EPEC™-O

Education in Palliative and End-of-Life Care for Oncology:

Cultural Considerations When Caring for African Americans

Plenary 2-AA:

Models of Comprehensive Care

Abstract

Comprehensive cancer care requires a balanced approach that begins with the day of diagnosis, treating the cancer and tending to the experience of the patient. Regardless of the eventual outcome, it is important to manage the physical, psychological, social, spiritual, and practical dimensions of each patient's cancer experience. While traditional medical care is diseased-focused, holistic medical care with the primary goal of relieving suffering and improving quality of life were first developed in the context of hospice programs and palliative care services. Their developmental history is explored in this plenary. To improve accessibility for African Americans and other disadvantaged populations, these holistic approaches to care need to be further customized and must respect the distinct cultural and spiritual values of each unique patient and his/her family.

Models of cancer care that yield the best outcomes combine the relief of suffering with attempts to cure or control the cancer, and are accessible to all patients with cancer and their families. Healthcare professionals need to become culturally competent and to acquire the core competencies of palliative care. Models to institutionalize the delivery of that care, including specialist-level expertise, are required to ensure reliable delivery of service. Together, these provide a comprehensive response to address the needs of all patients and families throughout the illness and bereavement experience. The module explains current models of comprehensive cancer care, and how these might be incorporated into future models.

Healthcare providers need to be aware of the rapidly evolving landscape of healthcare delivery, while advocating that emerging models integrate the principles of palliative and hospice care.

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, patient navigation, patient-centered medical home, community health workers, community-based collaborative care networks, evidence-based care transitions models, Chronic Care Model, the Patient Protection and Affordable Care Act, Accountable Care Organizations

Objectives

After reviewing this module, members of the healthcare team will be able to:

- Define hospice and palliative care and describe their history.
- Articulate a vision of comprehensive cancer care that includes palliative care from the day of diagnosis.
- Describe current and possible future funding and service delivery models for providing comprehensive cancer care.
- Identify appropriate points in the cancer trajectory when palliative care and hospice services are appropriate.
- Understand barriers and facilitators to access and utilization of hospice and palliative care services by African American patients.

Definitions:

Accountable Care Organization (ACO): An accountable care organization is a group of health care providers (for example, primary care physicians, specialists and hospitals) that have entered into a formal arrangement to assume collective responsibility for the cost and quality of care of a specific group of patients, and that receive financial incentives to improve the quality and efficiency of health care.[1]

Community Health Worker (CHW): A frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served. This trusting relationship enables the CHW to serve as a liaison/link/intermediary between health/social services and the community, in order to facilitate access to services and to improve the quality and cultural competence of service delivery. A CHW also builds individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support and advocacy.[2]

Community-based collaborative care network: A consortium of health care providers with a joint governance structure (including providers within a single entity) that provides comprehensive, coordinated and integrated health care services (as defined by the Secretary) for low-income populations.[3]

Comprehensive Cancer Care: An integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, screening, early detection, diagnosis, treatment, survivorship and palliative care.[4]

Hospice: A program that provides special care for people who are near the end of life and for their families, either at home (which includes nursing home and assisted living facilities), in freestanding facilities, or within hospitals.[5] Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice and palliative care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support that is expressly tailored to the person's needs and wishes. Support is provided to the person's loved ones as well.[6]

Palliative Care: Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of palliative care is to prevent or treat as early as possible: the symptoms of a disease; side effects caused by treatment of a disease; and psychological, social, and spiritual problems related to a disease or its treatment. Also called comfort care, supportive care, and symptom management.[7]

Patient Navigators: Trained, culturally competent health care workers who work with patients, families, physicians, and the health care system to ensure cancer patients' needs are appropriately and effectively addressed.[8]

Patient-centered medical home: A health care model that aims to provide structured, proactive and coordinated care for patients rather than episodic treatments for illnesses. In a medical home, the primary-care doctor operates as a "home base" for patients, oversees all aspects of patients' health, and coordinates care with any specialists involved in the patient's care.[1]

Program of All-inclusive Care for the Elderly (PACE): The PACE model of care includes, as core services, the provision of adult day health care and interdisciplinary team (IDT) care management, through which access to, and allocation of, all health services are managed. Physician, therapeutic, ancillary, and social support services are furnished in the participant's residence or on-site at a PACE center. Hospital, nursing home, home health, and other specialized services are generally furnished under contract. It is financed through prospective capitation of both Medicare and Medicaid.[9]

The Chronic Care Model: A model developed by Edward Wagner and colleagues that provides a solid foundation from which health care teams can operate. The model has six dimensions: community resources and policies; health system organization of health care; patient self-management supports; delivery system redesign; decision support; and clinical information system. The ultimate goal is to have activated patients interact in a productive way with well-prepared health care teams. Three components that are particularly critical to this goal are: (1) adequate decision support, which includes systems that encourage providers to use evidence-based protocols; (2) delivery system redesign, such as using group visits and same-day appointments; and (3) use of clinical information systems, such as disease registries, which allow providers to exchange information and follow patients over time.[1]

Video Vignette

This trigger tape provides the perspective of a founder of and pioneer in palliative care and oncology. Balfour Mount, MD, FRCSPC, speaks about his life and work in 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.

The video can be accessed by clicking on the following link:

http://www.youtube.com/watch?v=yB2FfZf3wnc&feature=BFa&list=PLB155BEB413DCED8C

Introduction

The gap between ideal comprehensive cancer care and current patterns of care needs to be closed. This gap is even more pronounced among African Americans and other disadvantaged populations.

To address this issue, healthcare professionals need the attitudes, knowledge, and skills to deliver quality palliative care to their cancer patients. However, we know that will not be enough to assure reliable results. It is now widely recognized that cognitive information like this curriculum is necessary, but not sufficient, to deliver good palliative care to cancer patients. Clinicians also need the opportunity to rehearse what has been learned, and to incorporate new practices into the daily care they deliver. In addition, systems of care need to be aligned to make it easy to provide the most effective evidence-based care.

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 undermine a comprehensive model of cancer care delivery. For example, in the United

States (U.S.), the responsiveness of a cancer to chemotherapy does not seem to influence the administration of chemotherapy in advanced stages of disease.[10]

Current cancer care systems were not conceived to incorporate the relief of suffering as a core focus of cancer care. In fact, these systems may at times even promote suffering. For healthcare professionals, the challenge is to be creative in using existing funding and service delivery models to optimize access to the care needed by patients and their families, in order to minimize their suffering and improve the quality of their lives throughout the experience of illness, survival, and bereavement.

This module traces the historical development of systems to deliver palliative care and hospice 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. At first, approaches were piloted in patients with advanced disease in the setting of hospice care. The approach was then tried in a broader patient population. Finally, the approach has been integrated into comprehensive cancer care.

Hospice Care

Hospice care was the initial testing ground for palliative care. Until the last third of the 20th century, hospice was a term used to describe places where the dying could be cared for. These facilities were generally run by religious orders. From listening closely to the experience of one hospitalized patient with unresectable sarcoma, Dr. Cicely Saunders began to draw on the first-hand experiences of many cancer patients, and eventually founded St. Christopher's Hospice south of London, England as a setting to test her hypotheses about the interdisciplinary care of the "whole" patient. St. Christopher's was organized as 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 occurred simultaneously with patient care. New approaches and insights were tested and disseminated. [11] (see **Appendix: History of Hospice Care**).

