• Loss, grief, Dying, and Death
• Chapter 9

Discussion? # 1

• What has been your experience regarding giving care to a dying person?
• What emotions did you experience?
• Recorder lists emotions
• Reported gives results of discussion

Loss, Grief, Dying, and Death

• Loss
  – An aspect of self no longer available to a person
• Death
  – Cessation of life
• Grief
  – Pattern of physical and emotional responses to bereavement
• Grief Work
  – Adaptation process of mourning a loss
• Mortality
  – The condition of being subject to death
Changes in Health Care Related to Dying and Death

- Before the 1950s, it was common for patients to die at home in their own beds with assistance from family.
- From the 1950s to 1980s, the health care system became highly mechanized and dying occurred mostly in institutions.
- By the early 1980s, when diagnosis related groups (DRG’s) came into play, this trend changed.
- Currently, the recuperating or terminally ill patient is often discharged to home, a convalescent home, or a nursing home.

Historical Overview

- 1960s
  - Pioneers in death and dying theory, such as Kubler-Ross and Glassner and Strauss, produced works that stimulated the health care industry to research topics about death and dying.
- 1970s
  - Hospices became recognized as health care delivery systems.
- 1980s
  - Grief therapy was introduced when Benoliel and Martocchio added new insights into the needs and care of the dying patient.

Loss

- Not all losses are obvious or immediate.
  - Obvious Losses
    - Death of a loved one
    - Divorce
    - Breakup of a relationship
    - Loss of a job
  - Not-So-Obvious Losses
    - Illness
    - Aging
    - Changing schools, jobs, or neighborhoods
Loss

• Maturational Loss
  – Loss resulting from normal life transitions
  – Loss of childhood dreams, the loss felt when adolescents when a romance fails, loss felt when leaving family home for college or marriage and establishing a home of one’s own
  – As an individual ages, they experience menopause and loss of hair, teeth, hearing, sight, and “youth.”

Loss

• Losses may be actual or perceived.
  – Actual loss is easily identified.
    • A woman who has a mastectomy
    • An abortion, or miscarriage
  – Perceived loss is less obvious.
    • Loss of confidence
    • A women who hopes to give birth to a female child delivers a male child instead
    • Perceived losses are easily overlooked or misunderstood, yet the process of grief involved is the same as an actual loss.
Loss

- **Situational Loss**
  - A loss occurring suddenly in response to a specific external event
  - Sudden death of a loved one, or the unemployed person who suffers low self-esteem

- **Personal Loss**
  - Any loss that requires adaptation through the grieving process
  - Loss occurring when something or someone can no longer be seen, felt, heard, known, or experienced; individuals respond to loss differently

Grief and Grieving

- **Grief**
  - The subjective response of emotional pain to actual or anticipated loss
  - The total process of reacting and responding to the losses in one’s life

- **Bereavement**
  - A common depressed reaction to the death of a loved one

- **Mourning**
  - A reaction activated by a person to assist in overcoming a great personal loss

Grief and Grieving

- Sudden death of someone who is not "supposed to" die is the most difficult grief to bear.
- Parents and siblings are often wracked by powerful and personal emotions of guilt, denial, and anger, as well as sorrow.
- Blame and guilt can destroy a family just when family members need each other most.
Special Supportive Care

- Sudden or Unexpected Death
  - Accident, homicide, and sudden illness are difficult to cope with.
  - There is "unfinished business," such as things left unsaid or undone.
  - There can be an obsessive need to understand or know why this has happened.

SUICIDE STATISTICS

- Every 78 seconds a teen attempts suicide - every 90 seconds they succeed. (National Center for Health Statistics)
- 63% of suicides are individuals from single parent families. (FBI Law Enforcement Bulletin - Investigative Aid)
- "Separation, divorce and unmarried parenthood seemed to be a high risk for children/adolescents in these families for the development of suicidal behavior". (Atilla Turgay, M.D. American Psychiatric Association's Scientific Meeting, May 1994)

Special Supportive Care

- Suicide
  - Survivors of a person who has committed suicide suffer all the emotions of grief, in addition to profound guilt or shame.
  - Survivors fear rejection and lack of social and religious support.
  - Survivors are at risk for suicide themselves, and a grief counselor may be helpful.
Special Supportive Care

• Perinatal Death
  – The death of a child before, during, or shortly after birth
  – Often viewed as **one of the most devastating losses that can occur in a family.**
  – When possible, the parents should see, touch, and hold the infant, so that the reality of the situation can be faced and resolution of the grief can occur.

Special Supportive Care

• Pediatric Death
  – PT’s should be aware of how children view or understand death, both for themselves and for others.
  – They need to be told the truth in language they can understand and be allowed to share fears, feelings, and opinions.
  – Parents may express hostility and anger toward health care providers, God, or the world in general.

