

EPEEC

Education for Physicians on End-of-life Care

Participant's Handbook

Plenary 1

**Gaps in End-of-
life Care**

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Abstract

This plenary provides background for the EPEC curriculum. It presents a profile of how people currently die in the United States and contrasts this with data about the way they would like to die. In doing so, it highlights how the current system fails to meet the expectations and needs of our patients and families who are living with advanced life-threatening illness.

Key words

barriers, caregiving burdens, coping, curriculum content, death denial, disparity, dying in America, fears, financial pressures, goals of EPEC, hospice, life expectancy, palliative care, physician training, place of death, protracted illness, psychological distress, social isolation, symptoms, values, wishes

Objectives

The objectives of this module are to:

- describe the current state of dying in America
- contrast this with the way people wish to die
- introduce the EPEC curriculum

Introduction

Every year more than a million Americans die of a variety of causes. Some die easily and comfortably. Others die with a great deal of suffering and distress. This plenary will set the stage for the EPEC curriculum by contrasting key aspects of the way Americans currently die with the way they say they would like to die. It will also highlight some of the barriers to providing high-quality end-of-life care that will be discussed throughout the curriculum.

How Americans died in the past

In the early 1900s, average life expectancy was 50 years. Childhood mortality was high. Those who became adults could expect to live well into their 60s. However, only a few people lived to the ages that we regard as normal today.

Historically, up until the development of antibiotics in the mid-20th century, people typically died quickly, often of infectious diseases or accidents. As only a few remedies were available to extend life, medicine focused on caring and comfort. While customs and traditions varied across cultures, most cared for their sick at home with support from their physician, if one was available.

Medicine's shift in focus

During the second half of the 20th century, the age of science, technology, and communication has shifted the values and focus of North American society on many levels. Many authorities have suggested that we have become a “death-denying” society—valuing productivity, youth, and independence and devaluing age, family, and interdependent caring for one another.

At the same time, new science and technology have offered the potential of medical therapies previously unknown. Where once physicians could only provide comfort in the face of serious illness, the modern health care system can now “fight aggressively” against illness and death. We frequently attempt to prolong life at all cost. We often succeed.

Already the effect has been significant. Improved sanitation, concerted efforts by public health, and the development of a wide range of antibiotics and other medical interventions have increased life expectancy to an average of 76 years by 1995 (79 years for women compared with 73 years for men), and every year the statistics continue to improve. A plethora of new medications and therapies have changed the way we experience illness. The shift in focus has been so complete that death has become the enemy to be beaten at all costs. Many organizations have held out promises that illness can be beaten. Many physicians and health care workers have come to believe that they have failed if they do not save their patients from death.

End of life in America today

Death has not been conquered—all of us will die. While our extraordinary health care system and biomedical science enterprise has learned to cure a few illnesses, it has primarily learned to prolong the experience of living with chronic illness, and the process of dying.

A few of us (< 10%) will die suddenly of a myocardial infarction, an accident, or another unexpected event (see Figure 1). Most of us (> 90%) will experience a protracted life-threatening illness with either a relatively predictable steady course and a relatively short “terminal” phase, eg, cancer (see Figure 2), or a slow decline punctuated by periodic crises, eg, congestive heart failure, emphysema, Alzheimer-type dementia (see Figure 3).

Figure 1: Sudden death from an unexpected cause

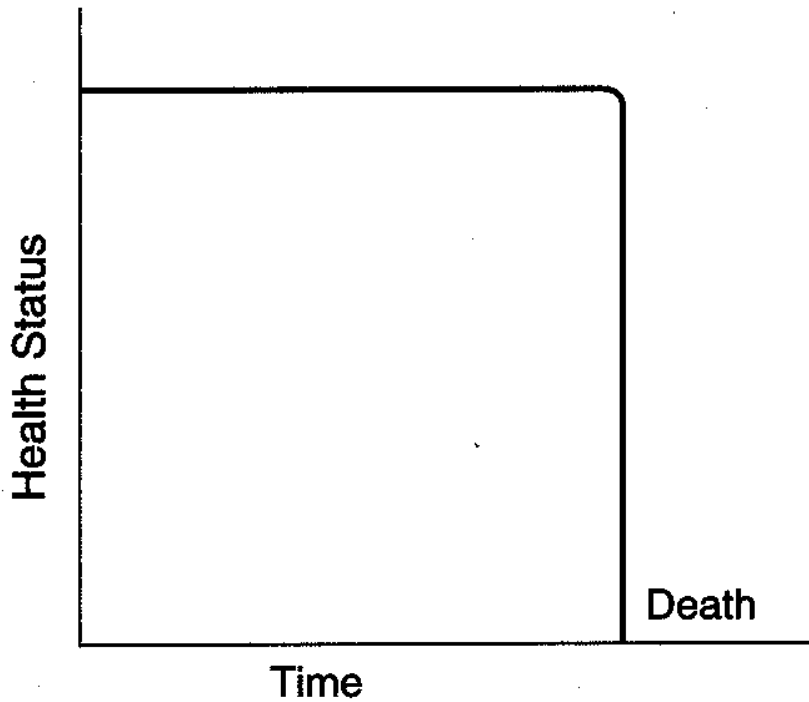


Figure 2: Advanced life-threatening illness with a steady decline and a short terminal phase

