

EPEEC-O

Education in Palliative and End-of-life Care - Oncology

Participant's Handbook

Plenary 2:

Models of

Comprehensive

Care

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Abstract

Comprehensive cancer care requires a balanced approach to treating both the cancer and the experience of the patient with the cancer 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 models of cancer care that combine relief of suffering with attempts to cure or control the cancer yield the best outcomes.

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.

Key words

Hospice, palliative care, comprehensive cancer care, palliative medicine, levels of care, core services, consultation services, inpatient units, home care, skilled nursing facilities, outpatient ambulatory care

Objectives

After studying 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.

Clinical case on trigger tape

This trigger tape describes the perspective of a pioneer in palliative care in oncology. Balfour Mount, MD, FRCSPC, speaks about his life and work forging the philosophical and clinical underpinnings of the integration of palliative care with the rest of oncology and other specialty practices. The Founding Director of the Royal Victoria Hospital Palliative Care Service at McGill University, he received the Order of Canada for his work.

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. Healthcare institutions and the 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 US, a cancer's responsiveness to chemotherapy does not seem to influence the administration of chemotherapy in advanced stages of disease.¹

The current systems of cancer care were not conceived within a comprehensive 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 meeting the broad needs of their patients and families and to use the existing funding and service delivery models to optimize patients' and family's access to the care they need to minimize their suffering and improve the quality of their lives throughout their 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. Then, the approach was tried with a broader scope of patient population. Finally, the approach has been integrated into comprehensive cancer care.

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. They were generally run by religious orders. In a remarkable development from first listening to one hospitalized patient with unresectable sarcoma, 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. It became a place where a team of professionals in a single institution pursued the medical, emotional, social, and spiritual care of patients and families. Most importantly, it developed as an academic hospice, where education and research are pursued simultaneously with patient care (see Appendix of 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 still 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.² While there is significant regional variation, eg, 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 the patients who are referred to a hospice program generally do not spend enough time in these programs to experience all of the potential benefits.³ As of 2003, the median survival after enrollment was only 22 days, and 36.9 % of the patients died within seven days of admission.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 as much resemblance to their forebearers as contemporary hospitals do to theirs. Similarly, 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, it is used to describe a benefit available to Medicare beneficiaries and 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

persist even though the majority of patients enrolled in hospice programs stay with their referring physicians as their primary care physician 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% want to die at home.

Figure 1: Hospice care

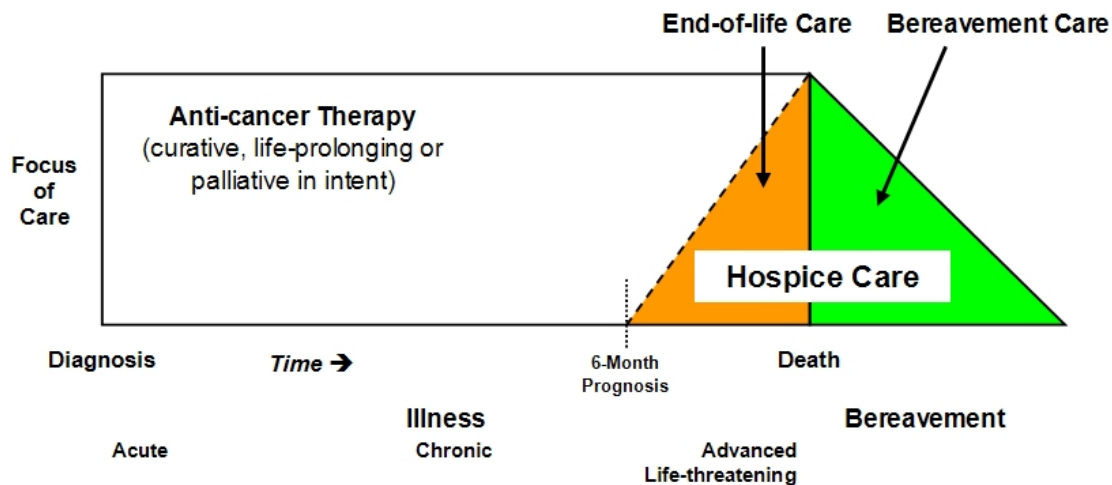


Figure 1 illustrates the application of hospice care today, in the United States, under the Medicare or other similar hospice benefits. The y-axis represents the total ‘quantity’ of concurrent therapies or the focus of care that evolves over time, the x-axis. Under these benefits, hospice is available 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 their underlying disease.