Special Supportive Care

• Gerontologic Death
  – The older patient must be treated as an individual, and the PT should assess the patient’s needs in the same way as for any patient facing a terminal illness.
  – Families who suffer the loss of an older person may accept the death but nonetheless must experience the grieving process.
• **Advanced Directives**
  - Signed and witnessed documents providing specific instructions for health care treatment in the event that a person is unable to make those decisions personally at the time they are needed.
  - Living wills
    - Written documents that direct treatment in accordance with patient’s wishes in the event of a terminal illness or condition
  - Durable powers of attorney
    - Designates an agent, a surrogate, or a proxy to make health care decisions on patient’s behalf

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• **Euthanasia**
  - **Active Euthanasia**
    - An action deliberately taken with the purpose of shortening life to end suffering or to carry out the wishes of a terminally ill patient.
  - **Passive Euthanasia**
    - Permitting the death of a patient that takes the form of withholding treatment that might extend life, such as medication, life-support systems, or feeding tubes.

• **Do Not Resuscitate (DNR)**
  - DNR decision should be a joint decision of the patient, family, and health care providers.
  - DNR means only not to resuscitate; it does not mean to withhold any other care.
  - All DNR orders and the discussion with the patient and family should be thoroughly documented in the patient’s chart.
  - Patients and families should control any decisions relative to any conditions that withhold or withdraw treatment.
**Organ Donations**

- Legally competent people are free to donate their bodies or organs for medical use.
- In most states (National Organ Transplantation Act), required request laws stipulate that **at the time of a person’s death, a qualified health care provider must ask family members to consider organ or tissue donation.**
- The Uniform Anatomical Gifts Act addresses many problems of organ donation and stipulates that the physician who certifies death shall not be involved in removal or transplantation of organs.

**Body Donation**

- UC Davis Med Center
  - 916-530-752-1918
- UC SF
  - 415-476-1981
- You can register in advance

**Grief and Grieving**

- Pt's Role
  - Assess for grieving behaviors.
  - Recognize the influence of grief on behavior.
  - Provide empathetic support.
  - Realistic goal: patient to do as much for self as possible…provides dignity
Grief and Grieving

- PT’s Grief
  - A PT must come to grips with
    - Understanding the grief process
    - Appreciating the experience of the dying patient
    - Using effective listening skills
    - Acknowledging personal limits
    - Knowing when there is a need to get away and take care of the self

The Dying Patient

- Assessments and Interventions for the Dying Patient
  - Most crucial needs are control of pain, preservation of dignity and self-worth, and love and affection.
  - Assessing for impending death
    - Restlessness
    - Discoloration of arms and legs
    - Changes in vital signs: slow, weak, and thready pulse; lowered blood pressure; rapid, shallow, irregular, or abnormally slow respirations

- As death becomes imminent
  - Pupils dilated and fixed
  - Cheyne-Stokes respirations
  - Pulse weaker and more rapid
  - Blood pressure continues to fall
  - Skin cool and clammy
  - Profuse diaphoresis
  - Death rattle: noisy respirations
The Dying Patient

• Clinical Signs of Death
  – Unreceptively and unresponsiveness
  – No movement or breathing
  – No reflexes
  – Flat encephalogram
  – Absence of apical pulse
  – Cessation of respirations

The Dying Patient

• Postmortem Care
  – This is care of the patient’s body after death.
  – The body should be cared for as soon as possible after death to prevent tissue damage or disfigurement.
  – Offer the family the opportunity to view the body.
  – Before the family views the body, prepare it and the room to minimize the stress of the experience.
  – The body should be made to look as natural and comfortable as possible.

Grief and Grieving

• Anticipatory Grief
  – This type of grief is to expect, await, or prepare oneself for the loss of a family member or significant other
  – It is somewhat easier to cope with loss if it is expected.
  – Having time for anticipation does not necessarily ease the pain of loss.
  – Emotions expressed at this time can make the loss less conflicted.
Grief and Grieving

• Bereavement Overload
  – The initial loss was compounded with an additional loss before resolution of the initial loss.
  – When you experience multiple losses and fail to adequately process them.
• Burnout
  – The stresses exceed the rewards of the job and the individual caregiver lacks the support of peers.

Grief and Grieving

• Stages of Grief and Dying
  – Kübler-Ross Stages of Grieving/Dying
  – Can you name them?
    1. Denial and isolation
    2. Anger
    3. Bargaining
    4. Depression
    5. Acceptance

Grief and Grieving

• Stages of Grief and Dying
  – Mustachio’s Manifestations of Grief and Bereavement
    • Shock and disbelief
    • Yearning and protest
    • Anguish, disorganization, and despair
    • Identification in bereavement
    • Reorganization and restitution
Grief and Grieving

• Unresolved, Dysfunctional Grief
  – Bereavement is a state of great risk physically, as well as emotionally and socially.
  – Unresolved Grief
    • There have been some disturbances of the normal progress toward resolution.
  – Dysfunctional Grieving
    • There is a delayed or exaggerated response to a perceived, actual, or potential loss.

