

# **EPECTM-O**

**Education In Palliative And End-Of-Life Care For Oncology**

**Plenary 2:**

## **Models of Comprehensive Care**

# Plenary 2: Models of Comprehensive Care

- Abstract ..... 3
- Introduction ..... 3
- Objectives ..... 4
- Hospice Care ..... 4
- Palliative Care ..... 8
- Comprehensive Cancer Care ..... 10
- Development as a Specialty ..... 14
- Summary ..... 15
- Key Take-Home Points ..... 15
- Appendix: History of Hospice Care ..... 16
- References ..... 20

## Abstract

---

Comprehensive cancer care requires a balanced approach to treating both the cancer and the experience of the patient from the day of diagnosis. No matter what the eventual outcome, the management of physical, psychological, social, spiritual, and practical dimensions of the cancer experience is important. Approaches to the relief of suffering and improvement of quality of life were first developed by hospice programs and palliative care services. Such services have proliferated across North America and internationally. It has become clear that the best outcomes are yielded by models of cancer care that combine relief of suffering with attempts to cure or control the cancer. Consequently, in addition to the need for oncologists to acquire the core competencies of palliative care, models to institutionalize the delivery of that care, including specialist-level expertise, are required for reliable service delivery. Together, they will provide a comprehensive response to address the needs of patients and families throughout the illness and bereavement experience.

## Introduction

---

The gap between ideal comprehensive cancer care and current patterns of care needs to be filled. For that to occur, individual oncologists need the attitudes, knowledge, and skills to deliver quality palliative care as part of their cancer practice. However, we know that will not be enough to assure reliable results. It is now widely recognized that cognitive information such as that covered in this EPEC™-O Curriculum is necessary, but not sufficient, to deliver good palliative care to cancer patients. Health care institutions and systems of cancer care are critically important to the care that patients and families receive. Pernicious and sometimes perverse systems of care have developed that oppose a comprehensive model. For example, in the United States, the responsiveness of a cancer to chemotherapy does not seem to influence the administration of chemotherapy in advanced stages of disease. (Ref. 1)

The current systems of cancer care were not conceived within a framework for relieving suffering as part of comprehensive cancer care. As different studies have demonstrated, current systems may in fact promote suffering. The challenge for oncologists is to be creative in using existing funding and service delivery models to optimize access to the care needed by patients and their families to minimize their suffering and improve the quality of their lives throughout the experience of illness and bereavement.

This module traces the historical development of systems to deliver palliative care to patients with cancer and their families. In some ways, the development of palliative care has followed the path of other approaches to cancer care. First, approaches were

piloted in patients with advanced disease. The approach was then tried with a broader scope of patient population. Finally, the approach has been integrated into comprehensive cancer care.

## Plenary 2 - Video 1

### Objectives

---

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

- Articulate a vision of comprehensive cancer care that includes palliative care from the day of diagnosis.
- Define hospice and palliative care and relate their history.
- Describe funding and service delivery models for providing comprehensive cancer care.
- Understand when palliative care services are appropriate for cancer patients.

### Hospice Care

---

Hospice care represents the initial testing ground for palliative care. Until the last third of the 20th century, hospice was a term to describe places where the dying could be cared for. These facilities were generally run by religious orders. In a remarkable development that stemmed from first listening to one hospitalized patient with unresectable sarcoma, and then many patients with cancer, Dr. Cicely Saunders founded St. Christopher's Hospice south of London, England, where she could test her hypotheses about the interdisciplinary care of the “whole” patient. St. Christopher's represented a single institution where a team of professionals pursued the medical, emotional, social, and spiritual care of patients and families. Most importantly, it developed as an academic hospice, where education and research were pursued simultaneously with patient care (see [Appendix](#) in this module for a more complete history of hospice care). New approaches and insights were tested and disseminated.

Those who visited St. Christopher's to learn the approaches went on to develop what has been called the modern hospice movement. This movement developed outside of traditional cancer care. The initial response from institutional medicine was perhaps understandable: no conventional system likes to be challenged by a “movement” that is critical of the mainstream.

In order to help families care for patients with advanced life-threatening illness at home, hospice agencies started to appear across the United States during the late 1970s. While volunteers initially ran them, and philanthropy supported them, hospices received a boost in 1982 when the federal government began reimbursing hospice care for Medicare beneficiaries with a prognosis of less than 6 months.

Subsequent decades have seen a marked growth in the number of agencies operating in the United States, primarily providing care at home. In 2003, there were 3,300 hospice organizations. However, even with this growth, hospices care for only a minority of dying patients. Of those patients dying of cancer in the United States, only about 40% are ever referred to a hospice agency. (Ref. 2) While there is significant regional variation (e.g., 40% of all patients with any diagnosis die with hospice care in Florida), the situation is generally less than ideal for both adult and pediatric patients across the country. Even those patients who are referred to a hospice program generally do not spend enough time in these programs to experience all of the potential benefits. (Ref. 3) As of 2003, the median survival after enrollment was only 22 days, and 36.9 % of patients died within 7 days of admission. (Ref. 4)

Today, in the United States, the single word hospice is used to describe four different concepts.

- Hospice can be a site of care for the dying, such as a free-standing facility or a dedicated unit within a hospital or nursing home.
- It can be a corporate entity that provides a number of “service lines” in a variety of settings. Some hospice organizations bear little resemblance to their forebears, as contemporary hospitals often do theirs. Hospice organizations differ from one another in the same ways that hospitals and health systems differ.
- The term hospice is also used to describe an approach to care that is integrated into all manner of care sites and practices, including bone marrow transplant services. In this sense it is synonymous with palliative care.
- Finally, hospice is used to describe a benefit available to Medicare beneficiaries that is subject to the rules and regulations promulgated by the Center for Medicare and Medicaid Services to govern that federal program.

