

Module # 20: Grief and Bereavement

Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 20: Grief and Bereavement

**James J. Peters VA Bronx Medical Center
Geriatric Research, Education & Clinical Center**

**Mount Sinai School of Medicine
Brookdale Department of Geriatrics and Adult Development**

This interdisciplinary curriculum is geared to allied health students and may be reproduced and used with attribution.

**Geriatrics, Palliative Care and
Interprofessional Teamwork Curriculum**

Module # 20: Grief and Bereavement

Table of Contents

	Page(s)
I. Overview	1
II. Learning Objectives	1
III. Reactions And Coping With Dying	2
IV. Settings At The End Of Life	6
V. Dying As A Physical, Psychological, Social, And Spiritual Event	7
VI. Care Of The Patient And Family Immediately Following Death	16
VII. Grief And Bereavement	18
VIII. Psychological, Physical, And Social Manifestations Of Grief	21
IX. Assessment Of Loss And Grief	23
X. Intervention Strategies For Loss And Grief	24
XI. Worden's Counseling Principles	25
XII. Complicated Grief Reactions	27
XIII. Conclusion	28
XIV. References	29

Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 20: Grief and Bereavement

I. Overview¹

- We are dying from the moment we were born.
- Dying persons are living human beings.
- Dying is a special situation in living.
- Death is the outcome of dying, not its equivalent.
- Like all other individuals, dying persons have a broad range of needs, desires, plans, projects, joys, suffering, hopes, anxieties, and fears.
- We cannot become effective providers unless we listen actively to those who are coping with dying and identify with them their own needs.
- We need to learn from those who are dying and coping with dying in order to know ourselves better.

II. Learning Objectives

1. Discuss the use of denial in coping with terminal illness.
2. Identify the settings of end of life care.
3. Discuss dying as a physical, psychological, social, and spiritual event.
4. Apply guidelines for interventions in end of life care.
5. Discuss ways of promoting an appropriate death.
6. Assess and treat the common physical symptoms during the last hours of life.
7. Describe physiological changes after death.
8. Identify the principles of care following death.
9. Discuss communication with families and ways of providing support following patient death.
10. Define key terms related to loss, grief, death, and bereavement.
11. Identify factors influencing the grief reaction.
12. Describe psychological, physical, and social manifestations of grief.
13. Discuss the processes of grief and mourning.
14. Conduct a grief assessment.

III. Reactions And Coping With Dying

- A. Initial Awareness of Dying From: ¹
- Direct or indirect statements from physicians, health professionals, or family
 - Changes in behavior of others
 - Changes in treatment
 - Changes in physical environment
 - Self-diagnosis from one's body
- B. Task-Based Model for Coping with Dying ²
- Physical tasks: satisfy bodily needs and to minimize physical distress in ways that are consistent with other values.
 - Psychological tasks: maximize psychological security, autonomy, and richness of living- get dressed use perfume, taste desired food (dignity).
 - Social tasks: sustain interpersonal relationships that are significant (concern for self and family) and to address social implications of dying. (i.e. Meals on Wheels, obtaining hospital equipment, and transportation assistance.)
 - Spiritual tasks: to identify, develop, or reaffirm sources of spiritual energy and in doing so to foster hope. (Life review)
- C. Three Spiritual Tasks When Dying: ³
1. Find meaning in life.
 2. To die appropriately consistent with one's identity.
 3. Find hope that extends beyond the grave.
 - Hope to be without pain.
 - Hope to see his grandchild born.
 - Time to say good-byes.
 - Hope may be based on personal aspirations or emphasize desires and welfare of the group.
 - Hope is grounded in reality and is really about faith and trust in the meaning and goodness of life.
- D. Emotional Reactions and Fears of the Dying Patient ¹
1. Anxiety
Deal with anxiety by breaking it down into its component parts to delineate the specific fears and address each one. Such fears may include:
 2. Fear of the Unknown-especially in the acute crisis phase.
 - a. Questions that may be answered or are philosophical and cannot be

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

answered:

- What life experiences will I not be able to have?
- What is my fate in the hereafter?
- What will happen to my body after death?
- What will happen to my survivors?
- How will my family and friends cope?
- What will happen to my projects and life plans?
- What changes will occur in my body?
- What will be my emotional reactions?

