Death & Dying

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Thanatology

The study of death and dying

- Death
  - A universal experience
  - A most difficult and painful realty to accept
- The United Nations definition:
  - Death is the permanent disappearance of every vital sign

Causes of Death and Demographic/Social Trends

	Early 1900's	Current
Medicine's focus	Comfort	Cure
Cause of death	Infectious, communicable diseases	Chronic illnesses
Age adjusted death rate	1720/100,000 (1900)	865/100,000 (1997)
Average life expectancy	50	76
Number of persons > 65 years old	3.1 million	35 million estimate for 2000
Site of death	Home	Institutions
Caregiver	Family	Strangers/ healthcare providers
Disease/ dying trajectory	Relatively short	prolonged

Site of Death

- Hospital 57%
- Nursing Home 17%
- Residences 20%
- Other 6%

(CME Resources May 2002, vol. 89, No.3)

Facts of Death in Elderly

- 73% of death in a given year are in the elderly
- 70% want to die at home, surrounded by love ones and fe free of pain
- Reality- “most die alone and suffering in pain and getting the treatment they don’t want”

(Dr Barry Baines, NCOA and ASA National Conference 2003)

Changes in Death/Dying 2015 transitioning to end of life care, death with dignity, palliative care.

Facts of Death in Elderly

- Most people have minimal direct involvement with dying individuals
- As direct experiences lessened
  - Death becomes more impersonal and unusual event
  - Resulting in difficulty to internalize and to accept one's own mortality (Charlotte Eliopoulos, Gerontologial Nursing, 5th edition, 2001)

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Personal Inventory

- An examination of one's own feelings and attitudes about death can be therapeutic to the caregiver personally, as well as helpful in the care of dying person
- When I think about death….
  - I face my own mortality
  - I face my own values/beliefs
  - I face my own fears/feelings

Person's Reactions to Dying Depends on

- Previous experiences
- Age
- Health status
- Culture
- Religious and spiritual beliefs
- Philosophy of life

Five Stages of Responses to Death and Dying (Kubler-Ross, 1969)

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

General Principles

- Persons may not necessarily move through the stages in order
- Not every person will experience all of these stages.
- Hope permeates all stages of the dying process.

Hope is a Key in Coping

- It involves faith and trust, which may or may not have a religious basis
- It may be related to a cure, the birth of a grandchild, a graduation, or reconciliation
- It will identify what the meaning of life is to the individual.

(Ebersole & Hess, Geriatric Nursing & healthey Aging, 1st ed., 2001)

General Principles

- All stages are adaptive…they are a way to cope
- There is no specific time limit
- One may create a “safe place”… but are powerless to move a person through the loss/grieving process
- Family members/friends rarely use similar coping mechanisms at the same time

Denial

- Aware f impending death, react by denying the reality:
  - "It is not true"
  - "There must be some mistake"
- Serves as a shock absorber
  - It allows for testing the information, to internalize the information and to mobilize defenses

<u>Interventions</u>

- To accept the individual's reactions
- To provide an open door for communication

Anger

- The person displaces the anger
  - "Why me?"
  - "What did I do to deserve this?"
- Expresses feeling that nothing is right
  - "Food tastes awful"
  - "Doctors and nurses do not know what they are doing."
- Unfulfilled desires and unfinished business may cause outrage

<u>Interventions</u>

- To accept the individual's reactions
- To let the person vent feelings
- To anticipate the person's needs
- To guard against responding to the anger personnallly

Bargaining

- An attempt to negotiate for a postponement of the inevitable
- Most bargains are made with God and usually kept a secret
  - "I will do anything if…."
  - Agree to be a better Christian if God lets me live

<u>Interventions</u>

- To accept the individual's reaction
- Listen, listen, listen
- To let the person vent and explore feelings

Depression

- Occurs with realization that death is inevitable
  - “yes…me.”
- An interest in prayer and a desire for visits from clergy are common
- This stage is necessary to approach the final stage of acceptance

Intervention

- To accept that depression is necessary to reach the final stage
- To respect the person’s silence
- To understand that cheerful words may be far less meaningful than holding their hand or sit silently
- To help the person with religious needs, contact clergy when needed

Acceptance

- Person has come to terms with death and has found a sense of peace
- Person says and does all the unfinished business of life
- The person may benefit more from nonverbal than verbal communication

Intervention

- Person is content with 1 or 2 close friends/family
- To assist the family in learning to understand and support the person

Common Fears

- Being alone
- Loss of independence
- Unrealized dreams/goals
- Spiritual questions
- Pain

Physical Care Needs: Pain

- It is the 5th vital sign
- It must be regularly reassed because it can increase or decrease with time
- Patients should be encouraged to report pain in a timely manner
- Use the pain scale of 0 to 10 (0 is no pain and 10 the most severe pain)
- Goals of pain management is to prevent pain from developing rather than treating it once it occurs.
  - Develop an analgesic schedule
  - "Narcotic addiction of a dying patient is not the issue: relief of pain is paramount" (Ebersole & Hess, Geriatric Nursing & Healthy Aging, 1st ed., 2001)