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

The first hospice in the U.S., The Connecticut Hospice Inc., began providing services at home in 1974 with National Cancer Institute (NCI) funding.[12] Other hospices soon followed, with the mission to help families care for patients with advanced life-threatening illness in the home setting. Most early hospices in the U.S. were run by volunteers and funded largely by philanthropy. Then, in 1979, the Health Care Financing Administration (HCFA) began providing funding to 26 hospices across the U.S. as a pilot demonstration project. After the project ended in 1982, the Federal government began reimbursing hospice care for all Medicare beneficiaries who had a prognosis of less than 6 months, provided they received care from a Medicare certified hospice.[11]

Subsequently, the number of hospice agencies operating in the U.S. primarily providing care at home increased dramatically. In 2009, 3400 of the approximately 5000 known hospices were Medicare-certified hospice providers, and hospices cared for about 42 percent of all deaths. Of those patients dying of cancer, hospice cared for only 40 percent,[13] and even those patients who are referred to hospice generally are not in these programs long enough to experience all of the potential benefits.[14] As of 2009, the median survival after enrollment was only 21 days, and over 35 percent of patients died within 7 days of admission.[13]

In the U.S., the word 'hospice' can be used to describe several different concepts:

- a site of care for the dying, such as a free-standing facility or a dedicated unit within a hospital or nursing home.
- a philosophy of care, emphasizing skilled and compassionate holistic care for patients near the end-of-life.
- a corporate entity that provides a number of "service lines," including hospice care, in a variety of settings. Some hospice organizations have expanded to include other activities that bear little resemblance to the original concept. Hospice organizations can differ from one another just as hospitals and health systems can differ.
- a benefit available to Medicare beneficiaries to fund end-of-life care, which is subject to the rules and regulations promulgated by the Center for Medicare and Medicaid Services to govern that federal program.
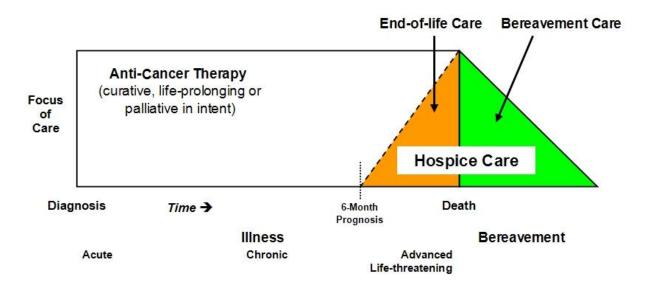
Unfortunately, the use of a single term for all of these meanings has led to confusion. For many patients, "hospice" still means a place to go to die. For many physicians, "hospice" means a poorly understood community-based program into which a patient disappears after the physician signs a form certifying a prognosis of less than 6 months. These perceptions persist even though the majority of patients enrolled in hospice programs continue to receive care from their referring physicians and live in their own homes until they die. Surveys suggest that— if they knew they had a life-threatening illness— 70 to nearly 90 percent of Americans would want to die at home.[15, 16] Although a significant number of African Americans surveyed would also prefer to die at home (approximately 50 percent in the Carolina Centers AARP study[17]), it is important to note that fewer report this preference than Caucasians.

Figure 1 below illustrates the current application of hospice care that is covered by Medicare hospice benefits, or other similar hospice benefits provided by private insurers and Medicaid. 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.

Care remains focused on curative and life-prolonging interventions until the patient is near the end of life; at that time the focus of care shifts away from curative intent to trying to relieve a patient's suffering. The y-axis represents the total "quantity" of concurrent therapies or the focus of care. The x-axis represents the time course of the patient's experience, including bereavement.

Figure 1: Hospice Care

Hospice is intended to facilitate:

- Safe and comfortable dying: to provide the best possible quality of life during the final months of a patient's life, and to ensure that the patient dies in the best way possible.
- Self-determined life closure: to facilitate closure of business, reminiscence, legacy creation, gift giving (for example, 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 then rebuild their lives.[18]

Levels of care

Medicare hospice benefits pay for four levels of hospice care that can be used to provide care to patients and their families, depending on their needs and the setting of care:

1. *Routine home care* is provided in the patient's home (that is, 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 management 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, if the patient has complex symptom management issues.
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 more than 50 percent needs to be skilled nursing care provided by a registered nurse (RN) or licensed vocational nurse (LVN).
4. *Respite care* is 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. It is limited

to 5 consecutive days at a time. Inpatient respite care requires that a nurse be available 24 hours per day.[19]

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.[19]

Factors influencing utilization of hospice in the African American cancer experience

In 2009, African Americans comprised 8.7 percent of patients cared for in hospice in the U.S. (down from 9 percent in 2007); the use of hospice varies by clinical setting, geography, and the effectiveness of community outreach.[13]

The California Healthcare Foundation conducted focus groups to determine end-of-life preferences among African Americans. African Americans placed great value on providers "who respect your culture" when making end-of-life decisions,[20] a finding consistent with other studies. For example, in a survey of 42 African Americans that included family caregivers for cancer patients and cancer survivors, "relationship-centered care" was an important element of the provider-patient team; this approach enhanced the context for a full discussion about cultural values.[21] Thus, healthcare teams that are competent in cultural assessments and which have effective communication skills are more likely to engage African American patients in successful advance care discussions and that lead to enrolling patients into hospice and palliative care programs.

The California Health Care Foundation study found that requirements for hospice enrollment may conflict with the preferences of African American patients.[20] Hospice enrollment often requires patients to choose between hospice and so-called curative or life-prolonging therapies. This dichotomy reinforces the belief held by many African American patients that "hospice care means you get no treatment." Johnson et al. found that these negative beliefs about hospice care were related to a number of culturally-based factors; compared to Whites, African Americans:

- are more likely to express discomfort discussing death;
- express greater preferences for aggressive care at the end of life;
- are more likely to have spiritual beliefs that seem to conflict with some goals of palliative care; and
- express more distrust of the healthcare system.[22]

Fishman et al. surveyed 283 cancer patients (81 African Americans, 202 Whites) receiving care in outpatient oncology clinics at the University of Pennsylvania to determine if the more aggressive treatment preferences of African Americans explained lower rates of hospice utilization. While African Americans assigned higher value to almost all hospice services than did Whites, they were nonetheless much more willing than Whites to continue aggressive cancer treatments that would preclude hospice enrollment "in return for a smaller likelihood of six-month survival." They also had stronger preferences for aggressive cancer treatment, even after adjusting for age, gender, socioeconomic status, performance status, and other measures of quality of life, including symptom burden.[23] These findings suggest that African Americans are likely to favor programs that integrate palliative services and supportive care with anti-cancer therapy.