Unfortunately, the use of a single term for all of these meanings has led to confusion. For many patients, the term hospice still means a place to go to die. For many physicians, it means a poorly understood community-based program into which a patient disappears after the physician signs a form certifying a prognosis of less than 6 months. These perceptions persist even though the majority of patients enrolled in hospice programs continue receiving care from their referring physicians and live in their own homes until they die. Surveys of the American public indicate that if they knew they had a life-threatening illness, more than 80% would want to die at home.

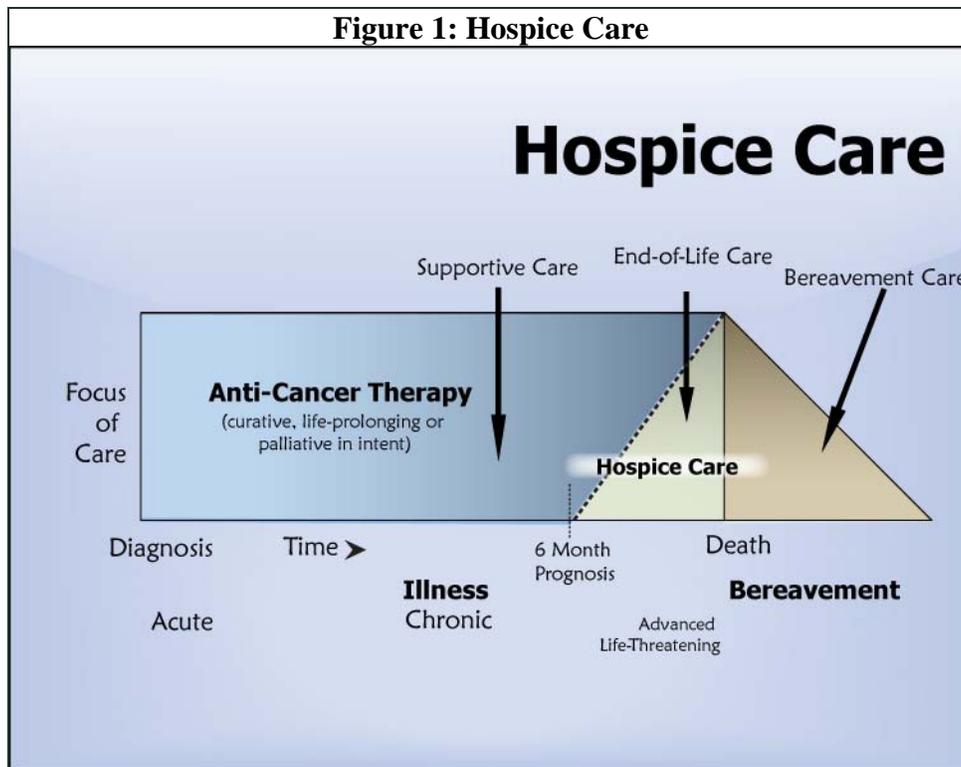


Figure 1 illustrates the application of hospice care today, in the United States, under the Medicare Hospice Benefit or other similar hospice benefits. The y-axis represents the total “quantity” of concurrent therapies or the focus of care that evolves over time, the x-axis. Under these benefits, hospice is available to patients:

- With a prognosis of 6 months or less, if the disease runs its usual course.
- When the patient's goals of care focus on palliation (rather than cure) of the underlying disease.

Hospice is intended to facilitate: ([Ref. 5](#))

- **Safe and comfortable dying:** to provide the best possible quality of life during the final months of a patient's life, and ensure that the patient dies in the best way possible.
- **Self-determined life closure:** to facilitate closure of business, reminiscence, legacy creation, gift giving (e.g., possessions, money, thoughts), and saying goodbye.
- **Effective grieving:** to help patients and families deal with their losses and grief throughout the illness and bereavement experience; to help families transition through the death of a loved one and rebuild their lives.

## Levels of care

Under the Medicare Hospice Benefit, there are four levels of hospice care that can be used to provide care to patients and their families, depending on their need and setting of care: (Ref. 6)

1. **Routine care** is care provided in the patient's home on a day-to-day basis (i.e., a private residence; a residential, assisted living, or long-term care facility; a jail or prison; on the street; or wherever the patient lives).
2. **General inpatient care** is short-term care provided in an acute care or long-term care facility when 24-hour nursing is required to:
  - Manage pain, other symptoms, or other issues that cannot be controlled at home.
  - Provide care during the last hours of life when symptoms may change quickly.
  - Provide care when the patient's caregiver is too fatigued or stressed to provide proper care
3. **Continuous care** is enhanced care provided for short periods in the patient's home when the patient needs 8 or more hours of care per day (of which >50% needs to be skilled nursing care provided by a registered nurse (RN) or licensed vocational nurse (LVN)).
4. **Respite care** is care provided in an inpatient setting or the patient's home to give the patient's informal caregiver(s) a break from the day-to-day care they provide at home. Respite care is typically preplanned for family events. It is limited to 5 consecutive days at a time. Inpatient respite care requires that a nurse be available 24 hours per day.

Requests for emergency respite care for a suddenly overwhelmed caregiver often result when the patient is sicker and requires more care than was anticipated. These patients should be carefully evaluated by a palliative medicine physician in collaboration with the patient's home hospice team to establish the severity of the underlying issues, appropriate goals, and a suitable plan of care.