Grief and Grieving

• Unresolved, Dysfunctional Grief
  – Dysfunctional grief occurs when an individual
    • Gets “stuck” in the grief process and becomes depressed
    • Is unable to express feelings
    • Cannot find anyone in daily life who acts as the listener he or she needs
    • Suffers a loss that stirs up other, unresolved losses
    • Lacks the reassurance and support to trust the grief process and fails to believe that he or she can work through the loss

Grief and Grieving

• Signs, Symptoms, and Behaviors of Dysfunctional Grieving
  – Acquisition of symptoms belonging to the last illness of the deceased
  – Alteration in relationships with friends and relatives
  – Lasting loss of patterns of social interaction
  – Actions detrimental to one’s social and economic well-being
  – Agitated depression with tension, insomnia, feelings of worthlessness, bitter self-accusation, obvious needs for punishment, and even suicidal tendencies
Grief and Grieving

- Signs, Symptoms, and Behaviors of Dysfunctional Grieving (continued)
  - A feeling that the death occurred yesterday, even though the loss took place months or years ago
  - Unwillingness to move the possessions of the deceased after a reasonable amount of time
  - Inability to discuss the deceased without crying, particularly more that 1 year after the loss
  - Radical changes in lifestyle
  - Exclusion of friends, family members, or activities associated with the deceased

Grief and Grieving

- Supportive Care During the Dying and Grieving Process
  - Assessment
    - To give compassionate nursing care and support to the family and patient during the grieving and dying process, the PT should consider the five aspects of human functioning:
      - Physical
      - Emotional
      - Intellectual
      - Sociocultural/psychosocial
      - Spiritual

Grief and Grieving

- Supportive Care During the Dying and Grieving Process
  - Physical Assessment
    - Sleeping patterns
    - Body image
    - Activities of daily living (ADLs); mobility
    - General health
    - Medications
    - Pain
    - Basic needs: nutrition, elimination, oxygenation, activity, rest, sleep, and safety
Grief and Grieving

• Supportive Care During the Dying and Grieving Process
  – Emotional Assessment
    • Patient’s and family’s anxiety level, guilt, anger, level of acceptance, and identification
    • Major fears: abandonment, loss of control, pain and discomfort, and the unknown

Grief and Grieving

• Supportive Care During the Dying and Grieving Process
  – Intellectual Assessment
    • Evaluation of the patient’s and family’s educational level, their knowledge and abilities, and expectations they have in regard to how and when death will occur

Grief and Grieving

• Supportive Care During the Dying and Grieving Process
  – Social Assessment
    • Assessment of the patient’s and family’s support systems is valuable.
    • Ascertain whether family members desire to assist in the patient’s daily care. Never assume they do; many do, others do not.
    • When families choose to take the patient home for care, be sure that they are well-prepared before discharge for what they need to know and do.
Grief and Grieving

- Supportive Care During the Dying and Grieving Process
  - Spiritual Assessment
    - Assess the spiritual dimension by gaining insight into the patient’s philosophy of life, religious resources, and how the rituals of the particular faith group have significance in dealing with his or her death.

- Rights of Dying Patients
  - Death with dignity is the goal in caring for the dying patient.
  - “The Dying Person’s Bill of Rights” is honored at hospitals and other health care agencies and is posted in prominent areas.

- Fraudulent Methods of Treatment
  - Often patient and family seek unconventional methods of treatment to prolong the patient’s life.
  - Treatments that are misrepresented, whether by concealment or nondisclosure of facts, for the purpose of inducing another to use the product are fraudulent.

The Dying Patient

- Communicating With the Dying Patient
  - Therapeutic communication expresses respect for the patient, maintains realistic hope, and offers appropriate reassurance and support.
  - Careful attention to what the patient expresses verbally and nonverbally is required.
  - If patients do not wish to communicate at a particular time, they need to know that this is acceptable and will be respected.
The Dying Patient

• Assisting the Patient in Saying Goodbye
  – This may be expressed in verbal, nonverbal, concrete, and symbolic ways.
  – Provide a private, comfortable environment.
  – They should be encouraged to express those feelings and thoughts they would most want their loved ones to know in their absence.

The Dying Patient

• Palliative Care
  – According to the World Health Organization, when health care providers deliver palliative care, they do the following:
    • Provide relief from pain and other distressing symptoms
    • Affirm life and regard dying as a normal process
    • Neither hasten nor postpone death
    • Integrate psychological and spiritual aspects of patient care

The Dying Patient

• Palliative Care (continued)
  – Offer a support system to help patients live as actively as possible until death
  – Offer a support system to help families cope during the patient's illness and their own bereavement
  – Enhance the quality of life
• Special Considerations for Children
  – The child’s developmental level determines the amount and type of detailed information that should be discussed with the child.

• Documentation
  – It must be objective, complete, legible, and accurate.
  – It should be frequent and include the signs of impending death as they occur.
  – The last entry should state where and to whom the body was transferred.

The Grieving Family

• Support
  – The needs of the grieving family and significant others should be met by a caring, compassionate health care provider.

• Resolution of Grief
  – Begins when the grieving person can complete the following tasks
    • Have positive interactions, participate in support groups, establish goals and work to achieve them, discuss the meaning of the loss and its effect.