The following approaches increase utilization of hospice and palliative care by African American patients while decreasing health disparities:

- Case identification of African Americans with advanced cancer in a public hospital, followed by routine palliative care consultation. This substantially increased the proportion of African Americans who completed advance directives, as well as the proportion who utilized hospice care upon discharge.[24]
- Use of video to enhance health literacy, goal-setting and care planning for patients and families with advanced illness.[25, 26, 27]
- Enrollment in "bridge" (home-based) palliative care programs, such as the Advanced Illness Management Program (AIM).[28]
- Enrollment in integrated health systems, such as Kaiser Permanente or the Veteran's Administration Health Centers, which have standardized processes and integrated electronic health records that can help to trigger discussions of palliative and hospice care.[29]

[see also Plenary 1: Cancer and the African American Experience]

Palliative Care

Definition

The term palliative care (*soins palliatif* in French) was first coined by Dr. Balfour Mount, a urologic surgeon working at Montreal's Royal Victoria Hospital in the mid-1970s.[30] He was looking for a word that would describe the care provided by English hospices, while avoiding the negative connotations "hospice" might have for French-speaking Canada. He established a palliative unit within 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 that was first developed by hospice programs, but later made available in hospitals, outpatient clinics, and through homecare services.

Various groups have defined palliative care in diverse but related ways. Each of the proposed definitions shares a focus on relieving suffering and improving quality of life throughout the trajectory of illness, from diagnosis through end-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 relieve suffering and facilitate the enhancement of life.

The Institute of Medicine defines palliative care as follows:

> "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."[31]
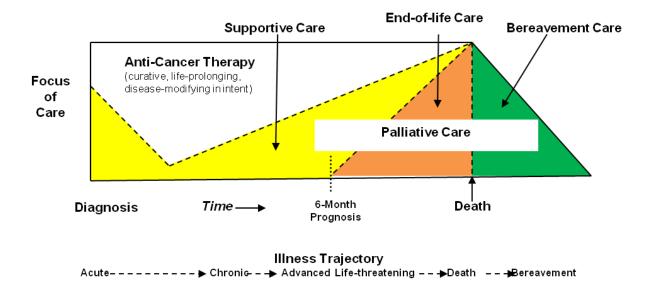
In 2002, the World Health Organization (WHO) revised their definition of palliative care:

> "An approach which improves quality of life of patients and their families facing the problem of 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."[32]

Over the past decade, palliative care programs and consult services have been developing across the U.S. that provide the expertise and standards of practice developed by hospice earlier in their illness to patients who need symptom control and supportive care. The prevalence of palliative care programs in U.S. hospitals with more than 50 beds has grown from 24.5 percent in 2000 to 63 percent in 2009.[33] These programs benefit from modern medical advances in 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. These programs are designed to improve the quality of patients' lives while they fight their disease. There is evidence to suggest that patients enrolled in such "combined" programs may live longer than patients receiving standard care.[34, 35]

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. The x-axis represents the time course of the patient's experience, including bereavement. The dashed line distinguishes anticancer therapies that intend to prolong life 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, palliative therapy may not be needed at all.

Figure 2: Palliative Care

Illness Trajectory
Acute – – – – – – – – ▶ Chronic – – ▶ Advanced Life-threatening – – ▶ Death – – ▶ Bereavement

Supportive care

In contrast to end-of-life and bereavement care, the term *supportive care* has been coined to describe approaches that enable or enhance cancer care earlier in the illness experience. The National Cancer Insitute defines *supportive care* as care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of supportive care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment. Supportive care may also be called comfort care, palliative care, and symptom management.[36] Counseling, hematopoietic growth factors, anti-emetics, and massage have all been offered under the banner of *supportive care.* Some healthcare professionals consider supportive care to be a more acceptable term than *palliative care* in their clinical environments. What matters is to deliver substantial and effective care, whether the care is called *hospice, palliative,* or *supportive* care.

Development as a Specialty

The development of academic palliative care has been slow but steady.[37] The first modern academic hospice, St. Christopher's Hospice, was developed by Dr. Cicely Saunders and opened in 1967.[38] Those who studied with Dr. Saunders and her colleagues developed similar academic programs at Oxford University, McGill University, and in conjuction with Yale University.[39]

In the United States, The Pain and Palliative Care Service at Memorial Sloan-Kettering Cancer Center began as the Pain Service in the department of Neurology under the leadership of Dr. Kathleen Foley, who initiated the fellowship training program in 1978.[40] The name was changed to the Pain and Palliative Care Service in 1996.[41] Dr. T. Declan Walsh developed an academic palliative care service as part of a comprehensive cancer center in 1987 at the Cleveland Clinic.[42] The development of a palliative care service at the Warren Grant Magnuson Clinical Center at the National Institutes of Health (NIH) represents both an example and a milestone in the professional development of palliative care in the United States. The fact that the nation's publicly funded research hospital on the campus of the NIH recognized the importance of having

quality palliative care available for its patients added impetus to the drive toward specialization of the field.[43] Other programs at the forefront of the movement to integrate palliative care into comprehensive cancer care include those at the Dana-Farber Cancer Institute in Boston,[44] the Fox Chase Cancer Center in Philadelphia,[45] the H. Lee Moffitt Cancer Center and Research Institute in Tampa,[46] and the University of Texas MD Anderson Cancer Center in Houston.[47]

Curricula on palliative care have been developed and broadly disseminated.[48, 49, 50, 51] Certifying boards to recognize subspecialists in hospice and palliative medicine have been established both for physicians and nurses, as well as other interdisciplinary healthcare providers.[52, 53, 54] There are more than 30 subspecialty peer-reviewed journals serving the field.[55] Chapters have been published in general medical textbooks and subspecialty textbooks.

In July of 2006, the American College of Graduate Medical Education (ACGME) approved the establishment of an accreditation process for hospice and palliative medicine fellowship training programs. In September of 2006, the American Board of Medical Specialties (ABMS) established the subspecialty in hospice and palliative medicine among several parent boards.[52, 56] Certification is also available for social workers, advance practice nurses, registered and licensed practical nurses, and nursing assistants.[53, 54]

For healthcare professionals, this should be welcome news. Such professionalization and subspecialization is the appropriate response to the expanding knowledge base.
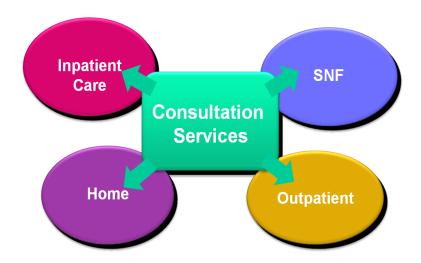
Delivering palliative care

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.[57] While every healthcare professional should be able to provide the core competencies of palliative care, trained subspecialists exist to consult about difficult cases. There is also a need for professionals to pursue the discovery of new knowledge related to palliative care.

Primary palliative care refers to the generalist skills and competencies required of all healthcare providers.[58] 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.