## Core services

All levels of hospice care must include the following core services:

- Interdisciplinary team care, including:
  - Chaplaincy, nursing care, physician services, medical social services and counseling, and volunteers
  - Dietary counseling
  - Occupational, physical, and speech therapy
  - Home health aide and homemaker services
- Bereavement counseling

- Medical equipment and supplies
- Medications and therapies related to the terminal diagnosis

## Plenary 2 - Video 2

### Palliative Care

---

The term palliative care (soins palliatif in French) was first coined by Dr. Balfour Mount, a urologic surgeon working at the Royal Victoria Hospital in Montreal in the mid-1970s. He was looking for a word that would describe the care provided by English hospices but avoid the negative connotations of the word for French-speaking Canada. He piloted his approach beginning in a unit in the Royal Victoria Hospital rather than in a free-standing, separate building. Subsequently, the term palliative care has been associated with the approach to care first developed by hospice programs but made available in hospitals, outpatient clinics, and homecare services.

Various groups have defined palliative care in diverse but related ways. Each of the proposed definitions has in common the focus on relieving suffering and improving quality of life. All of the definitions stress three important features:

1. The multifaceted, multidimensional nature of the experience of living with an acknowledged time-limiting illness
2. The importance of supporting the family and patient as a unit
3. The priority of working as a team to achieve the relief of suffering and facilitate the enhancement of life

The Institute of Medicine defines palliative care as: ([Ref. 7](#))

“Palliative care seeks to prevent, relieve, reduce or soothe the symptoms of disease or disorder without effecting a cure.... Palliative care in this broad sense is not restricted to those who are dying or those enrolled in hospice programs.... It attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them.”

In 2002, the World Health Organization (WHO) redefined palliative care as: ([Ref. 8](#))

“An approach which improves quality of life of patients and their families facing 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.”

Over the past decade, to provide the expertise and standards of practice developed by hospice to patients who have needs for symptom control and supportive care earlier in

their illness, palliative care programs and consult services have been developing across the United States. (Ref. 9) They have evolved in response to the success of modern medicine and cancer care to provide relief of suffering and improve the lives of patients who are living longer and dying over a more prolonged time, and their families. The Center to Advance Palliative Care has played a significant role in stimulating their development, particularly in acute care facilities. (Ref. 10) These programs are designed to improve the quality of patients' lives while they fight their disease, and there is evidence that patients enrolled in such “combined” programs live longer. (Ref. 11)

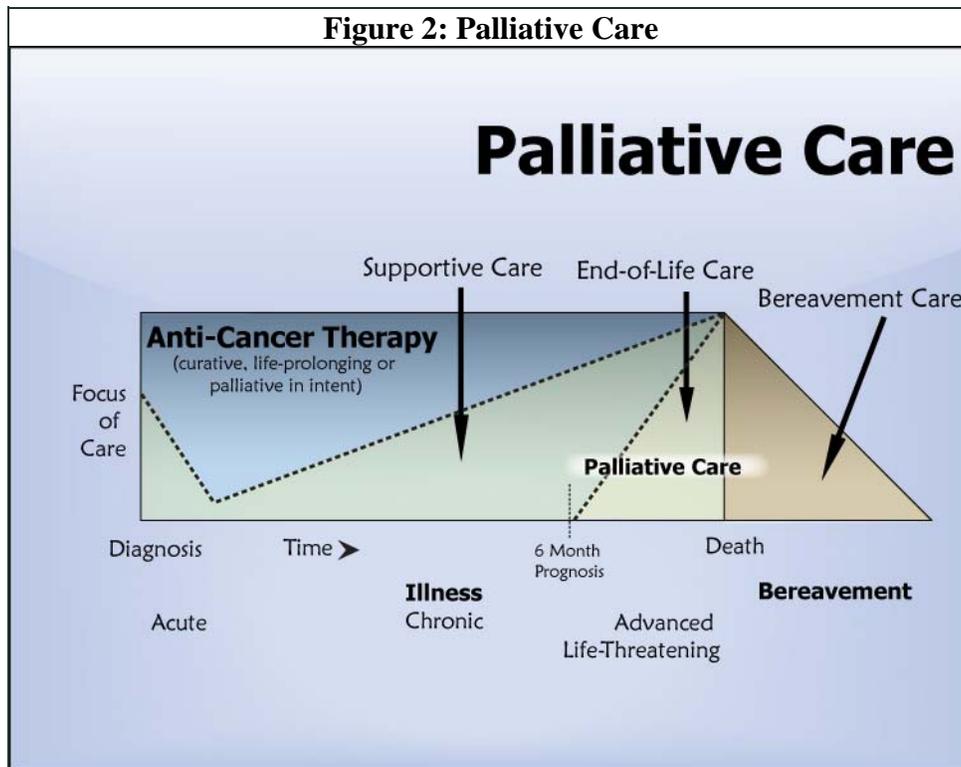


Figure 2 illustrates the application of palliative care across the illness and bereavement experience. The y-axis represents the total quantity of concurrent therapies or the focus of care. This evolves over time, the x-axis. The dashed line distinguishes anticancer therapies that may be curative, life-prolonging, or palliative in intent from therapies intended to relieve suffering and/or improve quality of life. In this figure, the dashed line is straight for simplicity. In reality, the total amount of therapy and the mix of concurrent therapies will fluctuate based on the patient's and family's issues, goals for care, and treatment priorities. During times of remission, when the patient is feeling well, there may not be any need for therapy at all.

## Supportive care

In contrast to end-of-life and bereavement care, the term supportive care has been coined as a linguistic way to describe approaches that enable or enhance cancer care earlier in the illness experience. Counseling, growth factors, erythropoietin, antiemetics, and massage have all been offered under the banner of supportive care. Some have used this as a more acceptable term than palliative care in their clinical environments. Whether it is called hospice, palliative, or supportive care is less important than the delivery of its substance.