3. Fear of Loneliness

In sickness, others are often uncomfortable to see the person ill and in pain, so there is avoidance leading to loneliness and isolation from social contacts. Family members have their own fear of death and isolation in hospital environment. Loneliness is the prospect that they will be abandoned in their sickness. In the acute phase, determine who will remain with the patient. In the chronic phase, need to engage person in everyday relationships so that dying does not become their sole focus. Indicate to the patient that he need not feel loneliness, although at times he may be alone.

4. Fear of Loss of Family and Friends

Dying person needs to clarify and accept ambiguous and conflicting emotions between himself and his loved ones in an effort to achieve some acceptable resolution and reaffirm the meaning and value of relationships.

5. Fear of loss of self-control

Help patient maintain control such as decision-making in daily tasks and arranging the funeral. This allays the sense of guilt, frustration and helplessness due to the illness.

6. Fear of loss of body parts and disability

Loss of body parts brings shame, inadequacy, guilt feelings, and fears of being unloved. Continue to show respect and not disclose aversion to them physically. Let the dying person do as much as possible in terms of feeding, bathing, grooming and exercise.

7. Fear of Suffering and Pain

Increase person's ability to tolerate pain by:

- Knowing that pain is not a form of punishment;
- That they will not be ignored or left alone;
- That pain will be managed as rigorously as possible.
- Remaining open and available to the person despite the pain and anxiety of attending to the terminally ill (also physical presence).

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

8. Fear of Loss of Identity
Loss of friends, function, and control along with attempts to maintain respect, dignity and integrity in the dying process-this can be accomplished through four processes:
 - a. Contact with those who have been an important part of their life.
 - b. Being treated as a living person rather than someone who is already dead (think of the person not the disease).
 - c. Maintain continuity with friends, family work and help them live as fully as possible.
 - d. Help recognize continuum of those who have died previously and those who will come after.

9. Fear of Sorrow
Identify sources of sorrow and work through them individually rather than all at once. Avoid premature detachment and sorrow.

10. Fear of Regression
Be attuned to the psychic changes of dying person turning inward and allow this withdrawal. Signs of withdrawal:
 - No interest in seeing others.
 - Stop watching TV and reading.
 - Lie down facing the wall rather than the door.

11. Fears of mutilation, decomposition, and premature burial
Allow choosing own body deposition and providing appropriate information about it.

12. Depression is a natural reaction to perception of imminent loss.

Signs of depression include:
 - expressions of sadness
 - social withdrawal
 - psychomotor retardation
 - apathy
 - nonverbal body language like facing away from people or crying
 - somatic complaints
 - agitation
 - restlessness.

13. Anger and Hostility

Evidenced by negative verbalizations, aggressive behavior, sarcasm, negativity, obstinacy, passive-aggressive, withdrawal, or jealousy. Anger may really be a cover for grief and anxiety. Anger by patient may lead to

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

avoidance of caregivers. Caregivers need to recognize the anger and hostility as natural and appropriate reactions. Do not react with counter-hostility. Allow the patient to express anger and hostility without being judged or made to feel guilty. Also investigate appropriate sources of anger.

14. Guilt and Shame

Guilt evident by words and behaviors that demonstrate self-punishment, withdrawal, or self-sabotage.

a. Guilt felt when:

- People behave contrary to their ethical principles.
- Fall short of their self-image.
- Violate their conscious or unconscious standards.
- Believe they are stressing loved ones and are drains on resources.
- Experience dependence on others-loss of self-reliance, and loss of independence and productivity.
- Believe that illness is a form of punishment for past real and imagined offenses.
- Experience guilt for angry feelings towards others who are not terminally ill.
- Feel guilty because he has lost control of emotions and cried.

b. Relieve Guilt by:

- Self-help group-see that feelings are normal.
- Irrational belief or standards may be relinquished.
- Learn to forgive self for changes that are out of one's control.
- Finishing unfinished business.

