

## ROLE OF HOSPICE, PALLIATIVE CARE

### Growth of Hospice Agencies in the United States

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

### Hospice Care Underutilized

- However, even with this growth, hospices still care for only a minority of dying patients:
  - 11% of all deaths in the US in 1993 occurred in hospice settings
  - This figure rose to 17% in 1995
  - Of those patients dying of cancer in the US, only about 40% are ever referred to a hospice agency
    - For example, 35% of all dying patients in Florida die with hospice care
    - The figure is 40% in Oregon
  - The situation is similar for both adult and pediatric patients
- Although the numbers of patients who die while being cared for by a hospice has been rising slowly, patients generally do not spend enough time in these programs to experience all of the potential benefits
  - In 1995...
    - The median length of hospice stay was 36 days
    - Nearly one fifth of patients died within a week of admission
  - By 1998, the situation was worse. For a variety of reasons, the median length of stay had dropped to less than 20 days

### Efforts to Expand Hospice Care

- More recently, palliative care programs and consult services have been developing across the US to provide the expertise and standards of practice developed by hospice to patients who have needs for symptom control and supportive care earlier in their illness
- These services are targeted to improve the quality of patients' lives while they fight their disease
- Anecdotal experience suggests that good palliative care may help to increase life expectancy in certain patients

### Gaps Between Reality and Desire

- When the current status of care for the dying is summarized, the large gap between the way Americans currently live with life-threatening illness and die, and the way they would like to experience the end of their lives at home becomes apparent
- With the shift to fight death "the enemy" at all cost
  - Treatments have frequently become excessively aggressive
  - Symptoms have not been controlled
  - Patients have lost their independence
- With the shift to care for very ill patients at home
  - Many families have not coped
  - Death far too frequently has occurred in institutions
- While generalizations may be misleading for individual patients and families, they do help to illustrate the general culture of dying in the US and how far it is from the one that is desired by most Americans
- The following table highlights common fears and desires related to death and dying that illustrate the gaps in end of life care in America today

<b>Gaps in End-of-Life Care</b> Large gap between reality and desire	
<b>Fears</b>	<b>Desires</b>
Die on a machine	Die not on a ventilator
Die in discomfort	Die in comfort
Be a burden	Die with family/friends
Die in institution	Die at home

## **Health Professionals and End-of-Life Care: Public Expectations and Training Realities**

### **Public Expectations**

- Despite their concerns, and the general consensus that end-of-life care must improve, the public still maintains an optimistic attitude toward end-of-life care, and especially the role of their physician
- In 1997, an AMA Public Opinion Survey asked, "Do you feel your doctor is open and able to help you discuss and plan for care in case of life-threatening illness?"
  - 74% responded "yes"
  - 14% responded "no"
  - 12% responded "don't know"
- The results showed that the majority of Americans (74%) expect their physician to be confident and competent to provide them with care when they do develop a life-threatening illness

### **Physician Training in End-of-Life Care**

- Until recently, formal education in end-of-life care has been absent from medical school and residency training
- Most physicians feel ill equipped, if not fearful, to care for the dying, as illustrated by the words of Charles F. von Gunten, the EPEC Project Director and EndLink Co-Principal Investigator, reflecting on one of his early experiences with a dying patient:
  - "They said there was 'nothing to do' for this young man who was 'end stage.' He was restless and short of breath; he couldn't talk and looked terrified. I didn't know what to do, so I patted him on the shoulder, said something inane and left. At 7 AM he died. The memory haunts me. I failed to care for him properly because I was ignorant."
- When surveyed by the AMA in 1997–1998:
  - Only 4 of 126 US medical schools required a separate course in the care of the dying
  - While 121 schools reported they covered the topic as part of a required course, the statistic may be misleading
    - It is not at all clear what is meant by "covered"—a lecture, a seminar, or a required reading
- It is certainly clear is that there is still no standardization of education in end-of-life care in medical schools at any level of training
- Without any training, how can physicians become confident and competent in end-of-life care?