## Delivering palliative care

Clinical palliative care can be made available at three distinct levels—primary, secondary, and tertiary care—in parallel with current concepts of all medical care. (Ref. 12)

Primary palliative care refers to the generalist skills and competencies required of all oncologists and other health care professionals. (Ref. 9) Examples are skills in communication, pain and symptom management, teamwork, and health care system savvy. These are no different than the skills and competencies needed in any of the content areas germane to contemporary cancer care, much as in the realm of infectious disease, which also involves specialist care.

Secondary palliative care refers to the specialist clinicians and organizations that provide consultation and specialty care. By analogy, while not all cancer patients admitted to the hospital require an infectious disease specialist, some do. In palliative care, specially trained clinicians and care delivery models, such as palliative care consultation services, provide care in a variety of settings: the patient's home, nursing homes, outpatient clinics, and hospitals.

Tertiary palliative care refers to the academic centers where specialist knowledge for the most complex cases is practiced, researched, and taught.

## Comprehensive Cancer Care

---

Comprehensive cancer care integrates palliative care along with anticancer therapy from diagnosis. It has been operationalized with a number of system innovations. (Ref. 10) (Ref. 13) Overall, the goal is to have “the right patient, in the right bed, at the right time, with the right payment.”

Supportive care can be provided in an ambulatory outpatient clinic, through an inpatient consult service, or in the patient's home (including long-term care).

End-of-life care can be provided in an ambulatory outpatient clinic, through an inpatient consult service or a geographically based unit, or in the patient's home (including long-term care).

Bereavement care is typically provided in an ambulatory outpatient setting. Sometimes it may be effective to ask for help from a psychiatrist or a psychologist.

## **Consultation services**

Consultation services can help deliver specialist palliative care in a manner similar to other consultation services. (Ref. 9) (Ref. 14) (Ref. 15) (Ref. 16) Their success in assisting oncologists to deliver palliative care reflects the role that consultation plays in the continuing education of oncologists. It is through consultation that most oncologists learn about new developments outside the focus of their clinical specialty. Palliative care consultation services provide oncologists with advice and can participate in management of patients anywhere in the hospital: surgical services, intensive care units, medical wards, and cancer centers.

Palliative care consultation services are a way to bring specialist knowledge and expertise about the relief of suffering and improving quality of life to bear in combination with other medical services in the hospital. (Ref. 17) Physician services are coded, billed, and reimbursed under traditional payment guidelines. As long as different diagnostic codes are used, the attending physician and the palliative care physician providing the consultation will both be reimbursed for services provided on the same day. (Ref. 18)

## **Inpatient units**

Palliative care units have developed in hospitals for the same reasons that oncology and intensive care units developed—they are a response to increasing knowledge and the desire to provide care efficiently. Palliative care units are distinguished by the quality of care delivered there, not by their interior decoration. When more than 200 family members were surveyed in a 12-bed palliative care unit, none described the décor. (Ref. 19)

Oncologists can admit patients to acute palliative care units in hospitals for a variety of reasons. Patients can be transferred from elsewhere in the hospital if it seems that would enable better care. Patients can be admitted directly from home when the “usual” evaluation in the emergency department or oncology unit of the hospital seems inappropriate. Patients can also be admitted from the emergency department, psychiatric unit, surgical recovery room, or intensive care unit. Because the environment and expertise is ideal for withdrawal of life-sustaining measures, physicians can admit patients to palliative care units on ventilators, pressors, or dialysis for the express purpose of withdrawing such support in a setting that can provide maximum palliative care expertise.

## **Home care**

Most patients with cancer experience the majority of their illness at home. Programs to extend palliative care services into the home are sometimes offered by oncologists or nurses making home visits themselves, or through organized services. Some home health agencies have developed special palliative care expertise. The most comprehensive programs for palliative care at home are hospice programs.

## **Long-term care**

A variety of arrangements for the care of the frail and the elderly have been developed. A variety of names (group homes, residential care for the elderly, nursing homes, skilled nursing facilities) connote the range of services available. Palliative care services are becoming more frequently available in all of these settings. Again, the most comprehensive programs for palliative care in long-term care settings frequently are hospice programs.

## **Outpatient ambulatory care**

Palliative care can also be provided in the outpatient setting, either as part of an existing oncology practice, or in a freestanding clinic. ([Ref. 20](#)) These are ideal settings for initial and follow-up visits with cancer patients who are early in their illness experience and may be seeking anticancer therapy with a curative intent.

## **Implementation in comprehensive cancer care**

Many comprehensive cancer programs have implemented elements of palliative care. Several programs have tested the hypothesis that palliative care combined with cancer care yields better outcomes than standard care alone. ([Ref. 21](#))