E. Exclusion of the Threat of Death or Its Significance from Awareness ^{1,3}

Done by repression, suppression, denial, rationalization, depersonalization, and projection.

1. Repression: Force anxiety-producing thoughts from your mind into the unconscious--only useful for a limited time since symptoms are constant reminders.
2. Suppression: Conscious attempt to dismiss anxiety-provoking thoughts by diversionary activities. It is helpful to allow patients to distance themselves from the ever-present threat of death. Constantly bombarding patients with questions and experiences and forcing them to face their own death can be harmful.
3. Denial: Pushes into unconscious uncomfortable thoughts and ideas. Respite from the threat of death.

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

4. Rationalization: Attempt to understand the circumstance and find a reason for the experience.
 5. Depersonalization: Consider the experience as not related to oneself.
 6. Projection: Project feelings about the experience onto other individuals.
- F. Denial in Terminal Illness ^{2,3}
1. Types of Denial:
 - a. Denial of specific facts about the illness.
 - b. Denial of the implications and extensions of the illness (realizes the seriousness but denies that it will end her life).
 - c. Denial of extinction (recognizes seriousness of the illness but does not believe that she will die of it).

If denial serves to hold the individual together then it is therapeutically useful.

During the illness, denial may be intermittently employed when the patient is confronted with anxiety that is too overwhelming.

In the living-dying interval, the individual will vacillate between denial and acceptance. There are different degrees and combinations of denial and acceptance over the living-dying interval. Yet, extreme denial is detrimental or harmful because eventually they will have to face the threat all at once.

Denial can have positive or negative value—if it blocks action it is negative; if it directs action, it may reduce the stress. Denial is time-related—helpful in the initial stage of coping with the illness. Denial of known is more harmful than denial of the unknown. Denial is more helpful if it is partial or minimal.

IV. Settings At The End Of Life ⁴

- A. In end-of-life care, an important role of the health professional is advocate for the patient/family in any setting.
 - Deaths occur in hospitals, homes, nursing facilities, assisted living facilities, prisons, hospice residences and other health care settings.
 - In a hospital setting, patients may die in intensive care or the emergency room, and infants may die in labor and delivery.
 - No matter where or how death occurs, the nurse has the responsibility to follow patient/family choice and create a supportive physical, psychological, social and spiritual care environment.

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

- Patient/family choice may include advocating for where the patient wants to die, and with who they want to die.
- B. Each setting should provide a supportive physical environment. Following are suggestions for various settings:
- Putting family pictures on the wall in a nursing facility, bringing a favorite blanket to the hospital, allowing a pet to visit in an assisted living facility, allowing family members to visit and/or stay during a death vigil in a prison are part of a supportive physical environment that may be comforting to the patient.
 - In the hospital setting, visiting hour restrictions and lack of space for privacy may require the nurse to be creative in providing a quiet place for family members to find privacy to be alone with loved ones.
 - In a nursing facility, privacy may also be an issue in terms of space for family members to spend time alone with their loved ones.
 - These situations and many others challenge the nurse to creatively find ways to provide a supportive physical environment according to patient choice.
- C. It is important not to change the setting in final stages of life unless desired by the patient
- Transferring an imminently dying patient such as from a nursing home to hospital can be very disruptive and distressing.
 - The setting should only be changed as a last measure and preferably only if the patient and family request the change.
 - Patients and families should be given options in care, education about care and/or increased support so the patient can die where he/she chooses.

