

## MODELS FOR CARE

- We have defined suffering and built a conceptual framework for its relief and for the enhancement of quality of life. Nevertheless, health care institutions are critically important to our system of care
- It is now widely recognized that cognitive information such as that covered in this curriculum is necessary, but not sufficient, to deliver good end-of-life care to our patients
  - Pernicious and sometimes perverse systems of care have developed that reinforce the status quo
  - Our current systems of health care were not conceived within a comprehensive framework for relieving suffering
  - As different studies have demonstrated, current systems may, in fact, promote suffering, particularly for those who are near the end of life
- Consequently, clinicians must often be creative in meeting the broad needs of their dying patients
  - Because physicians remain a key advocate for patients and their families within the health care system, you may be an agent for change within the health care systems in which you work
  - Urge yourself and your colleagues to insist on these elements for your patients. It is what you will want for yourself and your family when you need care
- An approach is developed for fostering health care systems that work well for dying patients. To prepare for this, it is important to understand the concept of palliative care
- The sections below cover the following essential topics:

### What is Palliative Care?

- 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 2 important features:
  - The multifaceted, multidimensional nature of the experience of living with an acknowledged time-limiting illness
  - The priority of working as a team to achieve the relief of suffering and facilitate the enhancement of life
- The importance of supporting the family and patient as a unit is clear
- An issue that continues to be debated has been whether the term **palliative care** should refer to a discrete period at the end of life, or whether it is a concept that is relevant wherever suffering accompanies illness

### Palliative Care—Definition 1

"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."

Institute of Medicine 1998

### Palliative Care—Definition 2

"The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment."

WHO 1990

### Palliative Care—Expanded Definition

- Affirms life and regards dying as a normal process
- Neither hastens nor postpones death
- Provides relief from pain and other distressing symptoms
- Integrates the psychological and spiritual care, fostering opportunities to grow

- Offers an interdisciplinary team to help patients live as actively as possible until death
- Offers a support system for the family during the patient's illness and their own bereavement

WHO 1990

- Some have depicted a continuum of care graphically, showing how disease-modifying therapy with curative, life-prolonging or palliative intent
  - Wanes as the illness progresses toward the end of a person's life
  - Tapers to nonexistence as active dying begins in the last hours of life
- Comfort-oriented symptom control and supportive care increase over time, maximizing as dying culminates in death. Often people receive this care through a hospice program
- Anticipatory grief over many different losses begins before death
- Bereavement continues for some time after death
- Palliative care provides for all 3 phases for the family as well as for the patient

### What is Hospice? History of the Hospice Movement

- In the 19th 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 listening to first 1 patient, then many patients, Cicely Saunders founded St Christopher's Hospice south of London, England, as a new kind of hospice
  - It was a place where a team of professionals in a single institution pursues the medical, emotional, social, and spiritual care of patients and families
  - Most importantly, it is an academic hospice, where education and research are pursued simultaneously with patient care
- What we now generally term **palliative care** has grown out of, and includes, hospice care
- In the short 30 years since the founding of St Christopher's, what has been called the hospice movement developed on the fringes of institutional medicine
- The response from institutional medicine was perhaps understandable—no conventional system likes to be challenged by a "movement" that is critical of the mainstream
- Nevertheless, in the US, it has developed widely, primarily as programs of care for patients at home
  - The Health Care Financing Administration (HCFA) reported in 1994 that there were:
    - 1682 Medicare-certified US hospices
    - serving nearly 20% of patients dying in the US
  - Many more have sprung up since then
  - The fruits of this movement are receiving considerable and well-deserved recognition

**Hospice in the U.S.** In the United States, the single word hospice is used to describe 4 different concepts

#### 1. A site of care for the dying

- Free-standing facility
- Dedicated unit within a hospital or nursing home

#### 2. An organization or program

- Coordinates and/or provides care to dying patients and loved ones
- Operates in a variety of settings but usually focused on the patient's home

#### 3. An approach or philosophy of care

- An approach to care that is integrated into all manner of care sites and practices, including intensive care units if necessary
- In this sense it is synonymous with palliative care

#### 4. A system of reimbursement

- Benefit available to Medicare beneficiaries
  - Subject to the rules and regulations promulgated by HCFA to govern that federal program
  - Unfortunately, the use of a single term for all of these meanings has led to some confusion
- For many patients, the term still means a place to go to die
- For many physicians, the term 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 misconceptions persist even though the majority of patients enrolled in hospice programs live in their own homes until they die, because that is where they want to 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
- It is incumbent upon all physicians to understand the concepts, as well as the details, so that their patients get the best possible care. Just as physicians work with their local hospitals, nursing homes, and other sites where health care is delivered, so physicians need to understand and work with their local hospice agencies so that the best possible care is administered