Figure 3: Comprehensive Cancer Care

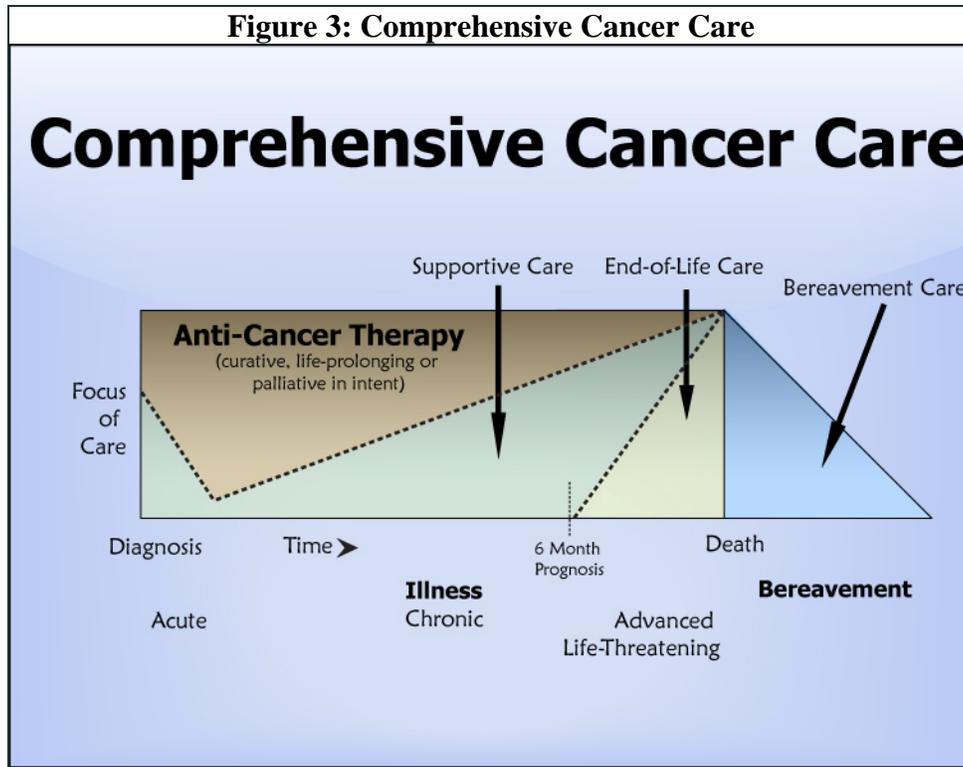


Figure 3 presents a continuum of comprehensive cancer care graphically over years, showing how anticancer therapy with curative, life-prolonging, or palliative intent changes as the illness progresses to the end of a person's life. It is no coincidence that comprehensive cancer care and palliative care share the same figure.

For some time after diagnosis, there is frequently a peak of intensity in supportive care. The need for supportive care then varies over the course of the illness with the tendency to increase over time, becoming the focus of care as the process culminates in death.

As part of a comprehensive cancer care program, hospice care might best be thought of as the funding and service delivery model through which patients and families receive enhanced palliative care at the end-of-life, and families receive bereavement care. The Medicare Hospice Benefit and other hospice benefits have been designed to be the funding mechanisms to take over and adequately pay for the care that patients and families need at the end-of-life, including care for the bereaved, when other health care funding and service delivery models are winding down.

### Case examples

The development of a palliative care service at the Warren Grant Magnuson Clinical Center at the National Institutes of Health represents both an example and a milestone

in the professional development of palliative care in the United States. (Ref. 22) Similar programs have been established at Memorial Sloan-Kettering Cancer Center in New York City, (Ref. 23) the Dana-Farber Cancer Center in Boston, (Ref. 24) Fox Chase Cancer Center in Philadelphia, (Ref. 25) the Moffett Cancer Center in Tampa, and the MD Anderson Cancer Center in Houston. (Ref. 26) As in the rest of health care, it is through the provision of subspecialist expertise that new knowledge is made practically available in the clinical setting. As these programs highlight, palliative care expertise is needed in the preeminent cancer research environment, just as it is in other clinical settings in this country.

The advent of clinical palliative care as part of comprehensive cancer care signals two important messages for oncologists. First, it signals that there need not be conflict between treatment of cancer and treatment of the suffering of the patient experiencing the cancer and his or her family. Both are legitimate and necessary aims of comprehensive cancer care. Any cancer center striving for excellence must now acknowledge the importance of including expert and effective palliative care within its reach. Second, it signals that palliative medicine is a legitimate medical discipline, a discipline that employs the tools of modern clinical research in order to continue to develop new knowledge and more effective techniques to relieve suffering.

## Development as a Specialty

---

The development of academic palliative care has been slow but steady. (Ref. 27) The first modern academic hospice, St. Christopher's Hospice, was developed by Dr. Cicely Saunders and opened in 1967. Those who studied with Dr. Saunders and her colleagues developed similar academic programs at Oxford University, McGill University, and in conjunction with Yale University.

In the United States, Dr. T. Declan Walsh developed the first academic palliative care service as part of a comprehensive cancer center in 1987 at the Cleveland Clinic. (Ref. 28) Other academic units and services followed.

Curricula on palliative care have been developed and broadly disseminated. (Ref. 29) (Ref. 30) Certifying boards recognizing subspecialists in hospice and palliative medicine have been established both for physicians and for nurses. (Ref. 31) (Ref. 32) (Ref. 33) There are at least seven subspecialty peer-reviewed journals serving the field. (Ref. 34) Chapters in general medical textbooks and subspecialty textbooks have been published. Fellowship programs are being developed to train physicians who wish to subspecialize. (Ref. 35) (Ref. 36)

In July of 2006, ACGME approved the establishment of an accreditation process for hospice and palliative medicine fellowship training programs, and in September of 2006, the ABMS voted unanimously to establish a subspecialty in hospice and palliative medicine. These actions grant the discipline of hospice and palliative medicine official status as a recognized subspecialty. ([Ref. 37](#))

For the oncologist this should be welcome news. Such professionalization and subspecialization is the appropriate response to the expanding knowledge base in health care. While every oncologist provides the core competencies of palliative care provided in EPEC™-O, he or she will want to be able to turn to a subspecialist for consultation about difficult cases (secondary palliative care). There is also a need for tertiary palliative care, where new knowledge is discovered and where clinicians are educated in the field.

Formal recognition of the subspecialty of palliative medicine will set standards on which oncologists can rely. Highly skilled subspecialists will be available to assist oncologists with the most difficult patients and support their colleagues in improving care for all patients. This does not mean that all cancer patients with symptoms or distress need to see a palliative medicine subspecialist.

Formal recognition also signals the field is worthy of pursuit. A recognized field is more likely to attract the “best and brightest” to commit their careers to further developing the field. This means that researchers will pursue efforts to extend and refine the knowledge base of the field, teachers will train the next generation of specialists, and administrators will devote resources to the clinical, research, and teaching needs of the specialty.

