

**Long Term Care
Intensive Train-The-Trainer Series**

Historical Perspectives of Dying and Death in America

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Presented by:
Institute of Gerontology
Wayne State University

In partnership with:
Hospice of Michigan

*The development of this training manual has been funded by a grant from the
Michigan Department of Community Health Long Term Care Initiatives*

Historical Perspectives of Dying and Death in America (Slide 1)

Module Overview: (Slide 2)

Attitudes toward dying and death in America have evolved throughout our history. Early settlers brought to America their values, customs, and beliefs regarding death and dying. Ever developing social and scientific ideas continued to shape these beliefs forming our current perceptions of death and how each of us wants to die. This module traces some of the significant historical events influencing hospice care. In addition it provides an introduction to the concepts of hospice and palliative care as practiced in a variety of settings today including long term care.

Definition of Terms: (Slide 3)

Death delayed experience: isolation from death events until adult years

Hospice: a program of care provided across a variety of settings based on the understanding that dying is part of the normal life cycle.

Palliative Care: model of care which focuses on providing information, services, and support to individuals with life-threatening illnesses of any type, from the time of diagnosis through course of illness, dying, death, and bereavement.

Quality of life: defined by the individual in four dimensions– physical, psychological, social, and spiritual

Suffering: a state of severe distress associated with events that threaten the intactness of the person.

Objectives: (Slide 4)

1. Describe how views of dying and death have changed over the last 150 years.
2. Differentiate between the terms hospice care and palliative care.
3. Describe what is meant by the phrase 'continuum of care'.
4. Describe the components of the 'hospice benefit' that can be integrated into the long-term care setting.
5. Discuss aspects of quality of life model.
6. Identify the impact suffering has on the individual at end-of life, family and caregivers.

Teaching Cues	Content	Resources
	Death and Dying in America: Historical Changes	
Describe history	<p>1.0 Late 1800's: (Civil War)</p> <p>1.1 Primary emphasis of care was on easing of symptoms.</p> <p>1.2 Most deaths occurred at home only a few days after onset of illness.</p> <p>1.3 If death was prolonged, it was due to TB or similar illnesses; patient and family had “time” to prepare for the death.</p>	Slide 5
Discuss significant historical events	<p>2.0 1900-1950's</p> <p>2.1 Growth of science and industry brought about broad, sweeping changes</p> <p>2.2 Length of life increased due to improvements in sanitation, living and working conditions (emphasis on public health).</p> <p>2.3 Life-saving and life-prolonging discoveries such as CPR, antibiotics, pain medications and advances in anesthesia also positively impacted length of life.</p> <p>2.4 The focus of the health care shifted from easing suffering to curing disease.</p> <p>2.5 Cared for people outside of their homes.</p> <p>2.6 Chemotherapies and radiation therapies advanced to the point that they were viewed as cures.</p> <p>2.7 Patients whose disease failed to respond to treatments were given less priority. Death itself became equated with medical failure.</p>	Slide 6

Teaching Cues	Content	Resources
Emphasize shift in care settings	<p>3.0 Changes in site of death</p> <p>3.1 Site of death shifted from <u>home</u> to <u>institution</u></p> <p>3.2 Health-care professionals administer care to dying individuals more frequently than did family members</p>	Slide 7
<p>Discuss current realities impacting death experience</p> <p>Emphasize how the “death delayed experience” influences our behavior</p>	<p>4.0 1950 – present</p> <p>4.1 4.1 Americans are living longer. Only 10% will die suddenly due to accident, heart attack, or another unexpected life event.</p> <p>4.2 90% or more are dealing with progressive diseases. Some individuals experience a steady decline with a short terminal phase while other experience a slow decline with periodic crises prior to death.</p> <p>4.3 Changes in disease course means individual is dependent on others for a longer period of time.</p> <p>4.4 There is a social trend toward family members to be separated by great distances “Death Delayed Experience”: death generally not experienced until adult years.</p> <p>4.5 Isolation from death experience has increased discomfort with death and dying process. As a result many people tend to experience a profound emotional response to the death of a loved one.</p> <p>4.6 Scientific advances have led to medicalization of care at end-of-life.</p> <p>4.7 Advances and change in focus to cure has lead, in some cases, to unrealistic optimism.</p> <p>4.8 Many health care providers have become increasingly uncomfortable in addressing end-of-life concerns with patient and families.</p>	<p>Slide 8</p> <p>Slide 8</p>