### **Barriers to End-of-life Care**

There are many other reasons why end-of-life care in the United States is not what it could or should be

#### **1. Lack of Acknowledgement of Importance**

- Frequently, neither the public nor health care providers acknowledge that end-of-life care is important
- Palliative care is often introduced too late to be effective
- Funding is frequently inadequate to deliver quality palliative care

## 2. Misinformed Fears

- Fears of addiction
- Exaggerated risks of adverse effects
- Restrictive legislation

## 3. Health Professional Discomfort

- Discomfort with communicating bad news and prognosis
- Frequent misunderstanding

## 4. Lack of Skill

- Lack of skill to assist patients and families to negotiate clear goals of care and treatment priorities
- Lack of understanding of patients' rights (or parents' rights if the patient is a child) to decline or withdraw treatment
- Excessive futile intervention may result

## 5. Personal Factors

- Personal fears, fantasies, worries, and lack of confidence around issues of death and dying are prevalent
- Many physicians avoid dealing with patients who are dying because of these issues

## Separating Suffering from End-of-Life

- Experiences toward the **end of life** are so closely associated in peoples' minds with **suffering** that it is hard to use one term without assuming the meaning of both
- The aim of quality end-of-life care is, however, to avoid needless suffering in order to permit experiences that will have positive meaning
- For this to happen it is necessary for everyone involved to understand something about:
  - Suffering
  - Other elements of experience when facing the end of life
  - The types of intervention that can be helpful
  - The resources and teamwork it takes to make these interventions available

## Medical Training Fails to Address Suffering

- As Eric Cassell has written so persuasively, the public imagines that we as a medical profession study the issue of suffering in medical school. Indeed, they expect us to be experts at the relief of suffering
- As he pointed out in a remarkable paper published in the New England Journal of Medicine in 1982, the public would be shocked to learn that this subject doesn't get much attention in medical training
- Conceptual frameworks, approaches for investigating and understanding suffering, and approaches for intervention to relieve suffering have been neglected in the training of physicians

## Conceptions of Suffering

**What does it mean to suffer?** As a medical profession, and as part of a health care system, we must have a conceptual framework within which to work, study, and teach if we are to have a hope of relieving suffering. This is similar to other aspects of medicine—for each disease, each condition for which human beings seek assistance from the health care professions, there is a conceptual framework to investigate, understand, and intervene.

## Suffering as Fragmentation of Personhood

- In an attempt to understand suffering in a way that would permit further study, understanding, and inform clinical care, Cassell outlined a conceptual framework for suffering

- He pointed out that "bodies do not suffer, only persons do"
- Persons are unique and do not experience a disease in the same way
- Persons suffer when their personhood is threatened
- Elements of what it means to be a person include having:
  - A past
  - A present
  - An anticipated future
  - A private life
  - A role
  - A transcendent dimension

### **Suffering as Broken Stories**

- Brody has built on the concept that personhood requires a past, present, and future by noting that human lives are, in a sense, stories
- Our story is our sense of self, and as we face dying, our story comes to closure. In so doing our story transforms into our legacy
- So often, when the patient comes to a physician, the emotional subtext of the patient's complaint can be heard as, "Doctor, my story is broken. Can you fix it?"
- Much suffering by patients facing the end of life can be understood in this perspective
  - The future looks different from before
  - The present is consumed with new physical degeneration
  - The patient's private life is challenged by many new transitions, as is his or her usual role
  - The transcendent dimension may take on a new meaning

### **Suffering as a Challenge to Meaning**

- Suffering is a challenge to meaning
  - Facing the end of life may challenge our usual sources of meaning
  - Loss of meaning is a form of suffering
- Meaning usually must be found in new ways when death approaches
  - As you consider what you would list as the things that give you the most meaning and value in your life, think about how the prospect of disease might affect those
- Byock has described the nature of opportunity brought by suffering and facing the end of life
- These same aspects apply to a child who is dying. In addition to the suffering of the child who is seriously ill, the parents and siblings suffer as they face the loss of this child, and their shared sense of the future

### **Suffering as Total Pain**

- The experience of illness and suffering is not unique to each individual
- In listening to patients with advanced illness describe what their needs and expectations of the medical profession and health care system were for care, Cicely Saunders, founder of the modern hospice movement, conceptualized suffering as "total pain" and as having 4 elements
  - Physical pain
  - Psychological (emotional) pain
  - Social (including practical) pain
  - Spiritual pain
- As you reflect on the things that you value most, and those that would be most important to you in the face of a life-threatening illness, most of them probably fit into these 4 categories

### **The Broad Perspective on Suffering**

- All of the conceptions of suffering described here have one thing in common; they take a very broad perspective from which to view human existence
- As health care providers, it is important that we have a comprehensive framework from which to work if we are to relieve suffering and enhance quality of life