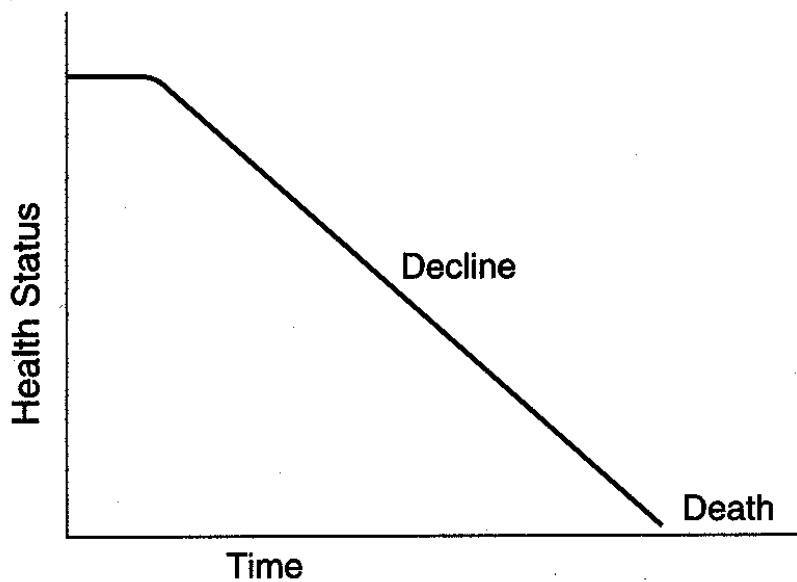
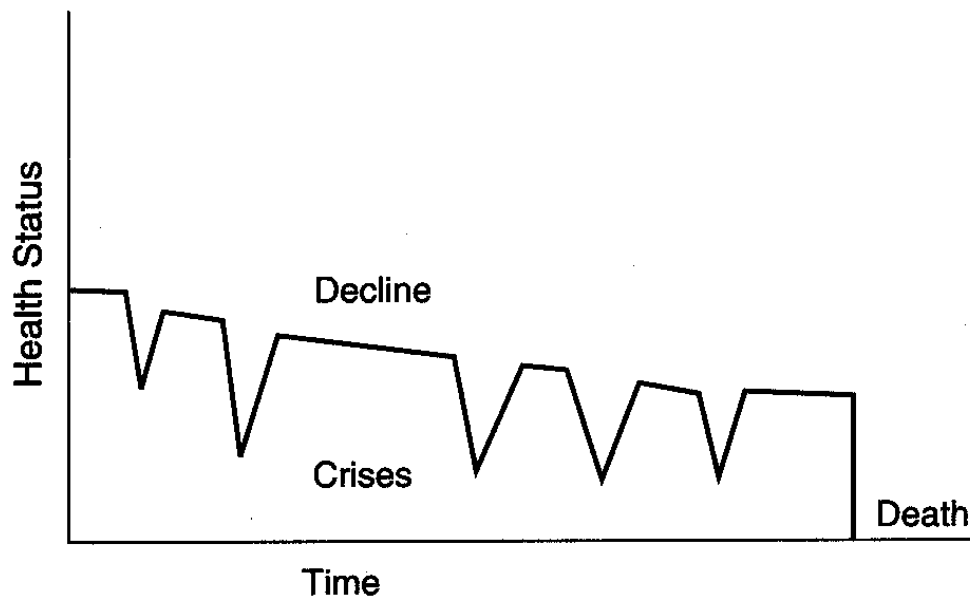


Figure 3: Advanced life-threatening illness marked by a slow decline with periodic crises and sudden death



Symptoms and suffering

As we imagine our own future and death, or the death of one of our children, fears and fantasies driven by past experiences and media dramatization frequently heighten anxiety about the events that may occur. Patients and families worry that symptoms won't be managed, that they will lose function and control. They wonder who will provide care, how they will pay for it, what dying will be like, and what comes afterward.

