



# ***Osteopathic EPEC***

**Education for Osteopathic Physicians on End-of-Life Care**

*Based on The EPEC Project, created by the American Medical Association and supported by the Robert Wood Johnson Foundation. Adapted by the American Osteopathic Association for educational use.*



# Plenary 1

## Gaps in End-of-Life Care



# Objectives

- Describe the current state of dying in America
- Contrast this with the way people wish to die
- Introduce the EPEC curriculum



# How Americans died in the past . . .

- **Early 1900s**
  - Average life expectancy 50 years
  - Childhood mortality high
  - Adults lived into their 60s
- *Osteopathic medicine made a difference in mortality during flu epidemic of 1918*



# . . . How Americans died in the past

- **Prior to antibiotics, people died quickly**
  - **Infectious disease**
  - **Accidents**
- **Medicine focused on caring, comfort**
- **Sick cared for at home**
  - **With cultural variations**



# Medical shift in focus . . .

- Science, technology, communication
- Marked shift in values, focus of North American society
  - “Death denying”
  - Value productivity, youth, independence
  - Devalue age, family, interdependent caring
- Breakup of extended family



# Medical shift in focus . . .

- **Potential of medical therapies**
  - “Fight aggressively” against illness, death
  - Prolong life at all cost
- **Improved sanitation, public health, antibiotics, other new therapies**
  - Increasing life expectancy  
1995 avg 76 y (F: 79 y; M: 73 y)



# . . . Medical shift in focus

- **Death “the enemy”**
  - Organizational promises
  - Sense of failure if patient not saved
- ***The Osteopathic Difference***
  - *Caring for families at the end-of-life has been a part of the traditional culture of osteopathic medicine*



# End of life in America today

- **Modern health care**
  - Only a few cures
  - Live much longer with chronic illness
  - Dying process also prolonged