Alternative Interventions to Pain Control

- Guided imagery
- Hypnosis
- Relaxation exercises
- Massage
- Acupressure
- Acupuncture
- Therapeutic touch
- Diversion
- Heat or cold application

Pain Response

- Cultural background
- Medical diagnosis
- Psychological state
- Social state

Psychological Pain

- Pain induced by depression, anxiety, fear, and other unresolved emotional concerns
- Unmet emotional needs can intensify the total pain experience
- Medication alone cannot give relief
- Allow the person to express feelings

"Patients over the age of 70 were at increased risk of under treatment of pain because of the health professional's fears of causing addiction, hastening death, and incurring legal liability."

(Ebersole & Hess, Geriatric Nurisng & Healthy Aging, 1st ed., 2001)

Pain Response

Respiratory Distress

- Elevate the head of the bed
- Administer oxygen
- Narcotics may be used for heir ability to control respiratory symptoms by blunting the medullary response.

(Charlotte Eliopouls, Gerontological Nursing, 5th ed., 2001)

Constipation

- Causes of constipation
  - Reduced food & fluid intake,
  - Inactivity
  - Side effects of medication
- Take intervention to promote regular elimination
- Fecal impaction can appear as diarrhea

Pain Response

Nutrition

- Causes of poor appetite
  - Anorexia
  - Nausea, vomiting
  - Fatigue
  - weakness
- Assist with oral hygiene
- Stimulate appetite with appealing & favorite meals
- Use antiemetics

Psychological Care Needs

- An individual is living until he or she has died
- No one wants to die alone
- The dying older adult is a living person with all the same needs for good relationships
- Dying is a multifaceted active process which involves the dying person, the family and the professional caregivers
- Individuals need to be in control
- Human contact is vital
- Family members need to remain involved with the patient

Spiritual Care Needs

- America has a diversity of religious beliefs
- Each religion has its own practices related to death
- We need to respect these practices to meet the individual's spiritual needs
- Assess individual's religious affiliation and practices
- Religion and spirituality are no synonymous

Spirituality

- It is two-dimensional
  - Between the person and God
  - Between the person and others
- It may be met through religious acts and/or through human caring relationships
- A person's internal beliefs, personal experiences, and religion ae expressions of spirituality

Hospice

- It is a philosophy of care that is offered through a rande of organizational settings-hospital, nursing home, home health agencies, primarily in the home
- It provides physical, medical, emotional, and spiritual care to patients and his or her support system
- Its focus is palliative care
- It is dedicated to help people who are beyond cure to remain in a familiar surrounding where pain (physical, psychological, social, and spiritual) is reduced and personal dignity and control over the dying process maintained
- First Hospice is America was developed in Connecticut in 1974
- Now over 4,100 exist

Hospice

- Majority provide in-home services for cancer, HIV/AIDS, chronic terminal patients with a prognosis of 6 months or less
- Only 17% of dying American of all ages participate in Hospice (Cloud, 2000)
- "The population over 75 years of age is generally underserved by hospice compared to other age groups with terminal illnesses. (Hooyman & Kiyak, Social Gerontology, 7th ed., 2005)

Hospice Team

- Patient's attending physician
- Medical director
- RN case manager
- Social worker
- Home health aide
- Spiritual counselor/chaplain
- Volunteer

Other Services Included

- Medications related to the Hospice diagnosis
- Durable medical equipment
- Nutritional consultation
- 24-hour availability
- Other therapies as warranted
- Bereavement services

Palliative Care

- " … a comprehensive, interdisciplinary care, focusing primarily on promoting quality of life for patients living with a (serious, chronic, or) terminal illness and for their families…assuring physical comfort (and) psychosocial support. Billings, J Pall Med, 1999;1:73-81.

The World Health Organization defines Palliative care as:

- " The active total care of patient s whose disease is not responsive to curative treatment, control of pain, other symptoms, and psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families" (World Health Organization, 1990).