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. Specially trained clinicians, and care delivery models such as palliative care consultation services, provide specialty care in a variety of settings, including the patient's home, skilled nursing facilities (SNFs), outpatient clinics, and hospitals. (See Figure 3)

Figure 3: Palliative Consultation

Palliative consultation services function in the medical system like other consultation services.[58, 59, 60, 61] Their success in assisting healthcare providers to deliver palliative care reflects the role that consultation plays in the continuing education of healthcare providers. It is through consultation that most healthcare providers learn about new developments outside the focus of their specialty. Palliative care consultation services offer healthcare providers advice and can participate in managing 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 to bear *in combination with* other medical services in the hospital.[62] 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.[63] Other interdisciplinary members of the palliative consultation service may or may not be able to bill under traditional reimbursement schemes (for example, nurse practitioners, social workers). Some hospitals underwrite the services of these professionals because engaging a palliative care consult service not only improves patient satisfaction and quality of care, but helps to avoid excess costs.[64]

Tertiary palliative care refers to the academic centers where specialist knowledge for the most complex cases is practiced, researched, and taught.[57]

Settings for the provision of palliative care:

Inpatient units

Palliative care units have developed in hospitals for the same reasons that oncology and intensive care units did: they provide access to increasing knowledge and create systems 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.[65]

Physicians can admit patients to acute palliative care units in hospitals for a variety of reasons. Patients can be transferred from anywhere in the hospital when it seems they would benefit from

an interdisciplinary palliative approach to care. Patients can be admitted directly from home when evaluation in the emergency department or oncology unit of the hospital seems inappropriate. Patients can also be admitted from the emergency department, psychiatric unit, post-anesthesia care unit, or intensive care unit. Because the environment and expertise is ideal for withdrawing life-sustaining measures, physicians can admit patients who are 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. Although hospice programs generally provide the most comprehensive set of coordinated palliative services in the home care setting, programs that extend non-hospice palliative care services into the home are sometimes offered by healthcare providers or organizations. Some home health agencies have developed special palliative care expertise. An example of this is the Advanced Illness Management (AIM) Program offered through the Sutter Visiting Nurse Association and Hospice in Emeryville, CA. The program was established as a "bridge" from curative to comfort care in order to meet the needs of chronically ill patients who were "falling between the cracks" of hospital, home health, and hospice services. Home-based palliative care is offered to patients and families who are not yet ready for hospice. Among African American enrollees in the AIM Program between 2003 and 2005, hospice referrals increased to 73 percent compared with 60 percent among patients receiving usual care. For patients enrolled in the AIM Program for at least 3 months, there were 63 percent fewer hospitalizations and an overall average savings of $2,000 per patient per month.[28]

Long-term care

Facility-based service delivery systems have been developed for the care of the frail and the elderly. A variety of names (group homes, residential care for the elderly, long term care facilities, skilled nursing facilities) suggest the range of services available. Palliative care services are becoming more commonly available in all of these settings. Again, hospice programs generally provide the most comprehensive set of coordinated palliative services in the long-term care setting.

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.[66] The outpatient setting is ideal for initial and follow-up visits with cancer patients who are early in their illness experience and may be seeking anticancer therapy with curative intent.

Monitoring the quality of palliative care

In 2001, leaders in the field of hospice and palliative care (American Academy of Hospice and Palliative Medicine, Center to Advance Palliative Care, Hospice and Palliative Nurses Association, Last Acts, National Hospice and Palliative Care Organization) formed the National Consensus Project (NCP); their mission was to create clinical practice guidelines to improve the quality of palliative care in the U.S. In 2004, the NCP produced *Clinical Practice Guidelines for Quality Palliative Care*, which were updated in 2009. The NCP collaborated with the National

Quality Forum (NQF), a national leader in healthcare quality improvement, to develop quality measures for palliative care. The NQF released *A Framework for Palliative and Hospice Care Quality Measurment and Reporting* in 2006 .[67]

On September 1, 2011, The Joint Commission launched a new Advanced Certification Program for Palliative Care for hospitals based on the work of the NCP and the NQF.[68] The certification emphasizes:

- A formal, organized palliative care program led by an interdisciplinary team whose members possess the requisite expertise in palliative care.
- Leadership endorsement and support of the program's goals for providing care, treatment and services
- A special focus on patient and family engagment.
- Processes which support the coordination of care and communication among all care settings and providers.
- The use of evidence-based national guidelines or expert consensus to guide patient care.

Comprehensive Cancer Care

Integration of palliative care into comprehensive cancer care

Comprehensive cancer care integrates palliative care with anticancer therapy, beginning at diagnosis. It includes not only supportive care, but also end-of-life care and bereavement care. Care models have changed in order to make this feasible. Overall, the goal is to have *"the right patient, in the right setting, at the right time, with the right payment."*[69, 70]

As with palliative care in general, supportive care for cancer patients can be provided in an ambulatory outpatient clinic, through an inpatient consult service, or in the patient's home (including in a long-term care facility). Similarly, end-of-life care for cancer patients can be provided in an ambulatory outpatient clinic, through an inpatient consult service or geographically based unit, or in the patient's home (including in a long-term care facility). Bereavement care is typically provided in an ambulatory outpatient setting, and may involve individual counseling or support groups. At times help from a psychiatrist or psychologist may be needed, particularly in the setting of complicated bereavement.

Models of care that integrate active treatment and palliative care may be more acceptable than stand-alone programs to African Americans for several reasons; they eliminate the need to choose between curative or palliative therapy, allow continued access to anti-cancer therapy for patients who prefer to receive more aggressive care toward life's end, minimize perceived conflicts with spiritual values, and may seem to be a less formal type of advance care planning.[22]

Many comprehensive cancer programs have successfully integrated components of palliative care.[71] Several programs have tested the hypothesis that palliative care combined with cancer care yields better outcomes than standard care alone. In a landmark study of adults with metastatic non-small cell lung cancer, Temel et al. compared concurrent palliative care plus standard anti-cancer therapy to standard care alone. Those patients who received concurrent palliative care along with their anti-cancer therapy were found to have better quality of life and fewer depressive symptoms, received less aggressive care at end of life, were referred to hospice

earlier, and had a longer median survival by almost 2 months than patients who received standard therapy alone.[35]

A survey of cancer centers by Hui et al. in 2009 compared National Cancer Institute (NCI) designated cancer centers with other cancer centers. NCI designated cancer centers were more likely to have: palliative care programs (98 percent vs. 78 percent), at least one palliative care physician on staff (92 percent vs. 74 percent), an inpatient palliative care consultation team (92 percent vs. 56 percent), and an outpatient palliative care clinic (59 percent vs. 22 percent). Only 23 percent of surveyed cancer centers had specifically designated palliative care beds and only 37 percent had an institution-operated hospice program. The authors' conclusion was that, at the present time, although most cancer centers report having a palliative care program, the scope of services and the extent of integration with the parent institution vary widely.[72]

There need not be conflict between treating cancer and responding to the suffering of the patient and those close to the patient. Both are legitimate and necessary aims of comprehensive cancer care. Any cancer center striving for excellence must provide expert and effective palliative care routinely.