- Well-intentioned efforts that are too narrow in scope will miss the target
  - **Example 1:** A narrow focus on physical pain can miss the patient who is depressed, or doesn't have the money for the pain medicines, or is afraid that the pain means that she is going to die. Yet, all of these aspects of human experience will influence the experience of pain
  - **Example 2:** A patient whose spiritual foundation is not challenged is less likely to complain about physical symptoms, while failure to address the spiritual dimension in a patient who is spiritually distressed will may distort the physical dimension
  - **Example 3:** A patient who feels abandoned by family, community or medical professionals may express his or her suffering by emphasizing a physical complaint, or by giving up hope. The clinician would miss an avenue for intervention if she only addressed the physical.
- A physical complaint must always be given the physician's attention, both in its own right and its related dimensions
- While each aspect of human existence is an integral part of who we are, undue focus on any once aspect may be detrimental (e.g., undue focus on a patient's social disconnection, may distract a clinician from attending to physical needs)
- Based on the conceptions of suffering discussed above and a commitment to the broad perspective of human existence, this plenary will consider the elements of the health care system that may be able to **relieve suffering** and **enhance quality of life**

### Elements of End-of-life Experience

- Elements in the broad conceptualization of end of life experience can be thought of in 4 categories:
  - Fixed elements
  - Modifiable elements
  - Interventions
  - Outcomes
- Some of what the patient brings with himself or herself cannot change; in fact it would not be desirable to change some aspects
- Knowing and accommodating these fixed characteristics, the clinician may then focus on a person's modifiable dimensions
- Then the task is to identify the patient's expectations and needs, and deliver the appropriate care interventions, whether directly by the clinician or through other aspects of the system
- Together these elements of need and care combine to determine the overall experience of the dying process—the outcomes by which the health care system and society must measure our performance

### Fixed Characteristics

- The most prominent fixed characteristic of a patient facing the end of life is his or her **diagnosis** and its **prognosis**
- Other fixed features have to do with the patient's background
  - Issues that arise as a person faces the end of his or her life (or as parents face the loss of a child) are handled differently by people depending on their background and experience of life, i.e., race, ethnicity, culture, religion, socioeconomic class, etc. To a great extent, patients neither can nor want to change these important features
- Some physicians may bring have competence in the care of patients with particular cultural backgrounds; others may not
  - In any case, the individual patient's background must be learned
  - Through respectful inquiry, the physician can quickly learn about the patient's specific cultural issues
- An individual's background can be broadly categorized into differences of:
  - Race
  - Ethnicity and culture
  - Religion
  - Socioeconomic class
- There are many ways in which these differences combine—race may not track culture, culture may not track religion, socioeconomic class may not track ethnicity, and so forth
- Nonetheless, the categories provide a framework from which to work through the issues for an individual patient

## **Race**

- As examples, several studies have demonstrated race-related differences in preferences for life-prolonging intervention toward the end of life
- Commentators have raised the possibility of mistrust across racial difference
  - In conducting advance care planning discussions or establishing goals for care, sensitivity to the possibility of mistrust may be helpful

## **Ethnicity and Culture**

- The impact of illness is handled differently in different ethnic and cultural groups
- Culture has been shown to be a strong determinant in attitudes toward end-of-life decisions and care
- A good deal of useful information is available on various cultural attitudes toward health, illness, and dying
- However, it is important to remember that people are individuals and the best way to understand another person's culture is to listen carefully to his or her values and beliefs
- Open, balanced communication is what is required to negotiate cultural differences
- Respect can be conveyed by erring on the formal side of normal interactions, at least to begin with
  - It is important to remember that our current-day norms in the US of informality are in the minority among cultural approaches
  - Ask patients and their families about these characteristics
  - If questions are respectfully posed they will rarely be offensive
- It is always best to use interpreters when language barriers exist
  - Using family members is fraught with difficulty
  - If there is a translator, you can also learn from him or her if someone is available and knowledgeable in the relevant group's context for living
- Further considerations of cultural issues in end of life care are treated in various modules, including:
  - Issues of information and truth telling (see Module 2: Communicating Bad News)
  - Maintaining reasonable hope (see Module 7: Goals of Care)
  - Involvement of translators (see Module 2: Communicating Bad News)

## **Modifiable Elements**

- While the patient comes to the physician with an unchangeable diagnosis and a background that is set, there are often aspects of a patient's experience that are more modifiable than may be apparent initially
- The following aspects can all change with time and effort:
  - Physical symptoms
  - Psychological and cognitive symptoms
  - Social relationships and support
  - Economic demands and caregiving needs
  - Hopes and expectations
  - Spiritual, cultural, and existential beliefs