Palliative Care Team

- Focus is the patient in control of making decisions
- U.S. Supreme Court ruled in 1997 that Americans have a right to palliative care

The Palliative Care Team

- Geriatricians
- Nurse practitioners
- Nurses
- Licensed clinical social workers
- Spiritual leaders
- Dietician
- Activates coordinators
- Primary physician

Loss

- Loss, Dying and Death are Universal
- Cannot be stopped or controlled (Ebersole & Hess, Geriatric Nursing & Healthy Aging, 1st ed., 2001)
- Losses of the Aged
- Loss of Relationships
  - Significant others
  - Social contacts through illness, death, distance, decreased mobility
- Life transitions
  - Significant roles,
  - financial security
  - Independence
  - Physical health
  - Mental stability
  - Life-death

(Ebersole & Hess, Geriatric Nursing & Healthy Aging, 1st ed., 2001)

Loss

- With increase in life expectancy, more older adults are seeing their adult children go before them, which is a heartbreaking loss
- "losing a spouse is like losing an arm, losing a child is like losing your heart."
- Older adults have gone through series of losses.
- They develop resiliency (tough) and coping skills from pain and loss experiences.
- Social connection and spirituality increase survival

(Living with Grief, Loss Later in Life", video Hospice Foundation, 2002)

Loss: Bereavement and Grief

- Bereavement, Grief, mourning are manifested with physical, psychological, and behavioral responses.
- Bereavement refers to both the situation and the long-term process of adjusting to the death of someone close
- Grief process is the complex emotional response to bereavement can include:
  - Shock and disbelief
  - Guilt
  - Anxiety
  - Depression
  - Anorexia and insomnia
- Mourning signifies culturally patterned expectations about the expression of grief.

Loss: Bereavement and Grief

- "Current concepts about grief recognize that it is not rigidly structured and is without a predictable pattern of responses. Some responses to grief occur internally and are not visible, whereas other aspects of grief may not occur at all." (Ebersole & Hess, Geriatric Nursing & Healthy Aging, 1st ed., 2001)

Tasks of Grieving

- Accepting the reality of the loss
- Working through the pain (physical, emotional, behavioral) the intensity will vary with the individual
- Adjusting to a change in environment
- Emotionally relocating the deceased and moving on with life
- To rebuild fait and philosophical systems
- Working through pain is an individual process and needs a support network
- Accepting the reality can be measured by the use of present or past references to the dead
- Adjusting to a changed environment takes time, especially if the relationship is close
- The emotional relocation (a letting go) may produce anxiety

(Ebersole & Hess, Geriatric Nursing & Healthy Aging, 1st ed., 2001)

Interventions for Grieving

- Listen, listen, listen-Active listening allows the griever to express feelings and to feel supported
- Reminiscing allows working through the loss
- Allow the griever to remain in control which is crucial to recovery
- Sometimes the most helpful response is simply "to be there".
- Listen carefully to the silences
- Identify concrete tasks by which to help, such as cooking meals, child care, and house cleaning, so the breaved has time and space to grieve
- "Healthcare providers now recognize the importance of grief work and counseling, and view grieving as a natural healing process. Assistance in grief resolution, perhaps through life review and new risk-taking, is especially important for older adults". (Hooyman & Kiyak, Social Gerontology, 7th ed., 2005)

Current Issues

- Decision making regarding life-prolonging procedures when death is inevitable have become legal, ethical, medical, and professional issues, resulting from the technological advances. (Ebersole & Hess, Geriatric Nursing & Healthy Aging, 1st ed., 2001)
- Legal aspects of end of life care
  - Patient Self-determination act is a federal law, requires that healthcare facilities (hospitals, skilled nursing facilities, hospice, home health care agencies, and HMOs) that receive medicare and Medicaid funsd o inform patient sin writing of their rights to execute advanced directives regarding how they want to live or die. (Hooyman & Kiyak, Social Gerontology, 7th ed., 2005)

Advance Directives

- Only 9% under age 30 have
- Only 35% over age 75 have
- Types
  - Durable power of attorney
  - Durable power of attorney for health care
  - Living will

Healthcare professional's responsibilities

- Serve as a resource person for people to learn about it and make one
- Must be sure of proper disposition when completed
- When a new client enters a facility with an advanced directive, make sure it is current and reflective of person's choices
- All residents should be given the opportunity to execute one
- Be aware of the types of directives that are legally recognized in the state
- Be aware of the forms used by the employed institution
- Recognize the barriers to completion of the directives, i.e. memory, language difficulty, fear of being untreated
- Elders in long-term care facilities usually ned tow witnesses, one being the ombudsman from Department of Aging

Suicide

- As longevity increases and risk of long term degenerative illnesses, a growing number of people consider a mature adult's choice of suicide a rational decision
- Incidence
  - 1998-29,000 people
  - Most prevalent among older men
  - Highest rate is among white men, over age 85
- Causes
  - Depression, Alcohol, Abuse, Social isolation
  - Sense of hope or purpose is life enhancing i.e. love, work
  - 9 of 10 people who kill themselves have depression or another mental or substance use disorder (NIMH, 1999a)
  - Older adults who attempt are more likely to complete it with the use of more lethal methods

Euthanasia

- Active euthanasia (sometimes called mercy killing)
  - Intervention taken deliberately to shorten a life in order to end suffering or allow a terminally ill person to die with dignity
  - It is illegal
- Passive euthanasia
  - Is deliberately withholding or discontinuing treatment that might extend the life of a terminally ill patient, such as medication, life support systems or feeding tubes