Figure 4 presents a continuum of comprehensive cancer care over years; anticancer therapy with curative or life-prolonging intent will change 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.
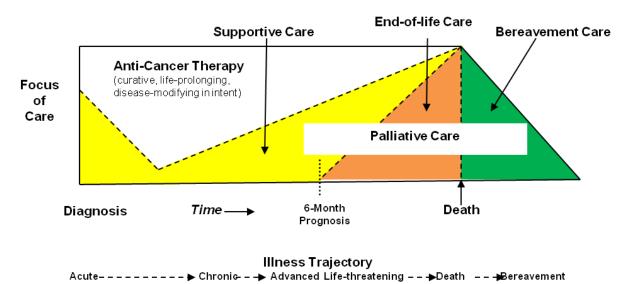
Figure 4: Comprehensive Cancer Care

There may be an initial high need for supportive care just after diagnosis. Thereafter, the need for supportive care varies but tends to increase over time, becoming the focus of care in advanced metastatic cancer, 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 <u>enhanced palliative care</u> at the end of life, and families receive bereavement care.* Medicare hospice benefits and hospice benefits offered by other insurers are the funding mechanism to pay for the care that patients and families need at the end of life, when other health care funding and service delivery models are winding down. Care for the bereaved is an essential component of hospice care.

Future trends in healthcare delivery

Current care deficits and recommendations for improvement

In cancer care, as in medical care in general, serious concerns have been raised about the quality of care delivered to patients and families. The 2001 Institute of Medicine (IOM) report, *Crossing the Quality Chasm*, documented serious shortcomings in the U.S. health care system, and wide variability in the quality of care delivered, including underuse, overuse, and misuse of medical therapies.[73] The committee proposed six aims to improve key dimensions of healthcare delivery. Health care should be:

- *Safe*— avoiding injuries to patients from the care that is intended to help them.
- *Effective*— providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit.
- *Patient-centered*— providing care that is respectful and responsive to individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions.
- *Timely*— reducing waits and sometimes harmful delays for both those who receive and those who give care.
- *Efficient*— avoiding waste, including waste of equipment, supplies, ideas and energy.
- *Equitable*— providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

They further recommended that private and public purchasers, health organizations, clinicians and patients should work together to redesign health care processes, following these principles:

1. *Care based on continuous healing relationships.* Patients should receive care whenever they need it and in many forms, not just face-to-face visits. Care should be available 24 hours a day, every day, and access should be provided in a variety of ways, such as internet and telephone, in addition to face-to-face visits.
2. *Customization based on patient needs and values.* The system should be designed to meet the most common types of needs, but have the capacity to respond to individual patient choices and preferences.
3. *The patient as the source of control.* Patients should be given the opportunity and the information necessary to exercise the degree of control they choose over those health care decisions that affect them. The health system should be able to accommodate differences in patient preferences and encourage shared decision making.
4. *Shared knowledge and the free flow of information.* Patients should have unfettered access to their own medical information and to clinical knowledge. Clinicians and patients should communicate effectively and share information.
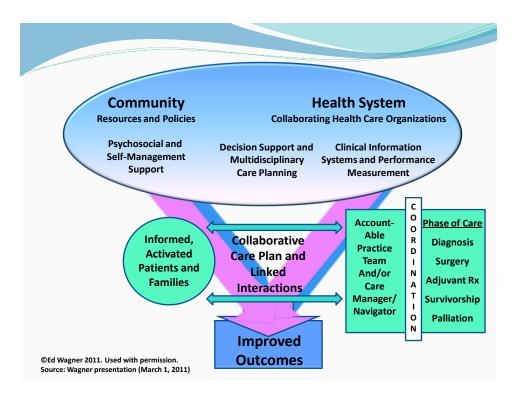
5. *Evidence-based decision making*. Patients should receive care based on the best available scientific knowledge. Care should not vary illogically from clinician to clinician or from place to place.
6. *Safety as a system property.* Patients should be safe from injury caused by the care system. Reducing risk and ensuring safety require greater attention to systems that help prevent and mitigate errors.
7. *The need for transparency.* The health care system should make information available to patients and families that allow them to make informed decisions when selecting a health plan, hospital, or clinical practice, or when choosing among alternative treatments. This should include information describing the system's performance on safety, evidence-based practice, and patient satisfaction.
8. *Anticipation of needs.* The health system should anticipate patient needs, rather than simply reacting to events.
9. *Continuous decrease in waste.* The health system should not waste resources or patient time.
10. *Cooperation among clinicians.* Clinicians and institutions should actively collaborate and communicate to ensure an appropriate exchange of information and coordination of care.

As treatments for cancer evolve and the prognosis for recovery or extended life improves, cancer is a chronic illness. The Robert Wood Johnson Foundation recognized deficits in the care of persons with chronic debilitating illness as they moved through a very disjointed healthcare system. Similar to issues identified in the IOM report, deficits included: practitioners failing to follow established practice guidelines, lack of care coordination, lack of active follow-up to ensure best outcomes, and patients inadequately trained to manage their illness. A conceptual model was developed to address these care deficits.[74] The resulting Chronic Care Model was developed and implemented by Edward Wagner at The MacColl Institute for Healthcare Innovation in the early 1990's, refined in 2003, and adapted for cancer in 2011.[75] The model identified those essential elements of a health care system that would encourage high-quality chronic disease management:

- *Health system*. Create a culture, organization, and mechanisms that promote safe, high quality care.
- *Delivery system design*. Assure the delivery of effective, efficient clinical care and self-management support.
- *Decision support*. Promote clinical care that is consistent with scientific evidence and patient preferences.
- *Clinical information systems*. Organize patient and population data to facilitate efficient and effective care.
- *Self-management support*. Empower and prepare patients to manage their health and health care.
- *The Community*. Mobilize community resources to meet needs of patients.[75]

(See Figure 5 below)

Figure 5: The Chronic Care Model

Community
Resources and Policies

Health System
Collaborating Health Care Organizations

Psychosocial and Self-Management Support

Decision Support and Multidisciplinary Care Planning

Clinical Information Systems and Performance Measurement

Informed, Activated Patients and Families

Collaborative Care Plan and Linked Interactions

Account-Able Practice Team And/or Care Manager/ Navigator

COORDINATION

Phase of Care

Diagnosis

Surgery

Adjuvant Rx

Survivorship

Palliation

Improved Outcomes

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Source: Wagner presentation (March 1, 2011)

McCorkle at al. reviewed one aspect of the Chronic Care Model, improvement in self-efficacy/ self-management, in the care of cancer patients and families. They highlighted the importance of the nurse's role in implementing improved patient self-management at all stages along the cancer care continuum. They advocate that several aspects of the Chronic Care Model be incorporated into clinician practice: forming strong partnerships with patient and families, developing care plans in discussions with patients and families, and enabling/ empowering patients to care for themselves in ways they prefer.[76]

Emerging Models of Care: Where does comprehensive cancer care (including palliative care) fit in?

As of 2012, there has been much experimentation with various models of healthcare delivery, all with the ultimate aim of improving access to, and coordination of, healthcare for all Americans, including the medically underserved, while at the same time improving the quality and consistency of the care delivered. The models described below are not mutually exclusive, and more than one model may be incorporated successfully into a truly integrated management system for patients with progressive chronic illness, including cancer. These models may incorporate some or all of the aspects of the Chronic Care Model, and may also incorporate some of the IOM recommendations. Many are intended specifically to address issues of access experienced by vulnerable populations.