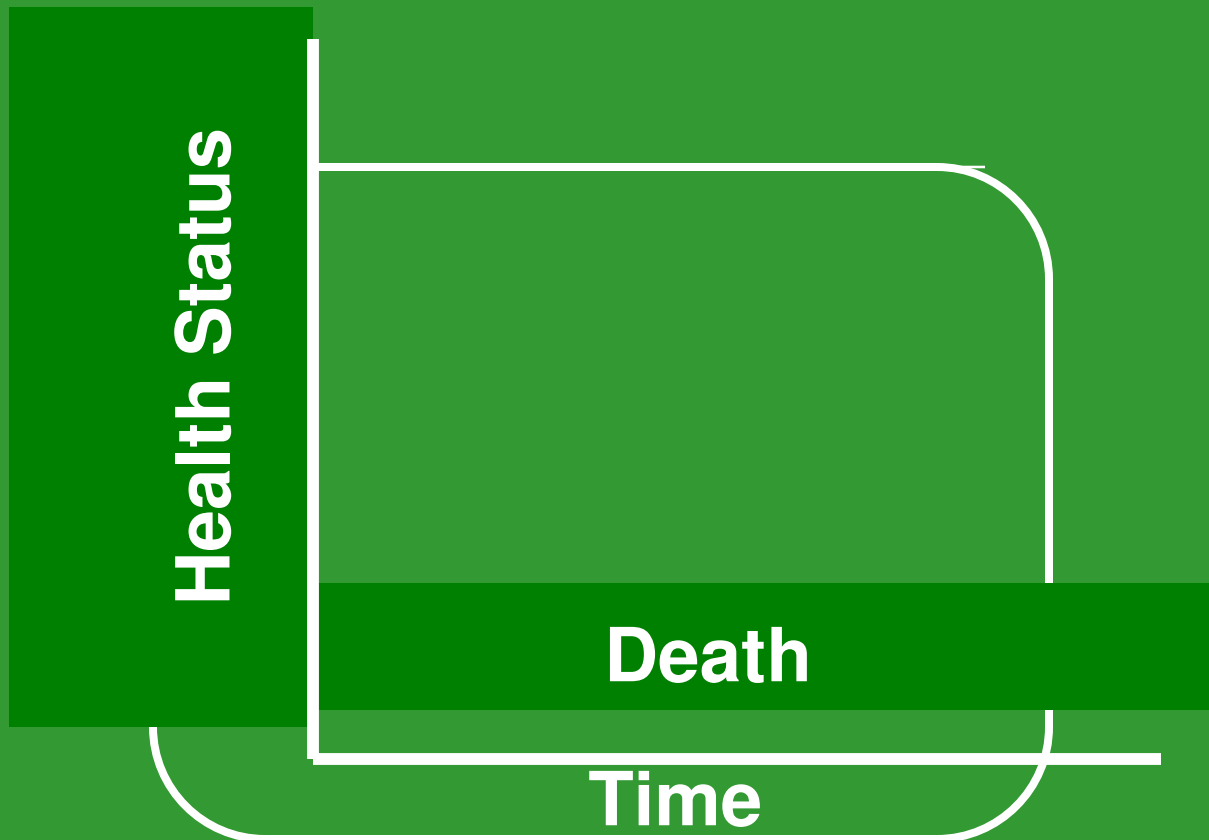
# Protracted life-threatening illness

- **Ninety percent of deaths are from an expected cause**
  - **Predictable steady decline with a relatively short “terminal” phase**
    - cancer
  - **Slow decline punctuated by periodic crises**
    - CHF, emphysema, Alzheimer’s-type dementia