V. Dying As A Physical, Psychological, Social, And Spiritual Event ⁴

A. General Considerations:

- Patient and family together are the unit of care (family is defined by the patient which may include friends, significant others, partners, lovers).
- To meet the needs of dying patients and their families, an interdisciplinary approach to care is crucial. The nurse should seek support from other professionals in care of the dying including psychosocial professionals (e.g. social workers, counselors), spiritual care providers (e.g. pastors, chaplains, priests, rabbis, and spiritual advisors), nurses' aides, volunteers, and physicians. Each discipline has expertise in specific areas and that combined expertise makes the highest quality care possible.
- The team will need to do an individualized assessment and identify problems, issues and opportunities specific to patient/family choice in end-of-life care.

**VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement**

At the time of nearing death, the interdisciplinary team serves as advocate for the patient/family and provides interventions directed at comfort, minimizing physical, psychological, social and spiritual pain and suffering, and honors and respects patient/family choices/wishes.

B. Dimensions of Care at the End of Life: ^{1,2}

1. Physical Care

- Relief of pain and other symptoms. Terminally ill patients do not become addicted to opioids but they will develop physical tolerance.

2. Psychological Care

- Most helpful is just be present.
- Anger must be recognized, acknowledged and expressed. Anger must be worn off (anger that others are enjoying life; anger at physical restrictions.) Most helpful just to listen.
- You don't know how they feel.
- Don't want them to stop having their negative feelings—that is our own distress as caregivers—dying people must be helped to identify their feelings, acknowledge their feelings as appropriate to the situation and give them permission to vent their feelings.
- Helpers should turn off their own internal monologue of the right response and listen empathetically.
- Touch, such as massage, holding hands or giving a hug, may be psychologically helpful.

3. Social Care

Helped by fostering interpersonal relationships and attachments. The dying person wants to be able to give care and receive care from special people in their lives. Caregivers need to be sensitive to the identities of these special people and to the nature of the attachments, and to how the relationships could be maintained and nurtured.

Social needs also include concerns for roles in family, work and community. Help patient cope by allowing them to discuss concerns and by being an advocate for the person. Help them identify their options.

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

4. Spiritual Care

Questions Patients may Ask: Where is God in all of this? What is the meaning of life and my suffering? Have I achieved the goals I wanted to achieve?

Frequently people ask these questions just to articulate their own thoughts but not to receive an answer. Just listen. Dying people need to work out their own answers to their own questions.

Care should give “Another good day of living” verses “Another terrible day of dying.” Hope centers on fulfilling expectations and a focus on what still can be done. We must listen to the individual to find out the object of their hope.

C. Guidelines for Interventions with Dying Patients ²

- Care requires collaboration to meet the individuals and families’ physical, emotional, social, legal, economic and spiritual needs.
- Dying involves the needs of patients, family, and caregivers.
- Isolation should be avoided. Social events and shared work are needed to sustain relationships.
- Profound involvement without the loss of objectivity by caregivers.
- Organizational structure that provides links with health care professionals in the community.
- An environment should be provided with adequate space and furnishing to put people at ease.
- Patients need professionals highly specialized in terminal care.
- Patient should be kept symptom free.
- Continuity of care should be provided.
- Patient's own values, frameworks and preferences must be respected.
- Patient’s wishes for information should be respected allowing full participation
- Patient should have a sense of security and protection with involvement of the family and friends.

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

- Twenty-four hours of care available.
- Help provided to the family.
- Interchange between the family and clinical team.
- Discuss all aspects of the dying process with the family.
- Patient and family should have time alone with privacy.
- Procedures arranged to provide maximal family time.
- Religious, philosophical and emotional components of care are essential and should be included in the team approach.
- Care for survivors who gave care and support to the deceased.
- Staff should be educated and supported in terminal care by the institution.
- Staff needs time to develop and sustain relationships with patients and families.
- Staff should receive support.