### **Standards for Hospice and Palliative Care**

The hospice industry in the US is regulated by standards and guidelines promulgated by HCFA and measured and regulated by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). These standards may also be applied to palliative care. These standards and guidelines cover the following principles:

#### **Access to Care**

- Hospice agencies cannot always provide care to all comers, but the obligation to care for the dying is such that turning patients away is intolerably difficult for many of them
- The best hospices have tended to expand rather than limit access
- Oregon is currently aiming for universal access to hospice care
- Medicare benefits are not panoramic and should be well understood if you are to provide the best benefits available to patients who need them

#### **Informed Choices**

- Delivery of care should meet the patient and family expectations as much as possible
- Relevant expectations include:
  - Having access to services
  - Being informed and in control of treatments to relieve pain and other physical symptoms
  - Receiving psychological, social, and spiritual support
- Patients will be treated with the family as a unit of care with a right to:
  - Participate in choice of settings
  - Choose among options for interventions including referrals for intervention
  - Have adequate information sharing and confidentiality from other parties
  - Have absence of discrimination
- Bereavement and grief support for survivors will continue even after the death

#### **Symptom Management and Support**

- Symptom management, mental and spiritual health, and social support often require different kinds of programs that were not anticipated when the Medicare hospice legislation was written in 1982
- Many hospices have worked with their communities, hospitals, and physicians to develop programs that stand outside the Medicare-regulated hospice delivery model in order to meet the needs of patients and families
- These have included palliative care units, bridge programs, and the like

#### **Grief and Bereavement Support**

- Support of the patient with anticipatory grief or grief over lost function
- Support of the family for some time after bereavement

## Transfer Options, Continuity of Care

- Sometimes patients, with their families and physicians, decide that medical interventions that require hospitalization in an acute care facility are needed; transfer from home or a hospice facility is necessary
- This is possible without jeopardizing the patient's place in hospice
- As far as possible, continuity of providers between settings should be available

## Evaluation, Research, and Education

- Hospice care is a mature enough field that there is a responsibility for systematic evaluation, research, and education of incoming professionals in the same way that we are introduced to the rest of the spectrum of health care
- Numerous committees, commissions, professional associations, and agencies are working with the nation's medical schools and graduate and postgraduate programs to be sure that physicians are well-educated in:
  - Their role in palliative care
  - The way in which they can use hospice to promote best end-of-life care for their patients
- Physicians are urged to support those developments, as well as the initiatives to critically study best practices so that the entire system may improve

## Making Hospice a Routine Aspect of Medical Care

- It is now up to us in the medical mainstream to make use of hospice as a routine part of medical care in the US
- Hospice should no longer be viewed as an alternative to standard care; rather it represents an important resource in the completion of good medical care
- The challenge is to do this without losing the quality and safe personal touch of smaller systems of care

## Five Important Themes in End-of-Life Care

- 1. Relief of suffering** is a cornerstone goal of medical care
- 2. Palliative care** is an extensive and complex area of expertise in medicine that has much to contribute to patients comfort and quality of life
- 3. Families and the community** play an essential role in the care and well being of patients as they face dying
- 4. Teamwork** on the part of the interdisciplinary professional team is an integral part of providing whole-person end-of-life care
- 5. Advocacy** - the physician is a critical advocate not only for the individual patient but also for creating the conditions in which to provide the care that patients need

### 1. Relief of suffering. Advances in the Relief of Suffering

- One of the most basic motivations for the profession of medicine, and the impetus for all of health care, is the relief of human suffering
- It has only been in the past few decades that there has been a concerted effort to understand the nature of suffering and to develop the conceptual, technical, and practical frameworks to relieve it
- In many ways, this has been made possible and necessary by the scientific advances in medicine
- Now, in the late 20th century, we appreciate both the promise of understanding human biology, as well as its limits
- Most of us will die after a long period of illness that will affect each of our dimensions of human experience:
  - Physical
  - Psychological
  - Social
  - Spiritual

## Meeting Patient Expectations

- In the US, patients expect that the medical profession has a deep understanding of both the nature of suffering and how to relieve it
- However, this expectation goes largely unmet in contemporary America

- Some of the dissatisfaction with modern medical care may relate to this unmet need
- It is one of the primary goals of the EPEC project to help the medical profession meet this public expectation