In fact, several studies indicate that most patients and families who are living with a life-threatening illness can expect to experience multiple physical symptoms and psychological, social, spiritual, and practical issues, many of which will be concurrent. Most of these problems add to a patient's and family's sense of suffering and reduce their quality of life, particularly if they are present for a long time.

In one study of patients with cancer, inpatients averaged 13.5 symptoms while outpatients averaged 9.7 symptoms. In patients with AIDS, symptom prevalence has been reported as being even higher. While some of these symptoms are related to the primary illness, some are adverse effects of medications or therapy, and others result from intercurrent illness. Many of the symptoms we see today were previously unknown or not considered as patients died quickly.

In all studies of symptom prevalence, pain, nausea/vomiting, constipation, and breathlessness are very significant. As patients lose weight and become weak/fatigued, loss of

function becomes increasingly present. For many people, the loss of their independence is devastating and a source of considerable suffering.

In addition to physical symptoms, many patients and families also experience considerable psychological distress, including anxiety, depression, worry, fear, sadness, hopelessness, etc. In 1 study where many fears were expressed, 40% of patients with advanced illness where death was expected were afraid of being a burden to their family and friends.

Social isolation

Today, in contrast to our past, many Americans live alone, or with only one other adult. Often both need to work or, if they are older, at least one of them may be frail or ill. Other family members—brothers, sisters, children, and parents—often live far away and have “lives of their own.” Friends have their own obligations and priorities. Although many Americans live in urban areas, there is considerable social isolation in this society that is built on independence and self-reliance.

While 90% of Americans believe it is a family’s responsibility to provide care for someone who is dying, this social isolation creates a very different situation from the one that existed in the past. Today, when a patient needs assistance, the burden of caregiving frequently falls to a very small number of people, often women, who may be unskilled and without the resources they need to provide that care.

Financial pressures

In addition to the issue of who will provide care, financial issues associated with caregiving have a significant impact on the family. In one study, 20% of family members had to quit work or make another major life change in order to provide care for a loved one. Even when they had medical insurance, a significant number of patients and families suffered financial devastation. In one study, 31% of families lost most of their savings caring for their loved one. In another study of cancer patients, 40% of families became impoverished providing care. For some families, the financial implications may prohibit any thought of caring for a loved one at home.

Coping strategies

Particularly in the face of prolonged suffering and unmanaged symptoms, strategies for coping with illness, disability, loss of control, lack of ability to do things that are meaningful, etc are varied. In some patients distress may be so significant if suffering is not relieved that goals may become destructive as they plan suicide or seek assistance to die prematurely by physician-assisted suicide or euthanasia (see Module 5: Physician-Assisted Suicide).

Place of death

In contrast to the desire to die at home expressed by 90% of the respondents to a Gallup survey commissioned by the National Hospice Organization (NHO) in 1996, as medicine developed increased technology to treat illness, death moved out of the home and into institutions. People died, shielded from the family's and community's sight, usually behind hospital doors. By 1949, 50% of deaths in America occurred in institutions. As of 1958, this had increased to 61%. Since 1980 it has remained at around 74% (in 1992, 57% of Americans died in hospitals, 17% died in nursing homes, and only 20% died in their own homes). Given the strongly expressed desire to die at home, the pattern of death in the United States is paradoxical. Although there is some regional variation, the majority of patients dying in hospitals and nursing homes are dying with illnesses where the expected outcome is death. They could be managed at home.

As care for patients with life-threatening illnesses has shifted into institutions, a generalized lack of familiarity with the dying process and death has evolved. Only a minority of people, including physicians, have ever watched someone die. Most nonprofessionals have never seen a dead body except, perhaps, at a funeral parlor. Fantasy about what death is really like is fueled by media dramatization, rarely reality.

Role of hospice, palliative care

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. However, even with this growth, hospices still care for only a minority of dying patients: 11% of all deaths in the US in 1993 and 17% in 1995. Of those patients dying of cancer in the US, only about 40% are ever referred to a hospice agency. There is significant regional variation, however. 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, while the median length of 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.

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. Designed to improve the quality of patients' lives while they fight their disease, good palliative

care may help to increase life expectancy in certain patients, according to anecdotal experience.

Gaps

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, and patients have lost their independence. With the shift to care for very ill patients at home, many families have not coped and 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.