## Summary

---

### Plenary 2 - Video 3

Comprehensive cancer care integrates palliative care from diagnosis. Such integration permits oncologists and other members of the cancer care team to address the issues that cause suffering and impact the quality of life for patients and their families.

Because oncologists remain a key advocate within the health care system, they are an agent for change within the systems in which they work. EPEC™-O urges oncologists and cancer care teams to integrate palliative care and access to hospice services throughout their comprehensive cancer care strategy. It may improve overall satisfaction with the care they provide. Ultimately, it is what they will want for themselves and their own families when they need care.

## Key Take-Home Points

1. Comprehensive cancer care integrates palliative care from diagnosis.
2. Palliative care defines a model for the relief of suffering and the improvement of quality of life across the spectrum of cancer care. What we now generally term palliative care has grown out of and includes hospice care.
3. Multiple delivery models facilitate the provision of core palliative care skills by oncologists and other members of the cancer care team, and expert services by palliative care specialists, when they are needed.
4. Hospice should be a routine part of the completion of comprehensive cancer care. It is not an alternative to standard care; rather, it represents the completion of good cancer care.
5. Hospice organizations will provide ongoing bereavement care and help families rebuild their lives after the death of the patient.
6. Most insurance, including Medicare, includes a specific capitated hospice benefit. Other palliative services are reimbursed under traditional payment guidelines.

## Appendix: History of Hospice Care

<p><b>Roman Era</b></p>	<p>Early civilizations responded to life-threatening illness as a group because death often posed a direct threat to the entire community. Often one special person was given the role of medicine woman or man. These people were said to have healing powers and were thought to be most closely in touch with the higher powers of gods and spirits.</p> <p>Death rates for mother and child were extremely high; 40-60% of children died before age 5. Few lived longer than 40 years.</p>
<p><b>4<sup>th</sup> Century AD</b></p>	<p>Fabiola, a Roman matron, opened her home to pilgrims, the sick, and the destitute as a Christian commitment. She chose the word hospice which comes from the Latin word hospes, meaning to host a guest or stranger.</p>
<p><b>Medieval times/Crusades</b></p>	<p>With the spread of Christianity, monasteries started to take in the sick and those who were disabled and unable to support themselves. During the 6<sup>th</sup> and 7<sup>th</sup> centuries, wealthy women and widows started working in the monasteries as the first “nurses.”</p> <p>In Medieval times, at the time of the Crusades, 1095 to the end of the 17<sup>th</sup> century, weary travelers found places of refuge in</p>

	<p>monasteries and nunneries. Often they were in ill health and many spent their last days being cared for by the monks and nuns and lay women.</p> <p>Though none of these early hospices set out specifically to care for the dying, travelers who were ill and couldn't afford other accommodations often died there.</p>
<b>Reformation</b>	In England and Northern Europe this came to an abrupt end with the Reformation and the dissolution of many monasteries.
<b>1842</b>	The term hospice was first applied to a place dedicated to the care of the dying when Mme. Jeanne Garnier founded Dames de Calvaire in Lyon, France. This evolved into the Federation des Associations des Dames de Calvaires and a network of seven hospices, including Calvary Hospital in New York City.
<b>1897–1905</b>	In 1897, the Irish Sisters of Charity opened Our Lady's Hospice in Dublin and in 1905 opened St. Joseph's Hospice in Hackney, East London. This was one of the first organizations with a specific mission to care for the terminally ill.
<b>1950–'60s</b>	In 1948, Cicely Saunders, a nurse turned social worker, encountered David Tasma, a Polish Jew dying of rectal cancer in a busy London teaching hospital. Based on her conversations with him, and her subsequent work as a volunteer at St. Luke's Home for the Dying Poor (founded in 1893 by Dr. Howard Barrett), Cicely Saunders decided to go to St. Thomas' Medical School in London, England.
<b>1967</b>	In 1967, after going to medical school to become a physician and many years of study and work at St. Joseph's Hospice, Cicely Saunders opened St. Christopher's Hospice in the south of London, England as the first academic hospice. It was a place where patients could go for relief of "total pain," with its physical, psychological, social, and spiritual dimensions. Through the education and research mission of St. Christopher's, Dame Cicely Saunders is credited with founding the modern hospice movement. Her contributions were recognized by the Queen of England by making her a Dame of the British Empire. She is now frequently referred to as Dame Cicely Saunders. Dame Cicely Saunders died on July 14, 2005.

<p><b>1974</b></p>	<p>In 1974, Connecticut Hospice opened the first hospice in the United States. See <a href="http://www.hospice.com/cthospice/index.html">http://www.hospice.com/cthospice/index.html</a>; accessed March 29, 2005.</p> <p>In the United States, early hospice services were provided almost exclusively in patients' homes. The early US hospice movement was created outside of the established health care system. In contrast with the United Kingdom, these teams were usually nurse and/or volunteer led.</p>
	<p>In 1974, Dr. Balfour Mount, a Canadian urologic surgeon, returned to McGill University in Montreal, Quebec, Canada after visiting St. Christopher's Hospice to open one of the first "hospice" units in Canada.</p> <p>However, the word hospice in French had meant a place of last resort for the poor and the derelict for hundreds of years. To fill the need for an acceptable term to describe the place to care for the dying, Balfour Mount coined the term palliative care (soins palliatifs in French) to be a synonym for hospice that would be acceptable to both English-speaking and French-speaking Canadians.</p>
<p><b>1975</b></p>	<p>Concurrently, a palliative care unit opened at the Royal Victoria Hospital, Montreal, Canada, and a terminal care unit opened at St. Boniface Hospital, Winnipeg, Manitoba, Canada. The latter later changed its name to "a palliative care unit."</p>
<p><b>1980</b></p>	<p>Twenty-six sites were selected to demonstrate the financial efficiency and humanitarian benefits of hospice care. The project was so successful, it led to early presentation to Congress.</p>
<p><b>1982-3</b></p>	<p>In the United States, the prevailing pattern of home-based care was systematized in the Medicare Hospice Benefit legislation passed in 1982 and implemented in 1983.</p>
<p><b>1990s</b></p>	<p>It is important to know the history of the movement and terms in order to avoid misunderstandings. While the terms hospice and palliative care both have historical roots that vary regionally and nationally, there was a convergent evolution in the development of clinical services to address the unmet expectations and needs of patients and families who were living with advanced life-threatening illnesses in many different countries and cultures.</p>