<p>Discuss disparities</p>	<p>5.0 Disparity between the way people die and the way they want to die: Patient/Family Perspectives</p> <p>5.1 Most adults prefer to be cared for at home if terminally ill.</p> <p>5.2 The majority of adults believe it would take a year or more to adjust to death of a loved one.</p> <p>5.3 Two greatest fears Americans express are being a burden to their family and being in pain.</p> <p>5.4 Many people have come to fear prolonged death characterized by over-treatment and invasive, debilitating treatments. Side effects of treatments are feared. “Cure is worse than the disease.”</p> <p>5.5 Patients and family fear abandonment by health-care providers when “nothing can be done.”</p> <p>5.6 Families frequently express uncertainty about how to provide physical care and adjust to role changes.</p> <p>5.7 Many families drain life savings in order to cover costs of care for terminally ill family members.</p>	<p>Slide 9</p> <p>This is a point where you can validate participants perceptions between the way we die and the way we want to die!</p>
<p>Outline barriers</p>	<p>6.0 Barriers to quality care at the end of life</p> <p>6.1 Failure of society to acknowledge the reality of life-limiting diseases – denial of death. May lead to inappropriate use of curative treatments. This in turn can prolong the dying process and contribute to physical and emotional distress.</p> <p>6.2 Unrealistic expectations of “medicine” continue to persist.</p> <p>6.3 Feelings of discomfort among professionals in communicating “bad news”. Health care providers reluctant to take away “hope”.</p> <p>6.4 Access to hospice and palliative care services delayed due to lack of understanding. This leads to confusion over when it is ‘ok’ to transfer care. More timely referrals are essential in order to help individuals and families reap full benefit of hospice.</p>	<p>Slide 10</p> <p>Ask participants to identify other barriers they feel exist in our culture that negatively impact quality care at end-of-life.</p>

<p>Define hospice care. Discuss each point.</p>	<p>7.0 Principles of Hospice and Palliative Care: Definition of Hospice</p> <p>7.1 Hospice outlines a specific program of care. 7.2 It provides support and care for persons in the last phases of incurable disease so that they may live as fully and as comfortably as possible. 7.3 It supports a principle that dying is part of the normal process of living 7.4 It focuses on maintaining the quality of the person’s remaining life. 7.5 It supports individual through dying process and family through dying and bereavement process. 7.6 It includes the provision of both medical and supportive services</p>	<p>Slide 11</p> <p>Handout A</p>
<p>Provide brief overview of hospice history in U.S.</p>	<p>8.0 History of Hospice</p> <p>8.1 Dame Cicely Saunders in England, a nurse who later became a physician, founded first hospice in 1960’s. 8.2 Hospice became grassroots effort in US starting in Connecticut in 1974. 8.3 Hospice care providers pioneered the standards for End of Life Care</p>	<p>Slide 12</p>