Patient Navigation

Patient Navigation is one model that has been proposed to address and overcome barriers to cancer care, including screening, treatment, survivorship, palliative, and end-of-life care. Patient navigation:

1. Is provided to individual patients for a defined episode of cancer-related care;
2. Has a definite endpoint when the services provided are complete;
3. Targets a defined set of health services required to complete an episode of cancer-related care;
4. Focuses on the identification of individual patient-level barriers to accessing cancer care;
5. Aims to reduce delays in accessing the continuum of cancer care services, especially timeliness of diagnosis and treatment and a reduction in the number of patients lost to follow-up.[77]

Patient navigation was initially introduced by Dr. Harold Freeman in early the 1990s as a strategy to increase access to recommended cancer screening among medically disadvantaged populations in Harlem. His initial study population was 70 percent African American and 26 percent Hispanic. Navigation was provided to help patients access free breast cancer screening. Those who screened positive were navigated through the diagnostic workup and to the onset of treatment. He found that navigated patients who screened positive for breast cancer presented at earlier stages of breast cancer (41 percent at stage 0 or 1) compared to 6 percent for historical controls; and the 5-year survival rate of navigated patients with breast cancer was 70 percent, compared with 39 percent of controls.[78, 79]

According to Paskett et al., the strongest evidence that patient navigation improves access to healthcare is found in screening programs for breast, colorectal, and cervical cancer. Some evidence indicates that patient navigation improves outcomes by reducing the time from diagnosis of cancer to initiation of treatment, or reducing the number of patients lost to follow-up between screening and treatment onset. How much patient navigation improves outcomes is often unclear because most studies employ several interventions concurrently with patient navigation, and several studies have methodological limitations. No studies were found that analyze the effectiveness of patient navigation in survivorship care.[77] Still, Pratt-Chapman et al. argue that survivorship navigation can reduce barriers and improve access to care for disadvantaged populations.[80]

Natalie-Pereira et al. propose patient navigation as an effective tool to reduce disparities in health and health care, with the potential to impact factors involved in prevention and early detection, health care access and coordination, insurance coverage and continuity, as well as diversity and cultural competency.[81]

Hauser et al. advocate that hospice and palliative care be included in patient navigation, specifically to improve symptom relief, communication efficacy, transitions of care, and access to palliative care, hospice, and bereavement care for diverse patients and families.[82]

Research is ongoing to evaluate the effectiveness of patient navigation used at all stages of the cancer treatment continuum.[83]

Community Health Workers

With their skills as culturally competent mediators, Community Health Workers (CHWs) act as brokers between providers of health services and the members of diverse communities. They support the prevention and control of chronic disease, including cancer, and assist in patient self-management. Seven core roles include:

- Cultural mediation between communities and healthcare systems;
- Providing culturally appropriate and accessible health education and information;
- Ensuring that people get the services they need;
- Providing informal counseling and social support;
- Advocating for individuals and communities;
- Providing direct services and administering health screening tests; and
- Building individual and community capacity.[84]

CHWs also: provide outreach to individuals in the community setting, educate patients and families on the importance of lifestyle changes and treatment adherence, and help with patient navigation. This model has been employed successfully in the management of diabetes and hypertension, and was used extensively by the National Breast and Cervical Cancer Early Detection Program to provide screening and diagnostic exams for breast and cervical cancer to low-income women who had little or no health insurance. CHWs also function as lifestyle coaches at centers such as the YMCA. Eighteen of the 40 CDC-funded Racial and Ethnic Approaches to Community Health (REACH) coalitions utilize CHWs to reduce health inequities and improve health outcomes in at-risk populations.[84]

Program of All-inclusive Care for the Elderly (PACE)

The Program of All-Inclusive Care for the Elderly (PACE) is a capitated government-sponsored benefit (authorized by the Balanced Budget Act of 1997) that features a comprehensive service delivery system and integrated Medicare and Medicaid financing. The program is modeled on the system of acute and long-term care services developed by On Lok Senior Health Services in San Francisco, California. The model was tested through CMS (then called the Health Care Finance Administration) demonstration projects that began in the mid-1980s. The PACE model addresses the needs of long-term care clients, providers, and payers. For most participants, the comprehensive service package permits them to continue living at home while receiving services, rather than be institutionalized. Capitated financing, wherein a defined, periodic, per-patient payment is provided for each enrollee, allows providers to deliver all of the services that participants need rather limiting coverage to those reimbursable under the Medicare and Medicaid fee-for-service systems.[85] Tan et al. examined outcomes for the 12 nationwide demonstration sites of the PACE program, comparing African Americans vs. Whites; after adjusting for baseline co-morbid conditions, functional status, site of care, and demographic characteristics, they found that African American patients had a lower mortality rate than Whites, and were more likely to improve in ADL function than Whites in the first year of the program.[86]

Community-Based Collaborative Care Networks

Section 10333 of the Patient Protection and Affordable Care Act directs the Health and Human Services secretary to award grants to support Community-Based Collaborative Care (CBCC) Networks. CBCC Networks are consortia of providers with a joint governance structure that provide a comprehensive range of coordinated and integrated health care services for low-income patient populations or medically underserved communities. They must include at least one hospital and all federally qualified health centers in the area.[87, 88] Carthon reviewed historical

applications of this model, and found that two Philadelphia-based civic associations were successful in developing networks among community members/organizations and health providers to improve the health of African American community residents.[89]

Evidence-Based Care Transitions Models

These are evidence-based, state pilot programs funded by the Agency on Aging and Centers for Medicare and Medicaid Services. They smooth the transition from one healthcare setting to another and, when successful, reduce re-hospitalizations and other adverse events.[90]

The models share:

- Interdisciplinary communication and collaboration,
- Patient/participant activation, and
- Enhanced follow-up.

The models include:

- Hospital-to-Home Transition Models (Coleman Model, Naylor Model, Boost, The Bridge Program) that utilize coaches (nurse, social worker, or both) and/or standardized discharge processes. Patients are followed for a specific time from pre- to post-discharge (3 days to 3 months).
- Practice-based Care Coordination Model (Guided Care, Geriatric Resources for Assessment and Care of Elders [GRACE]) where the primary care provider is the base of operations, and either a nurse (or a nurse practitioner) and a social worker coordinate care for chronically ill elders.