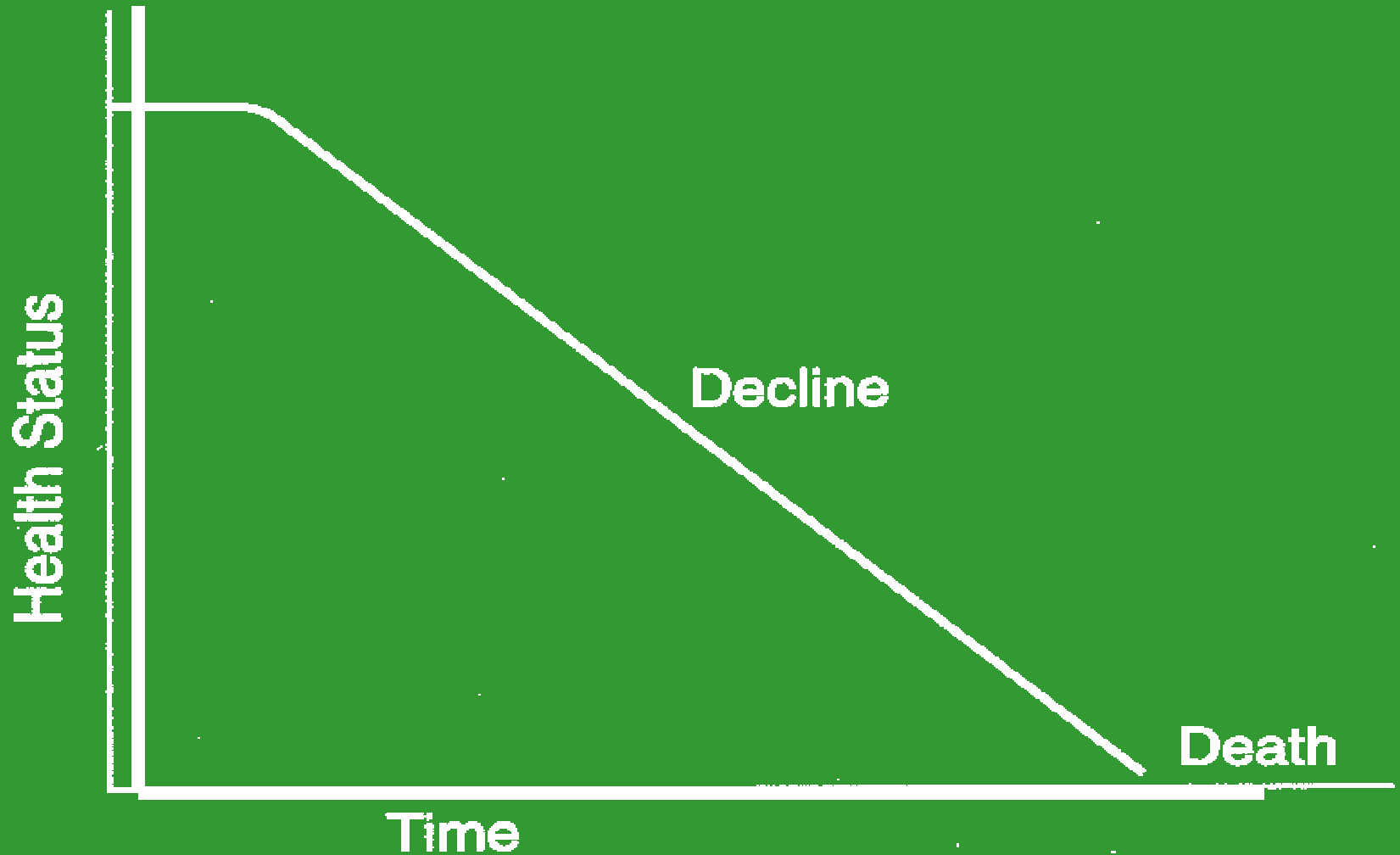


# Sudden death, unexpected cause

- 10%, MI, accident, etc



# Steady decline, short terminal phase



# Slow decline, periodic crises, sudden death



# Symptoms, suffering . . .

- **The nature of suffering**
- **Fears, fantasy, worry**
  - **Driven by experiences**
  - **Media dramatization**



# Symptoms, suffering . . .

- **Multiple physical symptoms**
  - Inpatients with cancer averaged 13.5 symptoms, outpatients 9.7
  - Greater prevalence with AIDS
  - Related to
    - primary illness
    - adverse effects of medications, therapy
    - intercurrent illness



# Symptoms, suffering . . .

- **Multiple physical symptoms**
  - Many previously little examined
  - Pain, nausea / vomiting, constipation, breathlessness
  - Weight loss, weakness / fatigue, loss of function



# • • • Symptoms, suffering

- **Psychological distress**
  - Anxiety, depression, worry, fear, sadness, hopelessness, etc
  - 40% worry about “being a burden”
- **Spiritual suffering**
  - Lack of meaning



# Social isolation

- Americans live alone, in couples
  - Working, frail or ill
- Other family
  - Live far away
  - Have lives of their own
- Friends have other obligations, priorities



# Caregiving . . .

- 90% of Americans believe it is a family responsibility
- Frequently falls to a small number of people
  - Often women
  - **May be ill-equipped to provide care**



# ... Caregiving

- **Growing shortage of caregivers**
  - Shifting demographics
  - Increased “caregiving burden”
  - Low pay and low status for career caregivers
  - Caregiver burnout



# Growing cultural diversity

- *Cultural and religious differences in beliefs and attitudes about death and dying evident in diverse population*
  - *European Americans*
  - *African Americans*
  - *Asian American (Chinese, Vietnamese, Japanese, etc.)*
  - *Hispanic and Latin American*
  - *Native American*



# Financial pressures

- 20% of family members quit work to provide care
- Financial devastation
  - 31% lost family savings
  - 40% of families became impoverished



# Coping strategies

- Vary from person to person
- May become destructive
  - Suicidal ideation
  - Premature death by physician-assisted suicide (PAS) or euthanasia



# Place of death . . .

- 90% of respondents to NHO Gallup survey want to die at home
- Death in institutions
  - 1949 - 50% of deaths
  - 1958 - 61%
  - 1980 to present - 74%
  - 57% hospitals, 17% nursing homes, 20% home, 6% other (1992)