<p>Compare palliative care with hospice care</p>	<p>9.0 Palliative Care</p> <p>9.1 Emerged in response to demands for improvements in the care and support of patients and families facing life-threatening illnesses.</p> <p>9.2 Patients and families began calling for end-of-life choices – when to “stop all treatments”.</p> <p>9.3 Palliative care begins in during the curative phase and extends through bereavement.</p> <p>9.4 Palliative care in the broad sense is not restricted to those who are dying or those enrolled in a hospice program. All treatment options, including curative and resuscitation are available to the patient receiving palliative care</p>	<p>Slide 13</p> <p>Handout B</p>
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<p>Discuss WHO definition of palliative care</p>	<p>10.0 As defined by the World Health Organization in 1990, Palliative Care is:</p> <p>10.1 “The active total care of patients whose disease is not responsive to curative treatment.</p> <p>10.2 Control of pain and . . . of other symptoms is paramount.</p> <p>10.3 The goal of palliative care is achievement of the <u>best possible quality of life for patients and their families.</u>”</p> <p>Many aspects of palliative care are also applicable earlier in the course of illness in conjunction with anticancer treatment.”</p>	<p>Slide 14</p>
<p>Discuss palliative care goals. Highlighted words should be emphasized.</p> <p>Use slide 16 to illustrate how goals are achieved and integrated with hospice care.</p>	<p>11.0 Palliative Care Goals</p> <p>11.1 Facilitate informed choice.*</p> <p>11.2 Promote comfort.</p> <p>11.3 Facilitate quality end-of-life closure by helping patient and family find positive experiences in face of suffering.</p> <p>11.4 Help patients and families find meaning and reach personal goals prior to and after death.</p> <p>11.5 Integrate physical, psychological, social, cultural and spiritual aspects of care.</p> <p>11.6 Recognize that goals of care change frequently as patient approaches death. Frequent reassessment and clarification of goals are essential.</p> <p>11.7 Support the co-existence of curative and palliative care measures as defined by patient and family.</p> <p>11.8 Use an interdisciplinary team to address needs of patient and their family.</p> <p>11.9 Introduce palliative care as early as possible in the course of the illness so that when subtle shifts occur, patients, families and health care providers can adapt goals accordingly.</p>	<p>Slide 15</p> <p>Slide 16</p>

* CULTURE

	Hospice Model of Palliative Care	
Each of the following five components should be reviewed	<p>12.0 General Principles Governing the Hospice Model of Palliative Care: Five Key Components</p> <p>#1 Patient/resident and family are the unit of care: Care is given in a manner that reflects the personal, cultural, and religious values, wishes, and goals of the individual and family.</p>	Slide 17
	<p>13.0 #2 Medicare guidelines determine eligibility:</p> <p>13.1 Originally designed to provide support to families caring for dying patients with predictable illness death “courses”.</p> <p>13.2 Hospices currently expanding service options so that individuals/families can receive palliative care long before the last six months of life. However, serious limitations remain under current Medicare benefit.</p>	Slide 18
<p>National Hospice Organization Guidelines</p> <p>National Hospice & Palliative Care Organization Guidelines</p>	<p>14.0 Current Medicare Benefit:</p> <p>14.1 14.1 Must be terminally ill as certified by two physicians.</p> <p>14.2 Must have a life expectancy of 6 months or less if illness runs its normal course.</p> <p>14.3 Patient must be informed of choice with clear understanding of benefits.</p>	Slide 18

15.0 #3 The Interdisciplinary Team (IDT) provides care:

Slide 19

15.1 Expertise and combined efforts of the IDT is key to providing comprehensive care.

15.2 IDTs share information and work independently to develop goals with the patient and family.

15.3 Unique needs of patient and family members drive the decisions regarding care.

15.4 Members of the interdisciplinary team include in addition to the patient and family:

Physician	Social Worker	Spiritual care	Home Health Aide
Nurse	Physical/Occupational Therapist	Pharmacist	
Dietician	Speech Therapist	Volunteer	