Public expectations of physicians

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 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?” 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

However, until recently, formal education in end-of-life care has been absent from medical school and residency training. Just as Charles F. von Gunten, the EPEC Project Director, once felt, most physicians feel ill equipped, if not fearful, to care for the dying:

“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. While 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. To name but a few:

- Frequently, neither the public nor health care providers acknowledge that end-of-life care is important. It is often introduced too late to be effective, and funding is frequently inadequate to deliver quality palliative care.
- Fears of addiction, exaggerated risks of adverse effects, and restrictive legislation have resulted in inadequate control of symptoms.
- Discomfort with communicating bad news and prognosis, lack of skill to assist patients and families to negotiate clear goals of care and treatment priorities, and lack of understanding of patients' rights (or parents' rights if the patient is a child) to decline or withdraw treatment have led to frequent misunderstanding and excessive futile intervention.
- Personal fears, fantasies, worries, and lack of confidence have prompted many physicians to avoid dealing with patients who are dying.

It is not the point of this plenary to analyze all of the determinants of the current state of affairs. There is enough blame to go around. However, as some day each one of us will confront the end of our lives, if we are to build a health care system and ethic that cares or will care for all of us, then end-of-life care must improve. Perhaps as we reflect on our own expectations for the end of our lives through this curriculum, we will gain insight into the expectations and needs of our patients and families.

Goals of EPEC

As one contribution to help bridge the gap between patient and family expectations and the current state of end-of-life care in America, the American Medical Association conceived the EPEC Project—"Education for Physicians on End-of-life Care." EPEC is intended to help physicians take care of their portion of the responsibility to develop good end-of-life care. EPEC will equip them with a core base of knowledge that, in its application, will help physicians to improve their competence and confidence, strengthen physician-patient relationships, and enhance personal satisfaction with end-of-life care.

Through 4 plenary presentations and 12 modules, EPEC covers the range of decision-making situations, approaches to manage the most frequently occurring symptoms, and the basic concepts of interdisciplinary supportive care that any physician in general practice will face in end-of-life care. It is not an attempt to make every physician an expert in palliative care.

The topics covered include:

- whole-patient assessment (Module 3)
- the communication of bad news (Module 2)
- approaches to:
 - negotiating goals of care and treatment priorities (Module 7)
 - advance care planning (Module 1)
- guidelines for symptom management:
 - pain (Module 4)
 - depression, anxiety, delirium (Module 6)
 - other common symptoms (Module 10)
- approaches to deal with:
 - sudden critical illness (Module 8)
 - medical futility (Module 9)
 - requests for physician-assisted suicide/euthanasia (Module 5)
 - requests to withhold or withdraw life-sustaining therapy (Module 11)
- the care required by the patient in the last hours of life, and those who are bereaved (Module 12)
- related legal issues (Plenary 2)
- models of end-of-life care (Plenary 3)
- goals for change, barriers to the improvement of end-of-life care (Plenary 4)
- approaches to sharing the burden of end-of-life care with colleagues through interdisciplinary teamwork (throughout)

Once completed, in a manner analogous to the way that you learned during training, this knowledge needs to be applied in the environment in which you work to develop skill in its day-to-day application. In the end, the AMA hopes that EPEC will push physicians to rediscover some of the core values of our profession and foster creative approaches to advocate for, and create, change in the myriad of situations and places in which physicians serve dying Americans.

While physicians cannot change everything, change will not be very effective without them. Physicians have a special responsibility and leadership opportunity in end-of-life care.

Summary

The end of a person's life can be one of the most important times in that life. While the way we die has changed considerably during the 20th century, neither our society nor modern medicine has valued end-of-life care. Physicians are not sufficiently trained to be competent or confident in it. The EPEC curriculum proposes to equip physicians with knowledge, skills, and attitudes that can be tailored to their unique practice settings. The ultimate goal: to relieve suffering and improve the quality of the lives of all Americans who are living with, or dying of, life-threatening illnesses.

Key take-home points

1. Historically, up until the development of antibiotics in the mid-20th century, people expected to die quickly, often of infectious diseases or accidents. During the second half of the 20th century expectations changed. While our health care system and biomedical science enterprise has learned to prevent or cure a few illnesses, it has primarily learned to prolong the experience of living with chronic illness and the process of dying.
2. Less than 10% of Americans die suddenly.
3. Several studies indicate that most patients and families who are living with a life-threatening illness can expect to experience multiple physical symptoms along with psychological, social, spiritual, and practical issues. While some of these symptoms are related to the primary illness, some are adverse effects of medications or therapy, and others result from intercurrent illness.
4. Ninety percent of the respondents to a Gallup survey in 1996 desire to die at home, yet nearly 80% currently die in institutions.
5. 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.
6. Many physicians and health care workers believe they have failed and experience a sense of shame if they do not save their patients from death.
7. End-of-life care is commonly introduced too late to be fully effective. Hospices care for only a minority of dying patients, 17% in 1995. Patients generally do not spend enough time in these programs to experience all of the potential benefits; median length of stay is less than 30 days.
8. Until recently, formal education in end-of-life care has been absent from medical school and residency training.

Resources

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