

Health Psychology, 6th edition
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Chapter Twelve:
Psychological Issues in Advancing
and Terminal Illness

Death Across the Life Span:
Overview

- What did people die from in the past?
 - Infectious diseases, such as influenza
- What are people likely to die from today?
 - Chronic illness like heart disease or cancer
- Average American
 - May know cause of death years in advance

Deaths: Leading Causes in the
U.S.

Table 12.1

Rank and Cause	Number of Deaths
1. Heart disease	700,142
2. Cancer	553,768
3. Stroke	163,538
4. Chronic respiratory diseases	123,013
5. Accidents (unintentional injuries)	101,537
6. Diabetes	71,372
7. Influenza/pneumonia	62,034
8. Alzheimer's disease	53,852
9. Nephritis*	39,480
10. Septicemia	32,238

*Includes nephrotic syndrome and nephrosis.

Source: Centers for Disease Control and Prevention, 2004. Statistics are for 2001.

**Death Across the Life Span:
Infancy and Childhood**

- U.S. infant mortality rate is high
 - 7.2 deaths per 1,000 births
- Countries that have lower rates
 - Have national medical programs
 - Provide free or low-cost maternal care
- Racial disparities exist in U.S. rates
 - Inequities in access to health care resources

**Death Across the Life Span:
Infancy and Childhood**

- SIDS: Sudden Infant Death Syndrome
 - Causes are not entirely known
 - Infant simply stops breathing
 - Gentle death for child
 - Enormous psychological toll for parents
- Mothers of SIDS infants adjust better if
 - They have other children
 - They don't blame themselves
 - They had some contact with the infant before the death

**Death Across the Life Span:
Infancy and Childhood**

- Death between ages 1 to 15 years
 - #1 cause of death is accidents (40%)
 - #2 cause of death is cancer (especially leukemia)
- Mortality for most causes of death in infants and children have declined

Death Across the Life Span:
Children's Understanding of Death

- Young children (< age 5 years) associate death with sleep
 - Death is not thought of as final
 - Person is in an “altered state”
 - Examples: Snow White, Sleeping Beauty
 - Curious about death
 - Not frightened or saddened

Death Across the Life Span:
Children's Understanding of Death

- Children aged 5 to 9
 - Develop concepts of the finality of death
 - May personify death as a shadowy figure
 - Ghost
 - Devil
 - Supernatural figure takes the person away
 - At ages 9 or 10, death is seen as universal and inevitable
 - Body decomposes, person doesn't return

Death Across the Life Span:
Box 12-1 Mainstreaming: Leukemic Children

- Leukemia once meant death
 - Now many children are mainstreamed
 - Requires sensitive preparation
 - The child looks different
 - The child's energy level may be low
- Comprehensive rehabilitation involves the child's total environment
 - Patient activity specialists work with the schools to ease transitions

Death Across the Life Span: Young Adulthood

- For those aged 15 to 24, death is due to
 - #1 unintentional injury (car accidents)
 - #2 homicide
 - #3 suicide
 - #4 heart disease
 - Cancer and AIDs account for remaining mortality
- Death of a young adult is considered tragic
 - Waste of life
 - Robbed of a chance to develop and mature

Death Across the Life Span: Reactions to Young Adult Death

- Reactions often include
 - Shock and outrage
 - An acute sense of injustice
- Medical staff
 - Difficult working with these patients
- Young adults who are the parents of young children feel
 - Cheated of chance of watching children grow
 - Concerned about how children will fare without them

Death Across the Life Span: Middle Age

- Death becomes more common
 - People develop chronic illnesses that ultimately kill them
- Premature death
 - Death before the projected age of 77
 - Usually occurs due to heart attack or stroke
- Most people say they would prefer
 - Sudden, painless, non-mutilating death

Death Across the Life Span: Sudden Death

Advantages

- Does not have to cope with
 - Pain,
 - Physical deterioration,
 - Loss of mental faculties
- Financial and other resources are not severely taxed

Disadvantages

- Family members may be
 - Estranged, now no hope for reconciliation
 - Poorly prepared to cope financially with the loss

Death Across the Life Span: Old Age

- Dying is not easy, but it may be easier in old age
 - Initial preparation may have been made
 - Some friends and relatives have died
 - May have come to terms with issues of
 - Loss of appearance
 - Failure to meet all of life's goals

Death Across the Life Span: Old Age

- Elderly typically die of degenerative diseases:
 - Cancer
 - Stroke
 - Heart failure
 - General physical decline
- Terminal phase is shorter than it is for those who are dying at younger ages

Death Across the Life Span: Old Age

What predicts declines in health?