## **Pain and Other Physical Discomfort**

- Patients may experience many physical symptoms as a result of their serious and life-threatening illness
- Pain, although exceedingly important, is not the only one. Fatigue, drowsiness, insomnia, dyspnea, anorexia, and nausea are but a few of the common symptoms suffered by patients
- For pain, and most of these symptoms, there are validated assessment tools and effective treatments
- While research is still necessary to improve our ability to manage symptoms effectively, the biggest need is timely application of knowledge that is already available
- Clinician assessment of a full range of possible symptoms, use of assessment tools, appropriate interventions, and outcome measures are now incumbent on the medical profession

## **Psychological and Cognitive Symptoms**

- Mental suffering is as vexing as physical suffering

- For some patients it is perhaps more so
- Its recognition by the physician, assessment and treatment are an integral part of end-of-life care
- **Depression** is widely under-recognized and under-treated in the general patient population and is an especially important problem in the dying patient
  - Too many clinicians rationalize helplessness and hopelessness in their patients with the thought that it is natural to be depressed when dying
  - On the contrary, depression is a frequently treatable complication of life-threatening illness
  - Feeling miserable is not an inevitable part of dying
  - Clinicians should be vigilant and skilled in its treatment
- **Anxiety** is another common form of emotional suffering
  - It is capable of exacerbating other forms of suffering and it is also treatable
- **Confusion**, whether due to the illness or to treatment side effect, is also common and can range from minor degrees of disorientation to major and distressing hallucination

### Social Relationships and Support

- Social relationships are usually challenged and changed by illness
- A person's ability to stay in his or her job or go to school, to fulfill his or her prior role in the family, to keep up friendships, and to be active in the community are all undermined
- Social attitudes to illness may isolate a person, and the burdens of care may lead to stresses in intimate relationships
- Fear as well as anticipatory bereavement can occur in both the patient and those around the patient, and can cause changes in the orientation of relationships
- All these challenges arrive at a time when the patient and family need extra support
- Effective social support will be much more likely with some professional assistance

### Economic Demands and Caregiving Needs

- The personal and economic burdens associated with a life-threatening illness can be enormous
- About one third of families report a significant loss of income and savings when there is a member of the family who is sick
- Usually the wife or mother or daughter of the patient provides the care
  - Many people have to leave their paid work to do so
- Women and single people have to pay for help more often than others
- Financial losses are also incurred by insufficient insurance coverage of delayed reimbursement for services
- Recognition of, acknowledgment of and assistance with these burdens, usually by involving social service support professionals, are critical
- You don't have to do the work yourself—
  - Insist on the assistance of the health care colleagues who are available to you
  - Involve the community if you can

### Hopes and Expectations

- A patient's (or parents' if the patient is a child) outlook is greatly affected by his or her expectations
- A traditional inclination to sustain a patient's (or parents') hope even at the price of deception has existed at various times in the history of the profession
  - Further, there has been an assumption in recent years that only cure can bring hope
- Yet, in numerous studies, the American public is quite clear that the vast majority expect the physician to tell them the truth
- In fact, there is positive work to be done in facing dying, and there are developmental goals to be realistically hoped for in finishing and reviewing life's achievements and in reaching closure well
- Through observation and study, we have learned that hope can be maintained, or strengthened, when we render a candid opinion to the patient of his or her prognosis
- The task of the clinician is to assist the patient and family in discerning and achieving their own realistic goals
- This skill can be learned, just like the skills of physical diagnosis or surgery

- Think in terms of the final stage of development and closure; expect that a patient's hope can be maintained, even in the face of dying
- This concept is perceived to be more difficult in pediatrics where the child truly is dying before the "normal" time. However, the concept that the truth is needed is especially true for parents facing the death of their child if appropriate decisions are to be made
- The specific focus of hope often changes over the course of the illness. In general, patients (and parents) can find fulfillment and closure in 4 general ways
  - They can find meaning in **understanding their achievements**
  - A sense of readiness can come from having a chance to bring **closure** to their life
  - Comfort can be found in understanding that **death is a natural part of the grand scheme of life**
  - Hope of **legacies** left or connection with something that will live on after they are gone
- For parents whose child is dying, comfort may be found in creating memories
  - The child's legacy can become the many lives affected by the child
  - Security can be found in realizing the strength of their spiritual lives

