goals of Care</p> <p>Module 10: Clinical Trials</p> <p>Module 11: Withholding Nutrition, Hydration</p> <p>Module 12: Conflict Resolution</p> <p>Module 13: Advance Care Planning</p> <p>Module 14: Physician-Assisted Suicide</p> <p>Module 15: Cancer Doctors and Burnout</p> <p>Teamwork: Approaches to sharing the burden of palliative care with colleagues through interdisciplinary teamwork is a theme throughout EPEC™-O.</p>

Once acquired, this knowledge needs to be applied in the environment in which you work to develop skill in its day-to-day application. In the end, we hope EPEC™-O will equip oncologists to rediscover some of the core values of their profession and foster creative approaches to advocate for and create change in the myriad situations and places in which they serve patients with cancer and their families.

Physicians have a special responsibility and leadership opportunity in palliative care, and while they cannot change everything, change will not be effective without them.

Summary

The diagnosis of cancer profoundly affects the lives of patients and their families. Comprehensive cancer care combines effective and appropriate anticancer care with palliative care to manage both the cause and the experience. Oncologists are not yet sufficiently trained to be competent or confident in providing palliative care. The EPEC™-O Curriculum will equip physicians with knowledge, skills, and attitudes that can be tailored to their unique practice settings. If appropriately applied, palliative care has the potential to enhance cancer care and improve outcomes. The ultimate goal is to relieve suffering and improve the quality of the lives of all Americans who are living with, or dying from, cancer.

Key Take-Home Points

1. More than 500,000 Americans each year will not be cured of their cancer.
2. Palliative care aims to relieve suffering and improve quality of life. It can be combined with antineoplastic therapy or become the main focus of care.
3. Studies indicate that most patients and families who are living with cancer can expect to experience multiple physical symptoms along with psychological, social, spiritual, and practical issues. While some of these symptoms are related to the primary illness, some are adverse effects of medications or therapy, and others result from intercurrent illness.
4. Ninety percent of respondents to a Gallup survey in 1996 reported wishing to die at home, yet nearly 80% currently die in institutions.
5. The majority of Americans (74%) expect their physicians to be confident and competent to provide them with care if they develop a life-threatening illness.
6. Many oncologists believe they have failed and experience a sense of shame if they do not save their patients from death.
7. Hospice care is introduced too late. When the median length of stay is less than 30 days, patients and families don't realize the full potential hospice offers.

8. Until recently, formal education in end-of-life care has been absent from medical school, residency, and fellowship training.

References

Plenary 1: Gaps in Oncology

- 1 Approaching Death: Improving Care at the End-of-Life-A Report of the Institute of Medicine. Washington, DC: National Academy Press; 1997. ISBN: 0309063728. PMID: 9566173.

This article is a seminal and influential report describing health care needs of patients with terminal illness in the United States.

- 2 Nixon R. The war against cancer. *Prog Clin Biol Res.* 1987;248:3-8. PMID: 3671418.

President Nixon hoped the declaration of the "war on cancer" in 1971 would be the most significant action taken by his administration.

- 3 Bailar JC, Gornik HL. Cancer undefeated. *N Engl J Med.* 1997;336(22):1569-1574. PMID: 9164814.

The article presents National Center for Health Statistics data on all deaths from cancer for 1970 through 1994. Age-adjusted mortality for cancer in 1994 was 6% higher than in 1970. Death rates from specific cancers have declined due to reduced cigarette smoking, improved screening, and a mixture of increases and decreases in the incidence of cancer.

- 4 Welch HG, Schwartz LM, Woloshin S. Are increasing 5-year survival rates evidence of success against cancer? *JAMA.* 2000;283(22):2975-2978. Available at: <http://gateway.ut.ovid.com/gw2/ovidweb.cgi>. Accessed March 28, 2005.

The article presents population-based statistics reported by the National Cancer Institute Surveillance, Epidemiology and End Results (SEER) Program. From 1950-1995 there was an increase in 5-year survival for each of 20 tumor types (range 3% pancreatic to 50% prostate). During the same period, mortality rates declined for 12 types of cancer and increased for the remaining 8 types. Changes in 5-year survival did not correlate with mortality data, but did correlate with incidence data.

- 5 Jemal A, Murray T, Ward E, et al. Cancer statistics, 2005. *CA Cancer J Clin*. 2005;55(1):10-30. PMID 15661684; full text.

The authors provide a summary of the most recent data on cancer incidence, mortality, and survival using incidence data from the National Cancer Institute and mortality data from the National Center for Health Statistics.
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- 11 Singer PA, Martin DK, Kelner M. Quality end-of-life care: Patients' perspectives. *JAMA*. 1999;281(2):163-168. PMID 9917120.
- 12 Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: Observations of patients, families and providers. *Ann Intern Med*. 2000;132(10):825-832. PMID 10819707.
- 13 Steinhauser KE, Christakis NA, Clipp EC, et al. Preparing for the end-of-life: Preferences of patients, families, physicians, and other care providers. *J Pain Symptom Manage*. 2001;22(3):727-737. PMID 11532586.