	<p>Today, both hospice and palliative care have evolved to describe the same concept of care that aims to relieve suffering and improve quality of life. However, variations in funding and service delivery models still lead to considerable variability in the way patients and families have access to this care.</p>
<p><b>2000s</b></p>	<p>The hospice care industry in the United States has grown to become a significant provider of end-of-life care to Americans. As of July 2003, there were over 3,300 hospice programs scattered across the nation. They cared for some 885,000 patients in 2002 (<math>\approx</math>30% of Americans who died). Forty-one percent of hospice programs were independent, freestanding organizations; 32% were hospital-based; 22% were home health agency based; and 5% were based in nursing homes or under other auspices. (Ref. 4)</p> <p>Over 700 of the 7,000 acute care institutions and an unknown number of the 17,000 long-term care institutions provide some form of palliative care service to their clients today. However data describing their services and collective effectiveness are not yet available. (Ref. 9) (Ref.14)</p>

## References

---

### Plenary 2: Models of Comprehensive Care

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

The article presents a retrospective cohort analysis of all Medicare patients who died of cancer in Massachusetts and 5% of Medicare cancer patients in California in 1996. In Massachusetts, 33% of patients (older than 65 years of age) received chemotherapy in the last 6 months of life, 23% in the last 3 months, and 9% in the last month. Chemotherapy use declined with age. Chemotherapy use did not differ by tumor type.

- 2 Virnig BA, Kind S, McBean M, Fisher E. Geographic variation in hospice use prior to death. *J Am Geriatr Soc.* 2000;48:1117-1125. PMID: 10983913.

In this retrospective analysis of Medicare data 155/1,000 (15.5%) deaths had hospice care. Rates varied geographically more than 11-fold from a low of 3.5% to 39.7%. Deaths with hospice care for patients with cancer ranged from 0 to 20%. Rates were higher for younger patients, nonblacks, persons living in wealthier areas, and persons living in urban areas. Hospice use was greater in areas with fewer hospital beds per capita and higher HMO enrollment.

- 3 Christakis NA, Escarce JJ. Survival of Medicare patients after enrollment in hospice programs. *N Engl J Med.* 1996;335:172-178. PMID: 8657216.

Using 1990 Medicare data, 6,451 hospice patients were analyzed. Mean age was 76.4 years; 92.4% were white. One-half were women; 80% had cancer; median survival was 36 days; and 15.6 % died within 7 days; 14.9% lived longer than 6 months.

- 4 National Hospice and Palliative Care Organization. NHPCO Facts and Figures, July 2003. Accessed April 11, 2005. <http://www.nhpc.org>.

- 5 National Hospice and Palliative Care Organization, Standards and Accreditation Committee. *A Pathway for Patients and Families Facing Terminal Illness*. Alexandria, VA: NHPCO; 1997. Available at <http://www.nhpc.org>.

- 6 Center for Medicare and Medicaid Services. Medicare Benefit Policy Manual, Chapter 9: Coverage of Hospice Services Under Hospital Insurance <http://www.cms.hhs.gov/manuals/downloads/bp102c09.pdf>
- 7 Field MJ, Cassel CK, eds. Approaching Death: Improving Care at the End-of-Life. Washington, DC: National Academy Press; 1997:31-32.
- 8 World Health Organization. WHO Definition of Palliative Care. Switzerland: WHO; 2002. Available at <http://www.who.int/cancer/palliative/definition/en/>. Accessed April 11, 2005.
- 9 Pan CX, Morrison RS, Meier DE, et al. How prevalent are hospital-based palliative care programs? Status report and future direction. J Palliat Med. 2001;4:315-324. PMID: 11596542

American Hospital Association Survey data showed that 1,751 hospitals (36%) reported having a palliative medicine service and 719 (15%) reported having an end-of-life care service. A focused survey of these hospitals showed that 30% had a hospital-based palliative care program and another 20% had plans to establish one. These services are most commonly consultation service and hospital-based hospice programs.

- 10 Center to Advance Palliative Care. [Center to Advance Palliative Care Web site.] Available at <http://www.capc.org>. Accessed April 11, 2005
- 11 Beresford L, Byock I, Twohig JS. Financial Implications of Promoting Excellence in End-of-Life Care. Princeton, NJ: Robert Wood Johnson Foundation; 2002.

The article presents a report of financial implications of pilot projects to test novel approaches to combining palliative and standard care. In Michigan, a Phase III randomized trial of combined palliative and standard cancer care for patients vs standard care alone showed longer survival in the intervention arm (n=79, 266 days) than in the control arm (n=81, 227 days).

- 12 von Gunten CF. Secondary and tertiary palliative care in US hospitals. JAMA. 12002;287(7):875-881. PMID: 11851580;full text
- 13 von Gunten CF, Ferris FD, Portenoy RK, Glajchen M. CAPCManual: How to Establish a Palliative Care Program. New York: Center to Advance Palliative Care; 2001. Available at <http://www.cpsonline.info/capcmanual/index.html> Accessed April 11, 2005.