## 2. Palliative care

- The skills that physicians use to relieve suffering and improve quality of life form a rapidly growing medical endeavor that has been termed **palliative medicine**
- We have tried to correct the misperception that palliative care is the absence, or withdrawal of medical care. We hope that the word "only" will fall out of the statement, "he only wants comfort care."
- Palliative care is a **positive, humanistic**, and **technically** powerful part of the general practice of medicine
  - In fact, never before in the history of medicine have we had the power and understanding to relieve suffering to the degree that is possible today
  - To realize the full potential requires an understanding of advanced pathophysiology in every area of medical specialization
  - It has a full complement of areas of special sophistication (e.g., pain and other symptom control), each with a growing literature
  - In addition, palliative care has its own demands for well-honed human skills
- We must have the competence and the will as a profession to be certain that our patients do not suffer unnecessarily

## 3. Families and the community

- When facing death, patients often need and want closer connections to their loved ones so they can complete their personal affairs and relationships
- Personal aspects of culture and meaning can be particularly important for patients and families when they are confronting death, and these significant aspects of life exist within the context of a network of people in a community
- In addition, families can help with decision-making, especially when the patient is no longer fully competent
- Either way, it is more important than ever to allow the patient to be the center of care along with his or her family

## 4. Teamwork

- Relief of suffering requires understanding and support of the **whole person**
  - It is the whole person who lives and dies, not just his or her physiology
- Support of the whole person requires teamwork. No one person, no matter how skilled, can meet all of the needs of the patient and family facing the end of life
- Relieving suffering in the physical, psychological, social, and spiritual domains requires a team effort that includes the combined efforts of:
  - Physicians
  - Nurses
  - Social workers
  - Chaplains
  - The host of other medical disciplines
- Hospice care is the most developed system of interdisciplinary palliative care for patients at the end of life
  - However, this interdisciplinary approach to care does not have to be limited to patients enrolled in a hospice program
  - It is a robust and positive way to relieve suffering and enhance quality of life that needs to be woven into the fabric of our mainstream health care systems

## 5. Advocacy. Is the current system one in which we would like to be cared for when we reach the end of our lives?

- Much of what has been covered in this education program is not widely practiced or available to patients in the United States
- Besides acquiring the knowledge, attitudes, and skills necessary to administer good end-of-life care, as health care professionals we need to use our moral persuasion to influence the system and advocate for high quality care for our patients

- There are a host of reasons why needless suffering persists despite the power of palliative care in one of the most advanced health care systems in the world
- Until recently, one of the greatest barriers has been the absence of health care professional advocacy demanding the best possible end-of-life care for their patients
- We should expect the best, both as health care professionals, and as human beings who will one day face the end of life ourselves
- ***Is the current system one in which we would like to be cared for when we reach the end of our lives?*** If not, then it is our duty as health care professionals to advocate for a system that provides good end-of-life care, both for our patients and for us when we need it

**Barriers to Good End of Life Care.** There are 4 areas that we can highlight where barriers to good end-of-life care reside:

### **Institutional Barriers**

- Health care institutions may or may not facilitate good end-of-life care
- The cultures that develop within these institutions are complex and not easily changed
- Although it is beyond the scope of this website to discuss these issues in detail, there are numerous projects and studies that aim to understand and change institutional practice so that good end-of-life care can be provided
- Examples of institutional barriers are:
  - Policies that prohibit families from freely visiting dying patients
  - Policies that insist that a dead body be moved within 4 hours of death
  - Absence of pain and symptom management services
  - Absence of policies that promote adequate assessment and reporting
- Change may be best accomplished by identifying and targeting small components of the institution for change

### **Regulations**

- There are a host of regulations at many levels that inhibit good end-of-life care
  - Institutional
  - Local
  - Regional
  - State
  - National
- Triplicate prescription programs for Schedule II drugs have been demonstrated to:
  - Limit the prescription of appropriate analgesics
  - Foster the prescription of inappropriate analgesics
- Existing regulations have led to a pervasive fear of prosecution of physicians for prescribing medications aimed at the relief of pain and symptoms
- Institutional policies and regulations may prohibit a patient from refusing a feeding tube or insisting on moving to another institution to die in order to avoid state scrutiny of their care
- Federal regulations are now restricting access of patients in advanced phases of illness to home care and hospice services at precisely the same time that there is increased focus on the need for these services

### **Reimbursement**

- Health care system administrators and physicians are influenced by the financial conditions attached to their activities
- High-technology care that is procedurally based remains the most remunerative
- Cognitive and counseling activities remain the least remunerative
- Yet, palliative and hospice care relies heavily on the latter skills
- Despite the well-documented gaps in contemporary end-of-life care, current utilization review guides are silent on the legitimate needs of patients and families near the end of life
- Some commercial insurers have gone so far as to insist that any patient with a do-not-resuscitate order must, by definition, not need to be in an acute care setting