- 14 Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end-of-life by patients, family, physicians and other care providers. *JAMA*. 2000;284(19):2476-2482. PMID: 11074777.

In this cross-sectional random national survey 340 seriously ill patients, 332 recently bereaved family, and 361 physicians were asked to rate the importance of 44 items. Freedom from pain was most important. Items ranked important by all groups included: achieving pain and symptom control, preparing for death, achieving a sense of completion, making decisions about treatment preferences, and being treated as a "whole person". Items ranked more important by patients than physicians included: being mentally aware, having funeral arrangements planned, not being a burden, helping others, and coming to peace with God. Dying at home was the least important.

- 15 Emanuel EJ, Fairclough DL, Slutsman J, Emanuel LL. Understanding economic and other burdens of terminal illness: The experience of patients and their caregivers. *Ann Intern Med*. 2000;132:451-459. PMID: 10733444; full text.

The article summarizes structured interviews with a representative sample of 988 terminally ill patients (prognosis <6 months) at home in 5 US cities: 51.8% with cancer; 59% over age 65; 51% women. Symptom prevalence was as follows: pain, 50% moderate to severe; ECOG Score >3, 18%; dyspnea, 71%; incontinence, 36%. Regarding pain control, 29% wanted more therapy, 34% feared addiction, and 31% were concerned with side effects (e.g., constipation). Thirty-five percent reported a subjective sense of economic burden. Of those with substantial care needs (34.7%), economic burden, percent of household income spent on health care, need for a loan, need to spend savings, and need to get an additional job were higher. Family caregivers were more likely to have depressive symptoms. Caregivers for patients whose physicians listened to patients' and caregivers' needs were less likely to be depressed (28%) than those with physicians who did not listen (42%).

- 16 Emanuel EJ, Fairclough DL, Slutsman J, Alpert H, Baldwin D, Emanuel LL. Assistance from family members, friends, paid caregivers and volunteers in the care of terminally ill patients. *N Engl J Med.* 1999;341(13):956-963. PMID: 10498492.

The article describes structured interviews with a representative sample of 988 terminally ill patients (prognosis <6 months) at home in 5 US cities: 51.8% with cancer; 59% over age 65; 51% women. In summary, 86.8% reported needing assistance, 62% needed help with transportation, 55.2% needed help with homemaking, 28.7% needed nursing care, and 26% needed help with personal care. Ninety-six percent of caregivers were family members (72% women). Only 15.5% used paid assistance. Volunteers provided less than 3% of care.

- 17 Portenoy RK, Thaler HT, Kornblith AB, et al. Symptom prevalence, characteristics and distress in a cancer population. *Qual Life Res.* 1994;3(3):183-189. PMID: 7920492.

The authors discuss a systematic assessment of prevalence and characteristics of symptoms in 243 patients at Memorial Sloan-Kettering Cancer Center. Mean age was 55.5 (range 23-86); 123 were inpatients; 40 to 80% experienced lack of energy, pain, drowsiness, dry mouth, insomnia, or symptoms of psychological distress. The mean number of symptoms per patient was 11.5 + 6.0; inpatients had more symptoms than outpatients (13.5 vs 9.7, respectively) and those with Karnofsky performance score <80 had more symptoms than those with a higher score (14.8 vs 9.2, respectively).

- 18 The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA.* 1995;274(20):1591-1598. PMID: 7474243.

The article describes a 4-year prospective study of 9,105 patients with a 47% 6-month mortality rate in 5 teaching hospitals testing a shared decision-making model to improve outcomes. The intervention failed to improve care or patient outcomes such as patient-physician communication or level of reported pain. This seminal study was a trigger for intense research into ways to improve palliative care.

- 19 The Gallup Organization. Knowledge and Attitudes Related to Hospice Care. Survey conducted for the National Hospice Organization. Princeton, NJ: The Gallup Organization; September 1996.

- 20 Center for Gerontology and Health Care Research. Facts on dying: Policy relevant data on care at the end-of-life. Available at <http://www.chcr.brown.edu/dying/FACTSONDYING.HTM>. Accessed March 27, 2005.
- 21 Center for the Evaluative Clinical Sciences, Dartmouth Medical School. Care at the end-of-life. In: The Dartmouth Atlas of Health Care. Available at <http://www.dartmouthatlas.org/atlas/98Atlas.pdf>. Accessed March 27, 2005.
- 22 Tang ST, McCorkle R. Determinants of place of death for terminal cancer patients. *Cancer Invest.* 2001;19(2):165-180. PMID: 11296621.