Hospice is intended to facilitate: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, eg, things, 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:⁶

1. **Routine care** is care provided in the patient's home on a day-to-day basis, ie, 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 (GIP)** 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 a 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 pre-planned 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

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 the 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: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 its definition of palliative care as: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.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 patient’s 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 to stimulate their development, particularly in acute care facilities.¹⁰ Designed to improve the quality of patients' lives while they fight their disease, there is evidence that patients enrolled in such 'combined' programs live longer.¹¹

Figure 2: Palliative care

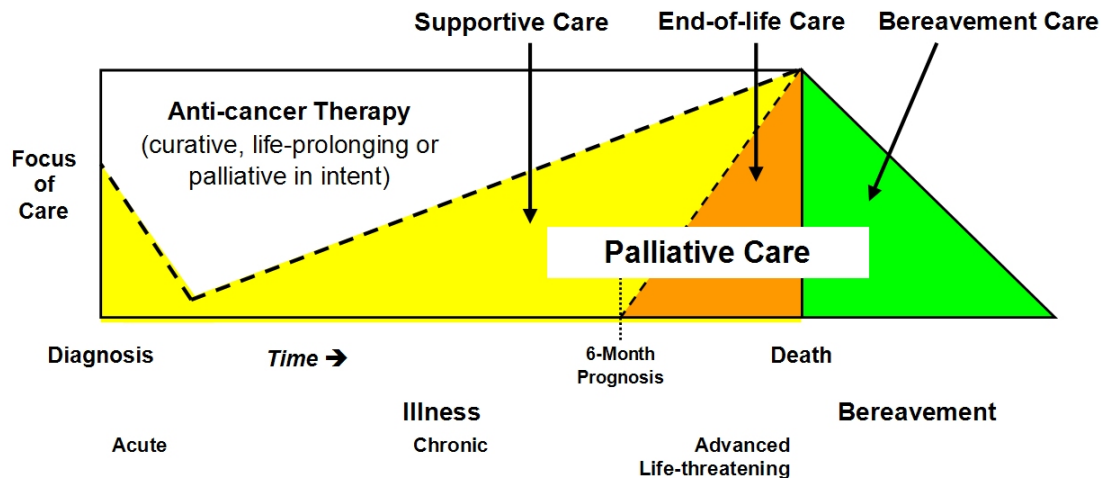


Figure 2 illustrates the application of palliative care across the illness and bereavement experience. The y-axis represents the total 'quantity' of concurrent therapies or the focus of care. This evolves over time, the x-axis. The dashed line distinguishes anti-cancer therapies that may be curative, 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 'quantity' of therapy and the mix of concurrent therapies will fluctuate based on the patient's and family's issues, their 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 the term as a more 'acceptable' term than palliative care for 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 3 distinct levels, primary, secondary, and tertiary care, in parallel with current concepts of all medical care.¹²

Primary palliative care refers to the generalist skills and competencies required of all oncologists and other healthcare professionals.⁹ Examples are skills in communication, pain and symptom management, team work, and healthcare system savvy. In this way, it does not differ from the skills and competencies needed in the variety of content areas germane to contemporary cancer care, such as infectious disease, where there is also 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 anti-cancer therapy from diagnosis. It has been operationalized with a number of system innovations.^{10,13} 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.^{14,15,16} 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 the 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.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.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 not distinguished only by their interior decoration. It is the quality of the care delivered there that is the distinguishing factor. In a 12-bed acute palliative care unit when more than 200 family members were surveyed, none described the décor.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 direct from home when the ‘usual’ evaluation in the emergency department or oncology unit of the hospital does not seem appropriate. Patients can also be admitted from the emergency department, psychiatric units, the surgical recovery room, and the intensive care units. 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 purposes 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 are frequently hospice programs.

Outpatient ambulatory care

The provision of palliative care can also be provided in the outpatient setting, either as part of an existing oncology practice, or as a free-standing clinic.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 anti-cancer therapy with a curative intent.