Psychological Issues: Continued Treatment

- Treatments may have debilitating side effects
 - Advanced diabetes
 - Amputation of extremities, such as fingers or toes
 - Advanced cancer
 - Removal of an organ, such as a lung
- Patients feel they are being disassembled
 - Whether to continue treatment may become an issue

Psychological Issues: Continued Treatment

- Patient Self-Determination Act
 - Passed by Congress in 1990
 - Applies to Medicare and Medicaid health care facilities
 - Must have written policies regarding patients' wishes for life-prolonging therapy
 - Include provision of a DNR (Do Not Resuscitate) order in the case of cardiopulmonary arrest

**Psychological Issues:
Continued Treatment**

- Moral and Legal Issues: Euthanasia
 - Literally means “Good Death”
 - Ending the life of a person with a painful terminal illness for the purpose of terminating the individual’s suffering.
 - 1994 Oregon passed law permitting physician-assisted dying
 - 1997 Supreme Court physician-assisted dying is not a constitutional right but legislation is up to states

**Psychological Issues:
Continued Treatment**

- Living Will
 - A will prepared by a person with a terminal illness
 - Requests that extraordinary life-sustaining procedures not be used in the event that the ability to make this decision is lost
 - Insures that the patients preferences, not those of a relative, are respected

**Psychological Issues:
Social Issues Related to Dying**

- Changes in the patient’s self-concept
 - Difficult maintaining control of biological functions (drooling, incontinent, shaking)
 - Mental regression, difficulty concentrating
- Issues of social interaction
 - Fear that their condition will upset visitors
 - Withdrawal may occur for multiple reasons
 - Fear of depressing others
 - Fear of becoming an emotional burden

**Psychological Issues:
Social Issues Related to Dying**

- Communication issues
 - Death is still a taboo subject in U.S.
 - Many people feel the proper thing to do is not bring up death
 - Survivors often try to bear their grief alone
 - Medical staff, family, and patient
 - May believe the others don't want to discuss death

**Psychological Issues:
Non-Traditional Treatment**

- When health deteriorates *and* communication deteriorates
 - Patients may turn away from traditional care
 - Patients may seek alternative remedies
 - Life savings may be invested in quackery in the hopes of a "miracle cure"

**Psychological Issues: Box 12-6
Death: A Daughter's Perspective**

- After nine days of testing, Carol's father's diagnosis: Cancer of the sinuses
 - "Let me alone. No more treatments. I am 75. I have had an excellent life. It is time for me to die in my own way."
 - The decision was not met with approval
- Conclusion: Death is a very personal matter between parents and offspring, husbands and wives, the dying ones and all who care about them

Are There Stages in Adjustment to Dying? Kübler-Ross's 5 Stages

- Denial
 - A mistake must have been made; test results mixed up
- Anger
 - Why me? Why not him? Or her?
- Bargaining
 - A pact with God, good works for more time or for health
- Depression
 - Coming to terms with lack of control, a time of "anticipatory grief"
- Acceptance
 - Tired, peaceful (not always pleasant), calm descends

Are There Stages? Evaluation of Kübler-Ross's Theory

- Her work is invaluable
 - As a description of dying patients' reactions
 - In pointing out counseling needs of the dying
 - In breaking the taboos surrounding death
- Her work has **not** identified stages of dying
 - There is not a predetermined order
 - Some patients never go through a particular "stage"
 - Her work does not fully acknowledge the importance of anxiety.