Several of the pilot programs have been carried out among diverse populations, with generally favorable results measured by perceived quality of care delivered and provider satisfaction. For instance, the Guided Care Program implemented at Johns Hopkins University is split about equally between White and African American participants.[91, 92] Some models, such as the Boost Program in the Piedmont Hospital in Atlanta, GA, have successfully reduced 30-day readmissions after hospital discharge, reduced the length of hospital stays, and reduced mortality among participants compared with historical controls.[93]

In a randomized clinical trial where 45 percent of patients were African American, Naylor et al. compared a program for hospitalized elders (n=186), where comprehensive discharge planning and home follow-up was led by an advanced-practice nurse, to a usual practice control group (n=177). Patients in the program had increased time to readmission, were less likely to be readmitted to the hospital (20.3 percent vs. 37.1 percent), less likely to have multiple readmissions (6.2 percent vs. 14.5 percent), and had fewer hospitalization days per person (1.53 vs. 4.09). The program cut Medicare costs in half ($600,000.00 in the intervention group compared with 1.2 million dollars in the control group).[94]

Patient-Centered Medical Home Model

In 2004, the American Academy of Pediatrics, the American Academy of Family Physicians, the American College of Physicians, and the American Osteopathic Association defined

comprehensive guidelines for the Patient-Centered Medical Home (PC-MH) and recommended it as a preferred central approach to improve health care in the United States. This model was also endorsed by the American Academy of Pediatric Dentistry. The Patient-Centered Medical-Dental Home proposes a model of care focused on the patient, who has a personal physician or dentist leading a team of clinical care providers to deliver comprehensive, coordinated, culturally competent, evidence-based care to address all of a patient's health care needs.[95]

The principles of the PC-MH include:

- *Personal physician* – each patient has an ongoing relationship with a personal physician trained to provide first contact, followed by continuous and comprehensive care.
- *Physician directed medical practice* – the personal physician leads a team of health professionals, at the practice level, who collectively take responsibility for the ongoing care of patients.
- *Whole person orientation* – the personal physician provides for all the patient's health care needs or takes responsibility to arrange for appropriate care with other qualified professionals. This includes care for all stages of life: acute care, chronic care, preventive services, and end-of-life-care.
- *Coordinated and/or integrated care* across all elements of the complex health care system and the patient's community. Care is facilitated by registries, information technology, health information exchanges and other tools to assure that patients receive the care indicated, when and where they need and want it, in a culturally and linguistically appropriate manner.
- *Quality and safety* are the hallmarks of the medical home.
- *Enhanced access* to care is available through systems such as open scheduling, expanded hours and other new options to enhance communication between patients, their personal physician, and practice staff.
- *Payment* appropriately recognizes the added value provided to patients who have a patient-centered medical home.

The PC-MH shares characteristics with the Chronic Care Model, including team-based care, importance of information technology, promotion of an active partnership with an educated patient, and coordination of care. The PC-MH is broader in focus, however, with coordinated management of each of the patient's medical conditions rather than management of a single chronic illness.

Some evidence exists for the clinical and cost effectiveness of the PC-MH, and it holds promise for reducing disparities in healthcare among disadvantaged populations.[96, 97]

Comprehensive Healthcare Reform: The Patient Protection and Affordable Care Act

The Patient Protection and Affordable Care Act (PPACA) was signed into law by President Obama on March 30, 2010. The PPACA is designed to usher in sweeping healthcare reform that will improve healthcare access, quality, efficiency and coordination, and also stem rising healthcare costs.[98]

Accountable Care Organizations

Section 3022 of the Patient Protection and Affordable Care Act directs the Secretary of Health and Human Services to implement an integrated care delivery model in Medicare using Accountable Care Organizations (ACOs).[99]

An ACO is a recognized legal entity under state law, comprised of a group of ACO participants (providers of services and suppliers) that have established a mechanism for shared governance and who work together to coordinate care for Medicare fee-for-service beneficiaries. ACOs enter into a 3-year agreement with CMS to be accountable for the quality, cost, and overall care of those traditional fee-for-service Medicare beneficiaries who may be assigned to it. This is a mechanism by which providers from different segments of the healthcare system care for a Medicare beneficiary over time and across care settings, while sharing accountability for cost, quality, and outcomes of care. The ACO will be held accountable by Medicare for meeting or exceeding quality performance standards; providers share in cost-savings achieved, or become jointly liable for losses. By thus aligning incentives in a rational way, the ACO mechanism is designed to assure that individuals will receive better-quality, more coordinated, and less costly care with improved clinical outcomes.[99]

Medicare currently does not prescribe what form an ACO should take, or which providers must be included. The American Academy of Hospice and Palliative Medicine has submitted comments to CMS in support of the concepts of value-based purchasing and shared savings to improve quality, coordination and cost efficiency, while also supporting requirements to promote evidence-based medicine, caregiver engagement, and accountability. The Academy has made the case for how palliative care providers and organizations, including hospices, will be essential if ACOs are to achieve the stated goals. It also recommended that quality measures appropriate to palliative care be included.[100] Similarly, the National Hospice and Palliative Care Organization— the largest nonprofit membership organization representing hospice and palliative care programs and professionals— has issued comments supporting the ACO concept, while advocating that hospice and palliative care be included in the model. They called for the use of quality measures appropriate to those receiving hospice care, while advocating that measures no longer improving patient well-being be removed.[101]

Our current health system in the United States is in a state of flux, and what lies ahead is uncertain. Although all stakeholders share broad common goals— improving quality and access to care— the specifics of how to accomplish them have yet to be determined. Healthcare providers have an obligation to advocate for improved access to and coordination of health care, and also for the best possible outcomes for their patients and families faced with life-threatening illnesses such as cancer.

Summary

Comprehensive cancer care integrates palliative care beginning at diagnosis, which helps interdisciplinary healthcare workers address issues that cause suffering and impact the quality of life for patients and their families.

African Americans currently suffer disparities getting comprehensive cancer care, including palliative and hospice care, though mechanisms and systems exist that can significantly reduce these disparities. Interdisciplinary healthcare providers can be key advocates within the healthcare system to incorporate palliative care throughout the spectrum of comprehensive

cancer care and to remove barriers of access to quality comprehensive cancer care. Healthcare providers should also advocate to include hospice and palliative care as future healthcare delivery systems evolve.

Key Take-Home Points

1. Comprehensive cancer care integrates palliative care beginning at diagnosis.
2. Palliative care defines a model across the full spectrum of cancer care to relieve suffering and improve quality of life. What we now generally term *palliative care* has grown out of, and includes, hospice care.
3. Multiple delivery models include applying core palliative care skills by health providers, and expert services by palliative care specialists, when they are needed.
4. Hospice should be a routine part of comprehensive cancer care. It is not an alternative to standard care— rather, it successfully completes good cancer care for the patient with incurable disease.
5. Hospice organizations will provide ongoing bereavement care that can help families rebuild their lives after the death of the patient.
6. Most insurance, including Medicare and Medicaid, includes a specific capitated hospice benefit. Other palliative services are currently reimbursed under traditional payment guidelines.
7. African Americans can benefit greatly from better access to hospice and palliative care services.

Patient Resources

American Cancer Society Patient Navigator Programs

Main number: 1-800-227-2345 Ask for information about Patient Navigation Programs.

