

END OF LIFE IN AMERICA

Our Goal in EndLink

- The end of a person's life can be one of the most important times in that life
 - Some die easily and comfortably
 - Others die with a great deal of suffering and distress
- While the way we die has changed considerably during the 20th century, neither our society nor modern medicine has valued end-of-life care, or trained health care professionals to be competent or confident in it
- Our goal in EndLink is to provide
 - A framework for health care professionals to use in thinking about the experiences and needs of persons who are near the end of their lives, and of families who continue in their lives without their loved one
 - Tools to help health care professionals build their skills in caring for persons who are dying and their families
- Our ultimate goal: to relieve suffering and improve the quality of the lives of persons who are living with dying, and of families who continue in their lives without their loved one

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
- Few people lived to the ages that we regard as "normal" today

Until the development of antibiotics in the mid-20th century...

- People typically died quickly, often causes such as:
 - Infectious diseases
 - 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
 - Infectious diseases
 - Accidents

Medicine's Shift in Focus: Impact on Death and Dying

Society's Shift in Values and 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
 - Independence
 - Devaluing
 - Age
 - Family
 - Interdependent caring for one another

Changes in Medical Technology

- 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

Impact of Change

Already the effect of the changes described above 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: An Overview

- Death has not been conquered—all of us will die
- While our extraordinary health care system and biomedical science enterprise has learned primarily to:
 - Cure only a few illnesses
 - Prolong the experience of living with most chronic illness
 - Prolong the process of dying
- A few of us (< 10%) will die suddenly of causes such as:
 - Myocardial infarction
 - Accidents
 - Another unexpected event
- Most of us (> 90%) will experience a protracted life-threatening illness with either:
 - A relatively predictable steady course and a relatively short "terminal" phase
 - Cancer
 - A slow decline punctuated by periodic crises
 - Congestive heart failure
 - Emphysema
 - Alzheimer-type dementia

Symptoms and Suffering: Fears, Fantasies, and Worries About Death and Dying

- As we imagine our own future and death, or the death of one of our children, our anxiety about the events that may occur is frequently heightened by fears and fantasies driven by
 - Past experiences
 - Media dramatization
- Patients and families often worry and wonder about:
 - Whether and how symptoms will be managed
 - Loss of function and control
 - Who will provide care
 - How they will pay for care
 - What dying will be like
 - What comes after death

Physical Symptoms

- Several studies indicate that most patients and families who are living with a life-threatening illness can expect to experience multiple physical symptoms

- Most of these problems, particularly if they are present for a long time:
 - Add to a patient's and family's sense of suffering
 - Reduce quality of life
- In one study of patients with cancer
 - Inpatients averaged 13.5 symptoms
 - 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, others are:
 - Adverse effects of medications or therapy
 - Results 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, highly significant symptoms include:
 - Pain
 - Nausea/vomiting
 - Constipation
 - Breathlessness
- 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

Psychological Distress

- In addition to physical symptoms, many patients and families also experience considerable psychological distress, including symptoms of:
 - Anxiety
 - Depression
 - Worry
 - Sadness
 - Hopelessness
- In one 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
- Additional sources of suffering, many of which will be concurrent with physical and/or psychological suffering, include:
 - Social
 - Spiritual
 - Practical Issues

Social Isolation

- Although many Americans live in urban areas, there is considerable social isolation in this society that is built on independence and self-reliance
- Today, in contrast to our past, many Americans live alone, or with only one other adult
 - Often both need to work
 - 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
 - Have "lives of their own"
- Friends have their own obligations and priorities

Caregiving

- 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 who are often:
 - Women
 - Unskilled
 - 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 have medical insurance, a significant number of patients and families suffer 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

Breakdown in 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
 - Seek assistance to die prematurely by physician-assisted suicide or euthanasia

Place of Death: Preferences vs. Realities

- 90% of the respondents to a Gallup survey commissioned by the National Hospice Organization in 1996 expressed a desire to die at home
- In contrast, as medicine has developed increased technology to treat illness, death has moved out of the home and into institutions. People die, 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 increased to 61%
 - Since 1980 it has remained at around 74%
 - In 1992:
 - 57% of Americans died in hospitals
 - 17% died in nursing homes
 - 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

Most Americans Lack Experience with Death and Dying

- 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

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).