This is a comprehensive Web-based guide to the development of a hospital-based palliative care program.

- 14 JA, Pantilat S. Survey of palliative care programs in United States teaching hospitals. *J Palliat Med.* 2001 Fall;4(3):309-314. PMID: 11596541.
- 15 von Gunten CF, Camden B, Neely KJ, Franz G, Martinez J. Prospective evaluation of referrals to a hospice/palliative medicine consultation service. *J Palliat Med.* 1998;1(1):45-53.
- 16 Manfredi PL, Morrison RS, Morris J, Goldhirsch SL, Carter JM, Meier DE. Palliative care consultations: How do they impact the care of hospitalized patients? *J Pain Symptom Manage.* 2000 Sep;20(3):166-173. PMID: 11018334;full text
- 17 Weissman DE. Consultation in palliative medicine. *Arch Intern Med.* 1997 Apr 14;157(7):733-737. PMID: 9125004.
- 18 von Gunten CF, Ferris FD, Kirschner C, Emanuel LL. Coding and reimbursement mechanisms for physician services in hospice and palliative care. *J Palliat Med.* 2000;3(2):157-164; full text.

The authors provide a review of coding and reimbursement mechanisms for physician services in hospice and palliative care services through Medicare in the United States.

- 19 Kellar N, Martinez J, Finis N, Bolger A, von Gunten CF. Characterization of an acute inpatient hospice palliative care unit in a U.S. teaching hospital. *J Nurs Admin.* 1996 March;26(3):16-20. PMID: 8618119
- 20 Rabow MW, Petersen J, Schanche K, Dibble SL, McPhee SJ. The comprehensive care team: A description of a controlled trial of care at the beginning of the end-of-life. *J Palliat Med.* 2003 Jun;6(3):489-499. PMID: 14509498;full text.
- 21 Meyers FJ, Linder J. Simultaneous care: Disease treatment and palliative care throughout illness. *J Clin Oncol.* 2003 Apr 1;21(7):1412-1415. PMID: 12663735; full text
- 22 National Institutes of Health. NIH Clinical Center, Pain and Palliative Care Service, Warren Grant Magnuson Clinical Center. [NIH Clinical Center Web site.] Available at <http://www.cc.nih.gov/participate/patientinfo/services.shtml#pain> Accessed April 11, 2005. than control patients.
- 23 Memorial Sloan-Kettering Cancer Center. Memorial Sloan-Kettering's Pain and Palliative Care Service. [Memorial Sloan-Kettering Cancer Center Web site. ] Available at <http://www.mskcc.org/mskcc/html/6385.cfm>. Accessed April 11, 2005.

- 24 Dana Farber Cancer Institute. Pain and Palliative Care. [Dana Farber Cancer Institute Web site.] Available at [http://www.dana-farber.org/pat/support/pain\\_default.asp](http://www.dana-farber.org/pat/support/pain_default.asp). Accessed April 11, 2005.
- 25 Fox Chase Cancer Center. Support Services. [Fox Chase Cancer Center Web site.] Available at <http://www.fccc.edu/clinical/support/palliative.html>. Accessed April 11, 2005.
- 26 The University of Texas MD Anderson Cancer Center. Palliative Care and Rehabilitation Medicine. [MD Anderson Cancer Center Web site.] Available at <http://www.mdanderson.org/departments/palliative/>. Accessed April 11, 2005.
- 27 von Gunten CF, Muir JC. Palliative medicine: An emerging field of specialization. *Cancer Invest*. PMID: 11107446.
- 28 Walsh TD. Continuing care in a medical center: The Cleveland Clinic Foundation Palliative Care Service. *J Pain Symptom Manage*. 1990 Oct;5(5):273-278. PMID: 2079577

The effects of ketone body metabolism suggests that mild ketosis may offer therapeutic potential in a variety of common and rare disease states.

- 29 Emanuel LL, von Gunten CF, Ferris FD. The education for physicians on end-of-life care (EPEC) Curriculum. Chicago: American Medical Association; 1999. Available at <http://www.epec.net>. Accessed April 11, 2005.
- 30 Smith T, Loprinzi C, von Gunten CF, eds. ASCO curriculum: Optimizing cancer care—the importance of symptom management. Alexandria, VA: American Society for Clinical Oncology; 2001. Available at <http://webapp.asco.org/eSeries/source/Orders/index.cfm>. Accessed April 11, 2005.
- 31 von Gunten CF, Portenoy R, Sloan PA, Schonwetter R. Physician board certification in hospice and palliative medicine. *J Palliat Med*. 2000;3(4):441-447.
- 32 American Board of Hospice and Palliative Medicine. [ABHPM Web site.] Available at <http://www.abhpm.org>. Accessed April 11, 2005.
- 33 Board for Certification of Hospice and Palliative Nurses. [NBCHPN Web site.] Available at <http://www.nbchpn.org/>. Accessed April 11, 2005.
- 34 Center for Palliative Study at San Diego Hospice. Journals in hospice and palliative care. [SDHPC Web site.] Available at <http://www.cpsonline.info/content/resources/journals.html>. Accessed April 11, 2005.

- 35 Billings JA, Block SD, Finn JW, et al. Initial voluntary program standards for fellowship training in palliative medicine. *J Palliat Med.* 2002 Feb;5(1):23-33. PMID: 11839224
- 36 American Board of Hospice and Palliative Medicine. Accredited Fellowship Programs. [ABHPM Web site.] Available at [http://www.abhpm.org/gfxc\\_40.aspx](http://www.abhpm.org/gfxc_40.aspx). Accessed April 11, 2005.
- 37 American Academy of Hospice and Palliative Medicine: <http://www.aahpm.org/>