Implementation in comprehensive cancer care

Already, 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.²¹

Figure 3: Comprehensive cancer care

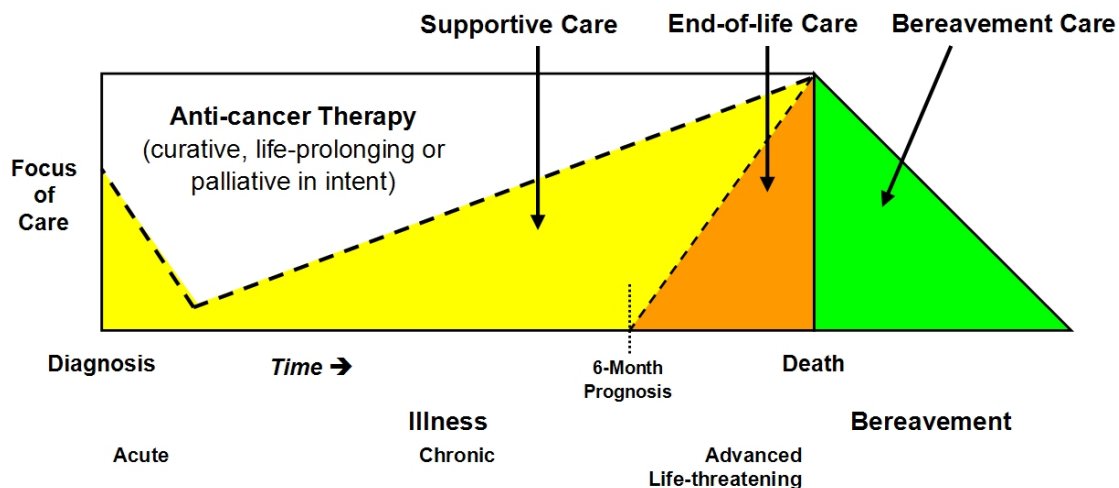


Figure 3 presents a continuum of comprehensive cancer care graphically over years, showing how anti-cancer therapy with curative, life-prolonging, or palliative intent changes as the illness progresses to the end of a person’s life. It is not a coincidence that comprehensive cancer care and palliative care share the same figure.

For some time after diagnosis, there is frequently a peak of intensity in supportive care. Then, the need for supportive care varies over the course of the illness with the tendency to increase over time, becoming the focus of care as dying 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 and other hospice benefits have been designed to be the funding mechanisms to take over and adequately pay for the care patients and families need at the end-of-life and the bereaved when other healthcare 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.²² Similar programs have been established at Memorial Sloan-Kettering Cancer Center in New York City,²³ the Dana-Farber Cancer Center in Boston,²⁴ Fox Chase Cancer Center in Philadelphia,²⁵ the Moffett Cancer Center in Tampa and the MD Anderson Cancer Center in Houston.²⁶ Just as in the rest of healthcare, 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 as needed in a preeminent cancer research center 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.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.²⁸ Other academic units and services followed.

Curricula on palliative care have been developed and broadly disseminated.^{29,30} Certifying boards recognizing subspecialists in hospice and palliative medicine have been established both for physicians and for nurses.^{31,32,33} There are at least seven subspecialty

peer-reviewed journals serving the field.³⁴ Chapters in general medical textbooks and subspecialty textbooks have been published. Fellowship programs are developing to train physicians who wish to subspecialize.^{35,36}

For the oncologist this should be welcome news. Such professionalization and subspecialization is the appropriate response to the expanding knowledge base in healthcare. While every oncologist provides the core competencies of palliative care provided in EPEC-O, s/he 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. A new subspecialty 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 the 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

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 their patient’s and family’s lives.

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

Pre-history to Roman Era Early civilizations responded to life-threatening illness as a group because death often posed a direct threat to entire community. Often one special person would be 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.

Death rates for mother and child were extremely high. 40-60% of children died before age 5. Few lived longer than 40 years.

4th Century AD 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.

Medieval times/crusades With the spread of Christianity, monasteries started to take in the sick and those disabled and unable to support themselves. During the 6th and 7th centuries, wealthy women and widows started working in the monasteries as the first ‘nurses.’

In Medieval times, at the time of the Crusades, 1095 to the end of the 17th century, weary travelers found places of refuge in monasteries and nunneries. Often they were in ill health and many spent their last days cared for, by the monks and nuns and lay women.

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.

Reformation In England and Northern Europe this came to an abrupt end with the Reformation and the dissolution of many monasteries.

1842 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 7 hospices, including Calvary Hospital in New York City.

1897–1905 In 1897, the Irish Sisters of Charity opened Our Lady's Hospice in Dublin and in 1905 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.

1950–60's 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. From 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.

1967 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.

1974 In 1974, Connecticut Hospice opened the first hospice in the United States. See <http://www.hospice.com/cthospice/index.html>. Accessed March 29, 2005.

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.

1974 In 1974, Dr. Balfour Mount, a Canadian urological 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.

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 en français) to be a synonym for "hospice" that would be acceptable to both English-speaking and French-speaking Canadians.

- 1975** Concurrently, a palliative care unit opens at the Royal Victoria Hospital, Montreal, Canada, and a terminal care unit opens at St. Boniface Hospital, Winnipeg, Manitoba, Canada. The latter, later changes its name to “a palliative care unit.”
- 1980** 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.
- 1982-3** 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.
- 1990’s** 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 has been 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.

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 that patients and families have access to this care.

- 2000’s** The hospice care industry in the U.S. 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 (\approx 30% of Americans who die). 41% 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.

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 that describes their services and their collective effectiveness is not yet available.¹⁴

References

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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.
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