According to the authors, in studies performed outside the United States 70% of cancer patients prefer to die in their own homes (range 53-89%). In studies that include the United States, only 20% do die at home. In studies of patients enrolled in hospice programs, 60% die at home.

- 23 Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA.* 2004;291:88-93. PMID: 14709580.

The article discusses a mortality follow-back survey of family members representing 1,578 decedents representing 1.97 million deaths in the United States. Sixty-seven percent of patients died in an institution. About one-fourth of all decedents with pain or dyspnea did not receive adequate treatment and about one-fourth reported physician communication concerns. Family members of patients receiving hospice services were more satisfied with overall quality of care.

- 24 Diem SJ, Lantos JD, Tulsky JA. Cardiopulmonary resuscitation on television. Miracles and misinformation. *N Engl J Med.* 1996;334(24):1578-1582. PMID: 8628340.

The authors observed three popular television programs (Chicago Hope, ER, Rescue 911) for depictions of CPR in the 1994-95 season. Short-term survival was 64% (Chicago Hope), 68% (ER), and 100% (Rescue 911). Implied survival to discharge was 36% (Chicago Hope), 58% (ER), and 100% (Rescue 911).

- 25 American Medical Association. Public Opinion on Health Care Issues: 1997. Chicago: American Medical Association; 1997.

- 26 World Health Organization. Definition of Palliative Care. Available at: <http://www.who.int/cancer/palliative/definition/en/>. Accessed December 14, 2004.

Palliative care is an approach that improves the quality of life of patients and their families facing problems 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.

- 27 Saunders C. The evolution of palliative care. *J R Soc Med*. 2001;94(9):430-432. PMID: 11535742; full text.

- 28 Foley KM, Gelband H, eds. *Improving Palliative Care for Cancer*. National Cancer Policy Board, Institute of Medicine, National Research Council. Washington, DC: National Academy Press; 2001. ISBN: 0309074029.

This publication builds on the 1997 report of the Institute of Medicine and makes 10 recommendations to the Congress and the National Cancer Institute to improve palliative care for cancer.

- 29 Ferris F, Balfour H, Bowen K, et al. A model to guide patient and family care. Based on nationally accepted principles and norms of practice. *J Pain Symptom Manage*. 2002;24(2):106-123. PMID: 12231127.

- 30 American Society of Clinical Oncology. Cancer care during the last phase of life. *J Clin Oncol*. 1998;16(5):1986-1996. PMID: 9586919.

The article provides a consensus view of the role of palliative care in comprehensive cancer care and the role of the oncologist.

- 31 Hilden JM, Emanuel EJ, Fairclough DL, et al. Attitudes and practices among pediatric oncologists regarding end-of-life care: Results of the 1998 American Society of Clinical Oncology survey. *J Clin Oncol*. 2001;19(1):205-212. PMID: 11134214; full text.

All members of ASCO in the United States, Canada, and the United Kingdom received a 118-question survey covering 8 categories. Predictors of particular attitudes and practices were identified using stepwise logistic regression analysis. Pediatric oncologists reported a lack of formal educational courses, a strikingly high reliance on trial and error, and a need for strong role models.

- 32 Von Roenn JH, Cleeland CS, Gonin R, Hatfield AK, Pandya KJ. Physician attitudes and practice in cancer pain management. A survey from the Eastern Cooperative Oncology Group. *Ann Intern Med.* 1993;119(2):121-126. PMID: 8099769; full text.

In this survey of the Eastern Cooperative Oncology Group (ECOG) 897 of 1,800 surveys were completed. Eighty-six percent of those responding thought the majority of patients with pain were undermedicated. Only 51% believed pain control in their own practice setting was good or very good. Thirty-one percent said they would wait until the patient's prognosis was 6 months or less before they would start maximal analgesia. Poor pain assessment was rated by 76% of physicians as the single most important barrier to optimal care; 62% reported patient reluctance to take analgesics as well as physician reluctance to prescribe opioids as significant barriers.

- 33 Whippen DA, Canellos GP. Burnout syndrome in the practice of oncology: Results of a random survey of 1,000 oncologists. *J Clin Oncol.* 1991;9(10):1916-1920. PMID: 1919641.

In this survey, 598 of 1,000 (60%) physicians returned a 12-point questionnaire mailed to randomly selected physician subscribers to the *Journal of Clinical Oncology*; 56% reported experiencing burnout in their professional lives. Frustration or a sense of failure was the most frequently chosen (56%) description. Administering palliative or terminal care, reimbursement issues, and a heavy workload were identified as contributing factors.

- 34 Emanuel EJ, Young-Xu Y, Levinsky, NG, Gazelle G, Saynina O. Chemotherapy use among Medicare beneficiaries at the end-of-life. *Ann Intern Med.* 2003;138(8):639-643. PMID: 12693886; full text.

This article discusses the frequency and duration of chemotherapy use in the last 6 months of life stratified by type of cancer, age, and gender using a retrospective cohort analysis.