## ... Place of death

- Majority of institutional deaths could be cared for at home
  - Death is the expected outcome
- Generalized lack of familiarity with dying process, death



# Role of hospice, palliative care . . .

- Hospice started in US in late 1970's
- Percentage of total US deaths in hospice
  - 11% in 1993
  - 17% in 1995



# Role of hospice, palliative care . . .

- Median length of stay declining
  - 36 days in 1995
    - 16% died < 7 days of admission
  - 20 days in 1998



# . . . Role of hospice, palliative care

- **Palliative care programs / consult services evolving**
  - **Earlier symptom management / supportive care expertise**
  - **Possible impact on life expectancy**



# Gaps

**Large gap between reality, desire**

## Fears

- Die on a machine
- Die in discomfort
- Be a burden
- Die in institution

## Desires

- Die not on a ventilator
- Die in comfort
- Die with family / friends
- Die at home



# Public expectations

- **AMA Public Opinion Poll on Health Care Issues, 1997**

**“Do you feel your doctor is open and able to help you discuss and plan for care in case of life-threatening illness?”**

- **Yes 74%**
- **No 14%**
- **Don't know 12%**



# Physician training . . .

- **No formal training, physicians feel ill equipped**

“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.”



# . . . Physician training

- 1997-1998: only 4 of 126 US medical schools require a separate course
- Physician training not comprehensive or standardized
- How can physicians hope to be competent, confident?



# Osteopathic physician training

- *How does the osteopathic profession fare by comparison?*



# Barriers to end-of-life care . . .

- **Lack of acknowledgment of importance**
  - Introduced late, funding inadequate
- **Fear of addiction, exaggerated risk of adverse effects**
  - Restrictive legislation



# Barriers to end-of-life care . . .

- **Physician concerns**
  - **Discomfort communicating “bad” news, prognosis**
    - misunderstanding
  - **Discomfort with *listening***
  - **Lack of skill negotiating goals of care, treatment priorities**
    - futile therapy



# . . . Barriers to end-of-life care

- **Physician concerns**
  - Personal fears, worries, lack of confidence, competence
    - avoidance of patients, families
  - Reflection on personal expectations will bring insight into patient, family expectations, needs
  - Understanding of cultural, religious and ethnic differences



# Goals of EPEC

- For practicing physicians
- Teaches core clinical skills
- Improve
  - Competence, confidence
  - Patient-physician relationships
  - Patient / family satisfaction
  - Physician satisfaction
- Not intended to make every physician a palliative care expert



# EPEC curriculum . . .

- *Self-assessment (Module 2)*
- **Whole patient assessment (Module 3)**
- **Communication of bad news (Module 2)**
- **Goals of care, treatment priorities (Module 7)**
- **Advance care planning (Module 1)**



# EPEC curriculum . . .

- **Symptom management**
  - Pain (Module 4)
  - Depression, anxiety, delirium (Module 6)
  - Other common symptoms (Module 10)
- **Sudden critical illness (Module 8)**
- **Medical futility (Module 9)**



# EPEC curriculum . . .

- **Physician-assisted suicide / euthanasia (Module 5)**
- **Withholding or withdrawing life-sustaining therapy (Module 11)**
- **Care in the last hours of life, bereavement support (Module 12)**



# EPEC curriculum . . .

- Legal issues (Plenary 2)
- Models of end-of-life care (Plenary 3)
- Goals for change, barriers to improving end-of-life care (Plenary 4)
- Interdisciplinary teamwork (throughout)



# . . . EPEC curriculum

- Apply each skill in your practice
- Rediscover professional fulfillments
- Foster creative approaches to create change in end-of-life care
  - Change will not be effective without physician change
- *Taking care of yourself*



# **Gaps in End-of-Life Care**

## **Summary**