### **Individual Attitudes**

- Finally, attitudes toward end-of-life care may represent one of the biggest barriers
- There are still patients, families, and professionals who feel there is "nothing more to do" for a patient who has a life-threatening prognosis
- Society in general still tends to shun the dying and deny attention to the suffering
- It is difficult to be around death, even for professionals, and many walk away in the face of unrelieved suffering
- The first step to improving any problem is to acknowledge the problem exists. If it is deemed unimportant, then no progress can be expected

### **Health Care Professionals' Personal Support Needs**

#### **Patients are asking health care professionals to do better**

- Unfortunately, physicians are among the individuals thought most likely to abandon care as the prognosis declines, or so patients, other professionals, and the public perceive
- Perhaps it is because of our extra obligation as physicians to stay present and to continue care
- Either way, we must address this widely acknowledged duty to do better

#### **Health care professionals need a forum for candid discussion of experiences**

- Many health care professionals who engage in extensive end-of-life care find it important to provide for their own personal care
- This may occur in a variety of settings:
  - Professional counseling
  - Religious or spiritual learning
  - Supportive personal or collegial relationships where experiences can be candidly discussed

#### **Transference is powerful**

- In order to be comfortable around the dying it may be necessary to be comfortable with the fact of our own eventual mortality
- There is not one health care professional, indeed not one person, who does not have a reaction to the fact of mortality and to our own mortality as a part of that
- The connection between the feelings of a patient and the feelings of a professional are known to be profound; transference is an entire area of inquiry in psychology and psychiatry
- Knowing our own emotional relationship to suffering and dying and maximizing the health of that relationship are essential

#### **Professional distance and empathic closeness must balance**

- Finding the correct balance between engaging in the patient's experience and keeping a professional distance is the key to empathic and effective end-of-life care

#### **Health care professionals working with persons at the end of life must be self-aware**

- In assessing how to best support each one of our own personal abilities to provide care to patients facing the end of life, consider for yourself ***how you would characterize your own responses to patients who were suffering and dying in your past personal and professional experiences***
  - Most health care professionals, even the best, will be able to identify negative emotions
  - Most will also be able to identify positive emotions
- Some of the health care professionals who provide model care to patients near the end of life find the experience deeply gratifying
- In considering yourself and your end-of-life care, ask yourself how you would characterize your own negative and positive responses to dying patients and their families

### **Confronting Barriers**

- If we are to advocate for the best possible care for our patients, we need a clear idea of the barriers that must be overcome to get there
- Experience has shown time and again that barriers can be confronted and resolved
- In order to implement change, it helps to consider possible plans with colleagues

**Creating your own IOU list - An exercise on confronting barriers**

Action Plan	
Barrier	Plan

**1. Identify changes needed and potential barriers**

- Consider for a minute what things in your practice setting need changing, or present barriers, to good end-of-life care for patients and their families
- On the left side of a piece of paper, list the most important issues
- On the right side of the page indicate the concrete or specific plan that would help overcome that barrier

**2. Identify the source of the barriers**

- Now that you have written down potential barriers, look at your list and identify which barriers are:
  - **Institutional**, meaning they are barriers that are present as a result of the organization or system in which you work or by legal mandate. Put an "I" next to those barriers that are institutional
    - These barriers can only be addressed by your interaction at an institutional level
  - A result of **"others"** actions, beliefs, or concerns. "Others" may include partners in your practice, other members of the health care team, community members, and of course, your patients and their families or significant others. Put an "O" next to those barriers that you believe are a result of "others"
    - These are barriers that you might influence as a role model or be able to influence in an indirect way
    - They are not things that are directly in your power to change
  - **Personal** - if the remaining barriers are not institutional and they cannot be linked to "others" as discussed a moment ago, then consider these to be your barriers that you can influence, personally. Personal barriers can be based on personal values, expectations, plans, or beliefs. Examples might be attitudes toward death or poor end-of-life care. Place a "U" next to those barriers you believe are related to your own personal values

**"I" = Institutional "O" = Others "U" = Personal**

- As you can see, we have conveniently created an IOU list. This is your customized IOU list for discussion with colleagues and that we would ask you to address when you return to your practice so that you can provide optimum care for your patients at the end of life

**3. Share your ideas with others**

- Encourage collective discussions with colleagues about barriers that exist in your practice environment
- Brainstorm solutions with colleagues as a group

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