Psychological Management of the Terminally Ill: Medical Staff

- Hospital staff are significant to the patient
 - Dying need help for simple things, brushing teeth or turning over
 - Pain management
 - See the person on a regular basis
 - Are privy to a most personal and private act: dying
- Patients can be candid with medical staff
 - Don't need to put on a "cheerful front"

Psychological Management of the Terminally Ill: Medical Staff

- Definitions
 - Terminal care
 - Medical care of the terminally ill.
 - Palliative care
 - Care designed to make the patient comfortable, but not to cure or improve the patient's underlying disease
 - often part of terminal care.

Psychological Management of the Terminally Ill: Medical Staff

- Palliative care
 - Least interesting type of care
 - Staff may burn out watching patient after patient die
 - Staff may become efficient, not warm, to minimize their own pain

Terminal care involves unpleasant custodial work as well as emotional strain for the hospital staff

Psychological Management of the Terminally Ill: Medical Staff

- Avery Weisman's Goals for the Staff
 - Informed consent
 - Safe conduct
 - Significant survival
 - Anticipatory grief
 - Timely and appropriate death

Psychological Management of the Terminally Ill: Counseling

- Thanatologists
 - Those who study death and dying.
- Clinical thanatology
 - The clinical practice of counseling people who are dying on the basis of knowledge of reactions to dying.

Psychological Management of the Terminally Ill: Counseling

- Symbolic immortality
 - The sense that one is leaving a lasting impact on the world, as through one's children or one's work
 - The last weeks of life can crystallize the meaning of a lifetime

Psychological Management of the Terminally Ill: Family Therapy

- Common issues
 - Communication
 - Death-related plans and decisions
 - Need to find meaning in life while making a loving separation
- Family and patient may be mismatched in adjusting to the illness
 - Family may be hopeful, patient may be resigned

Psychological Management of the Terminally Ill: Children

- Typically, staff serve limited rotations in units with terminally ill children
 - Hardest death to accept
 - Death can be physically painful
 - Children and parents are confused and fearful
 - Children may not express their concerns in a direct way

Alternatives to Hospital Care: Hospice Care

- Hospice
 - Institutions for the dying that encourage personalized, warm, palliative care
 - Acceptance of death in a positive manner
- Hospice Care
 - An alternative to hospital and home care, designed to provide comfort for terminally ill patients and their families
 - May be residential or home based

Alternatives to Hospital Care: Hospice Care

- Psychological comfort is stressed
 - Patients encouraged to personalize their living areas
 - Patients wear their own clothes
 - Patients establish their own routines
- Hospice care is less stressful for the families of the dying
 - Families encouraged to spend full days and stay over if possible

Alternatives to Hospital Care: Home Care

- Care for dying patients in the home
 - Choice of care for many terminally ill patients
 - Sometimes problematic for family members
 - Escalating hospital costs mean many people cannot afford extended hospitalization

Alternatives to Hospital Care: Box 12-7 Cultural Attitudes

- Traditional Japanese culture
 - Death is a process of traveling from one world to another
 - Death rituals help the spirit make the journey
- Andaman Islanders, in the Bay of Bengal
 - Ritual weeping (bonds have been broken)
- Hinduism
 - Death is like any transition in life
 - Belief in reincarnation: birth, death, rebirth

Problems of Survivors: The Adult Survivor

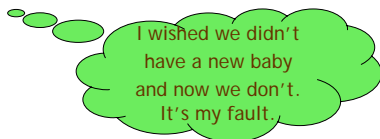
- Survivor's routine
 - Before death filled with illness-related activities
 - After death, it is hard to remember what one used to do
 - Often doesn't feel like doing those activities that are remembered
 - Has to take on new and unfamiliar tasks

Problems of Survivors: The Adult Survivor

- Grief
 - A response to bereavement involving a feeling of hollowness
 - Often marked by preoccupation with the dead person, expressions of hostility toward others, and guilt over death
 - May involve restlessness, inability to concentrate, and other adverse psychological and physical symptoms

Problems of Survivors: The Child Survivor

- Children
 - May expect the dead person to return
 - May believe a parent left because the child was “bad”
 - May feel “responsible” for a sibling’s death



Problems of Survivors: Death Education

- Death education
 - Programs designed to inform people realistically about death and dying
 - Purpose is to reduce terror and avoidance connected with the topic of death
- College courses are a viable means of death education
- *Tuesdays with Morrie* was a best seller