### **Spiritual, Cultural, and Existential Beliefs**

- Different patients may have different needs for spiritual support
  - Some patients will do better without a pastor—if the physician simply frees them from their physical suffering so that they can get on with their own work
  - Other patients appreciate the pastor's support
- Spiritual support can come from several sources
  - Many clinicians have pastoral care professionals who can be included in a patient's team of care
  - Another approach is to involve the patient's own pastor
  - But be careful; involvement in a religious denomination does not necessarily enable a pastor to engage successfully in the relief of spiritual suffering any more than attendance in medical school gives you the ability to perform cardiothoracic surgery
  - Study, interest, practice, and facility are what make a good chaplain—as is true for a good surgeon
- While medical professionals need not involve themselves directly in a patient's spiritual life, it is a critical aspect of life in advanced illness
- Therefore, insist on competent chaplaincy in the settings where you work. Your patients deserve nothing less
- Clinicians must be able to assess the importance of this sphere of life and help to engineer a plan that will address this unique aspect of human experience when it is appropriate—it is much easier with skilled colleagues working with you

### **Health Care System Interventions**

Technical interventions have been the main focus of much of medicine. In this larger perspective it is clear that technical intervention is just 1 of many elements in end-of-life care. Furthermore, it is not all provided by physicians and other professionals. Far from it. Support and care may also come from:

### **Family and Friends**

- The "front line" of care has always been provided by family and friends for a great majority of patients
- Even in an age when many patients die in an institution, this is still true
- Currently, care is moving back into the home, which is where 9 out of 10 patients want to be, and health care delivery systems now favor this as well
- Clinicians who understand and encourage helpful family involvement in patient care can bolster and be assisted by rather than feel interrupted by and undermine this important source of care
- In addition, the clinician who is aware of the burdens of care, and can direct the caregiver to a source of support, will help foster quality of life for patients and families with the best possible experience

### **Communities**

- Some patients are involved in communities that can provide spiritual activities, support groups, and even volunteer nursing-aide care
- Other members of the health care team may know about more resources than you do—ask them



- These resources can be invaluable and the clinician should welcome them in whatever way best supports the patient
- A few calls from yourself or a member of your team to the patient's religious institution, school, workplace, or neighborhood community can put a network of care in place
- One willing coordinator of community volunteers who can provide transportation, help with shopping and home chores, or a few friendly visitors

### Professionals

- The medical professional can uniquely guide and provide sources of care for suffering in all the 4 elements of physical, psychological, social, and existential experience
- The importance of interdisciplinary teams for this care cannot be overstated
- Technical interventions are the unique province of clinicians, and their importance is great
- Nonetheless, clinicians should not lose track of the fact that some interventions do not involve adding on a treatment but rather withholding or withdrawing an unwanted or a no-longer-wanted intervention
- In addition, clinicians must always recall the fact that empathic communication can itself be an intervention

### Societal Institutions

- Institutions in society powerfully determine peoples' activities and experiences as well as outcomes of those activities. This is no less true in end-of-life care
- For instance, the Medicare Program greatly influences the type of care people over the age of 65 receive. Medicare policies on hospice care determine who may receive what services in many cases
- Private institutions may also be influential in a patient's experience toward the end of life, whether these institutions are disease-based advocacy or support groups or community churches
- The critical affects caused by the nature of health care delivery systems greatly determines the possibilities for care, and this is taken up in the next major section

**Outcomes.** Now, let's consider outcomes. There are both objective and subjective measures that are important in assessing the overall quality of care for dying patients and their families.

### Objective Outcomes Measures

- Objective measures include documentable portions of care such as physician's orders that evidence proper planning and care
- **Scales of symptom intensity** should be used and can be correlated with treatment approaches to assess quality of care
- **Quality-of-life scales** should be used as well
- **Global scales of suffering and of quality end-of-life care** are being developed to provide clinically useful indicators as well as outcome measures
- **Scales for institutional processes of care** are also under development

### Subjective Measures: Patient/Family Satisfaction

- Patient and family satisfaction with care remains an important measure
- Although surveys of satisfaction often show poor correlation with other indicators of quality care, it remains an important concept and a tangible outcome measure
- In the end it is the subjective experience of dying, caring, and bereavement that is are critical to the continued life of those who survive the patient's death
- Much of the fear, trepidation, and distrust of contemporary health care comes from direct experiences with a beloved family member or friend. We have the ability to alter this perception

*National Cancer Institute grant (R25 CA76449) to Sara J. Knight, Ph.D., at the Robert H. Lurie Comprehensive Cancer Center provided the funding for the development of this program. This material was adapted from the EPEC project (Education for Physicians on End-of-life Care).*