Health Professional Resources

National Cancer Institute: Cancer Health Disparities
http://www.cancer.gov/cancertopics/disparities Accessed 7/10/12

National Cancer Institute Center to Reduce Cancer Health Disparities
http://crchd.cancer.gov/ Accessed 7/10/12

Centers for Medicare and Medicaid Services: Shared Savings Program
https://www.cms.gov/sharedsavingsprogram/ Accessed 7/10/12

Agency for Healthcare Research and Quality:
2010 National Healthcare Quality & Disparities Reports http://www.ahrq.gov/qual/qrdr10.htm
Accessed 7/10/12

Care Coordination, Quality Improvement. http://www.ahrq.gov/clinic/tp/caregaptp.htm
Accessed 7/10/12

Center to Advance Palliative Care
www.capc.org Accessed 7/10/12

National Hospice and Palliative Care Organization
www.nhpco.org Accessed 7/10/12

Improving Chronic Illness Care
http://www.improvingchroniccare.org/index.php?p=The_Chronic_Care_Model&s=2 Accessed 7/10/12

Duke Institute on Care at the End of Life: Resources
http://divinity.duke.edu/initiatives-centers/iceol/resources Accessed 7/10/12

Administration on Aging: Aging & Disability Resource Centers Evidence-Based Care

Transitions

http://www.aoa.gov/AoA_programs/HCLTC/ADRC_CareTransitions/index.aspx Accessed 7/10/12

Appendix: History of Hospice Care

Time period	Development
Prehistory to Roman Era	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. Death rates for mother and child were extremely high; 40-60 percent of children died before age 5. Few people 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/The Crusades	With the spread of Christianity, monasteries started to take in the sick and those who were 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, the Crusades began around 1095 and recurred through the end of the 17th century; there were many weary travelers who found places of refuge in monasteries and nunneries. Many were in ill health and many spent their last days being 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

Time period	Development
	who were ill and couldn't afford other accommodations often died there.
Reformation	In England and Northern Europe these de facto hospice services 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 seven 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 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.
1950–'60s	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.
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 who appointed her a Dame of the British Empire. Dame Cicely Saunders died on July 14, 2005.
1974	In 1974, Connecticut Hospice opened the first hospice in the United States. It was funded by NCI for the first 3 years. See http://www.hospice.com/pages/about/about.html ; accessed June 19, 2012.

In the United States, early hospice services were provided almost exclusively in patients' homes. The early U.S. hospice movement was created outside of the established health care system. In contrast with the United Kingdom, these teams were usually led by nurses and/or volunteers.

After visiting St. Christopher's Hospice, Dr. Balfour Mount, a Canadian urologic surgeon, returned to McGill University in Montreal, Quebec, to open one of the first "hospice" units in Canada.

In the French language, the word *hospice* for centuries had meant a place of last resort for the poor and the derelict. As an alternative term to *hospice* that would describe a place to care for the dying, Balfour Mount coined the term *palliative* |

Time period	Development
	care (*soins palliatifs* in French) that would be acceptable to both English-speaking and French-speaking Canadians.
1975	A palliative care unit opened at the Royal Victoria Hospital, Montreal, Canada, and at the same time a terminal care unit opened at St. Boniface Hospital, Winnipeg, Manitoba, Canada, which was later named "a palliative care unit."
1980	Twenty-six sites in the United States were selected to demonstrate the financial efficiency and humanitarian benefits of hospice care. The pilot project was so successful, it was soon presented 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.
1990s	It is important to know the history of the movement and its 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. 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.
1993	Establishment of the National Board for Certification of Hospice and Palliative Nurses. The Board now offers certification in: Advanced Certified Hospice and Palliative Nurse Certified Hospice and Palliative Nurse Certified Hospice and Palliative Pediatric Nurse Certified Hospice and Palliative Licensed Nurse Certified Hospice and Palliative Nursing Assistant Certified Hospice and Palliative Care Administrator
1996	The American Board of Hospice and Palliative Medicine was established.
2000s	The hospice care industry in the United States has grown and become a significant provider of end-of-life care to Americans. As of 2010, there were over 3,400 Medicare-certified hospice programs in all parts of the nation. They cared for 42 percent of those who died (including 40 percent of those dying

Time period	Development
	from cancer).
	Sixty-three percent of hospitals with more than 50 beds had a palliative care program in 2009. Ninety-eight percent of NCI-designated Cancer Centers and 78 percent of non-NCI cancer centers reported having a palliative care program in 2009.
2006-7	ACGME approved an accreditation process for hospice and palliative medicine fellowship training programs; ABMS established a subspecialty in hospice and palliative medicine co-sponsored by the American Boards of Internal Medicine, Anesthesiology, Family Medicine, Physical Medicine and Rehabilitation, Psychiatry and Neurology, Surgery, Pediatrics, Emergency Medicine, Radiology, and Obstetrics and Gynecology. In 2007 The American Osteopathic Boards of Family Medicine, Internal Medicine, Neurology & Psychiatry, and Physical Medicine & Rehabilitation began to offer the Certificate of Added Qualification in hospice and palliative medicine.
2009	National Board of Social Workers began to offer the Advance Certified Hospice and Palliative Social Worker certificate.

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Self-Assessment Questions

Plenary 2-AA: Models of Comprehensive Care

1. Core services of hospice under the Medicare Hospice Benefit include:

   ☐ a). Interdisciplinary care from physician, nurse, social services, chaplain, volunteer
   ☐ b). Bereavement counseling for the family
   ☐ c). Medications, medical equipment, and supplies
   ☐ d). All of the above

2. African Americans, when compared with Whites are:

   ☐ a). More likely to use hospice
   ☐ b). More likely to utilize aggressive care at the end of life
   ☐ c). Less likely to prefer informal advance care planning
   ☐ d). More likely to desire to die in the home setting

3. African Americans who were enrolled in the Advanced Illness Management (AIM) Program:

   ☐ a). Were referred to hospice at decreased levels compared with those not enrolled
   ☐ b). Did not utilize hospice, as the AIM Program met all their end of life needs
   ☐ c). Were referred to hospice at increased levels compared with those not enrolled
   ☐ d). Were hospitalized more frequently than those not enrolled

4. Accountable Care Organizations (ACOs) as defined in Section 3022 of the Patient Protection and Affordable Care Act include which of the following elements?

   ☐ a). A group of participants (providers of services and suppliers)
   ☐ b). A mechanism for shared governance
   ☐ c). Accountable for care quality, coordination, and cost
   ☐ d). All of the above

Self-Assessment Answers

Question 1. The correct answer is: d)

Medicare Conditions of Participation specify that all of the above are required core services to be supplied by Medicare certified hospices.

Question 2. The correct answer is: b)

On a population basis, African Americans are less likely to enroll in hospice, more likely to prefer aggressive interventions at life's end, more likely to prefer an informal advance care planning process as opposed to a formal advance care planning process, and less likely to prefer dying at home (50% vs. 90%) than Whites. Avoid making assumptions of individual preferences based on population estimates.

Question 3. The correct answer is: c)

AIM is a bridge program of the Sutter Visiting Nurse Association and Hospice at Emeryville, CA branch. Between 2003 and 2005, among African Americans enrolled in the AIM program, they found hospice referrals increased 60% to 73% compared with usual care patients. The AIM program has also documented that for patients enrolled for at least 3 months, there were 63% fewer hospitalizations and an overall average savings of $2,000 per patient per month.

Question 4. The correct answer is: d)

An ACO is a recognized legal entity under State law and comprised of a group of ACO participants (providers of services and suppliers) that have established a mechanism for shared governance and work together to coordinate care for Medicare fee-for-service beneficiaries. The ACO agrees to be accountable to the Centers for Medicare and Medicaid Services for the quality, cost, and overall care of traditional fee-for-service Medicare beneficiaries who may be assigned to it.