	<p>16.0 #4 Levels of Care: Four different levels of care are offered depending on needs of patient/resident goals of care</p> <p>16.1 Routine: Most common level of hospice care. Routine care can be provided in home, nursing home or residential setting. Includes care from team members on regularly schedules visits.</p> <p>16.2 Continuous: This is an expanded level of skilled care in the person's home. Nursing care must equal more than 50% of total hours necessary to prevent hospitalization.</p> <p>16.3 Inpatient: This level of care is provided in a hospital for the purpose of symptom management.</p> <p>16.4 Respite: This is short-termed inpatient care designed to give caregivers a rest from handling the individual.</p>	<p>Slide 20</p> <p>Handout C</p>
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	<p>17.0 #5 Services:</p> <ul style="list-style-type: none"> • -- Assistance by trained volunteers • -- Dietary and other counseling • --Education about dying process • --Home health aide services • --Medical care • --Nursing Care • --Physical, occupational, and other therapies • --Short-term inpatient care • --Spiritual counseling • --Bereavement care • --Durable medical equipment • --Grief support services • --Laboratory service • --Medical supplies • --Outpatient drugs • --Social work care • --Transportation 	<p>Slide 21</p> <p>Handout D</p>
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	Quality of life Model	
	18.0 Hospice and palliative care are provided within the quality of life framework. It helps healthcare providers understand the dying process and the interventions of care required by the dying patient and family.	Slide 22
Emphasize that quality of life is a key component of quality of care	19.0 Dimensions of quality of life (QOL): 19.1 Quality of life encompasses the physical, psychological, social, and spiritual dimensions of a person. 19.2 The dying experience impacts all dimensions. 19.3 Meaning of QOL differs from person to person. QOL can only be defined by the patient based on their own life experience. 19.4 QOL is considered throughout the illness/dying process and includes the time of death and the bereavement period.	Slide 23 Slide 24
Help participants understand the “pain” suffering can create in residents and families.	20.0 Concept of Suffering 20.1 A factor that marked impact the patient’s QOL is the “degree” of suffering experienced by the person at end-of-life. 20.2 Suffering is defined as a state of severe distress associated with events that threaten the intactness of the person 20.3 It involves the whole person and transcends the physical, psychological, social, and spiritual dimensions. 20.4 It is a highly personal experience. It is impossible for another to assume the presence or absence of suffering in another. 20.5 Failure to respond to the psychological and spiritual needs of individuals and families may intensify suffering.	Slide 25

<p>Although suffering is a universal experience the depth of the experience varies. Emphasize its “diversity”</p>	<p>21.0 Depth of suffering</p> <p>21.1 Suffering to some degree is universal, but the depth of it varies immensely.</p> <p>21.2 For most, dying process includes numerous losses.</p> <p>21.3 For some, suffering leads to finding meaning in life.</p> <p>21.4 For many, suffering cannot be relieved.</p> <p>21.5 For all persons and families, suffering should be considered and included in the plan of care</p>	<p>Slide 26</p>
<p>Point out that health care providers can unwillingly increase suffering</p>	<p>22.0 Focus on cure may increase suffering</p> <p>22.1 Inappropriate focus on cure may actually increase suffering</p> <p>22.2 In trying to maintain hope, physicians and other health care providers often continue to provide curative treatments even when there is a minimal chance for cure or improvement.</p> <p>22.3 These treatments frequently lead to diminished QOL, isolation from family, and may hasten death.</p>	<p>Slide 27</p>

Additional Learning Exercises:

Personal loss inventory exercise

1. Have participants list six items of MOST importance to them.
2. Have them remove one.
3. Have them remove another.
4. Continue until only one remains.
5. Have them remove the last item.

Have them reflect on how this related to the person who is dying.

Priorities Assessment Exercise

1. Ask participants how life priorities may change if an individual were to learn that she/he would die within the next 12 months, 6 months, or 1 month.
2. Discuss what the individual and family may need to do in those time periods.
 - Providing books to family members.
 - Encourage to seek counseling, involve others e.g. pastor, friends.
 - Decide who the spokesperson would be.

Personal Reflections Exercise

1. Based on spiritual and cultural perspective of participants themselves, ask them to share their perspectives on living with life-threatening illness, family communication patterns, and attitudes toward dying and death.
2. Ask them to describe what aspect of death they finding most challenging as a health care provider.

Resources

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