D. Objectives for Interventions:

1. Safe conduct for the dying
 - Alleviate emotional suffering, loneliness and anguish of patient and family.
 - Engage patient and family in the treatment.
2. Significant survival and dignified death
 - Realizing the value in what we are and what we do—find significance in the last few phases of living.
 - What was significant to the patient during earlier and healthier days to recall a sense of well-being and self-esteem—Remembrances preserve dignity.
3. Dignified death
 - When an individual is regarded as a responsible personal, capable of clear perceptions, honest relationships, purposeful behavior, with privacy and without neglect or infantilization.

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

4. Appropriate Death

- One that is not necessary ideal but is consistent with an ego ideal with the continuity of important relationships and with reactive grief resolved. There is an absence of suffering and exercise of options.

E. Suggestions to Promote an Appropriate Death²:

- Accept person as he would be like without the illness.
- Make allowances for deterioration and disability.
- Encourage the person to talk about how the illness has changed him.
- Understand the difference between the sickness, disease, and sickness until death.
- Ask about the person, his pursuits and possessions that meant the most to him.
- Preserve communication that preserves self-esteem.
- Monitor your own feelings and elicit support.
- Time your discussions about death.
- Unless the person's consciousness has compromised his judgments, do not exclude the patient from decisions and information.
- Encourage decisions to be made with the family.
- Assess the changes that death will bring to the family.
- Help bereaved families with the practical adjustment.
- Recognize iatrogenic distortions and psychosocial complications.
- Recognize the patient's cultural, social and personal value systems along with personality characteristics and factors specific to the illness.

F. Common Physical Symptoms During the Last Hours of Life ^{5,6}

1. Increased Weakness and Fatigue (Asthenia)

a. Weakness and fatigue are likely to increase as the patient gets closer to death. In the last hours of life, it is likely that the patient will not be able to move very much.

b. Joint position fatigue: joints become uncomfortable if they are not moved and require passive movement of the joints every 1 to 2 hours

c. As death approaches, the need for turning lessens as the risk of skin breakdown becomes less important.

2. Decreased Appetite (Anorexia)

a. Most dying patients lose their appetite and lose weight (cachexia). Anorexia and cachexia are due in part to proinflammatory cytokines and

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

other humoral factors which induce catabolism. Therefore, artificial feeding to improve nutrition often does not impede weight loss.

b. Families often fear that the patient is giving in, or suffering from starvation. They should be reminded that food may be nauseating for the patient and anorexia may be protective. By forcing food, the risk of aspiration is increased and tensions. Clenched teeth on the patient's part often-express desires and control. Help family find alternative ways to care.

c. Families should be educated that there is little evidence that prolonged anorexia is uncomfortable.

3. Decreased Fluid Intake

a. Oral rehydrating fluids – parenteral fluids, either intravenously or subcutaneously may be considered, especially to reverse delirium. However excess can lead to fluid overload with consequent peripheral or pulmonary edema, worsened breathlessness, cough, and orotracheobronchial secretions, particularly if there is significant hypoalbuminemia. There is no evidence that indicates that rehydration improves patient comfort. In contrast, dehydration may improve comfort by inducing uremia, hyperosmolality and endorphin release.

b. Families often fear that the patient is suffering from dehydration and thirst. They must be reminded that dehydration does not cause distress and that it may be protective.

c. Mucosal / Conjunctival Care: In order to alleviate discomfort, moisture should be maintained in the mucosal membranes. Oral mucosa should be moistened and cleaned every 15-30 minutes with either baking soda mouthwash or an artificial saliva preparation to minimize the sense of thirst. Lips and anterior nasal mucosa should be coated every hour with a thin layer of petroleum jelly. If eyelids are not closed, the conjunctiva should be moistened either with ophthalmic lubricating gel every 3-4 hours or with artificial tears every 15-30 minutes.

4. Decreased Blood Perfusion and Renal Failure

a. Tachycardia, hypotension, peripheral cooling, cyanosis, and mottling of the skin are normal.

b. Diminished urine output as perfusion of the kidney diminishes.

c. Parenteral fluids will not reverse this circulatory shut down.

5. Neurological Dysfunction During the Last Hours of Life

The result of multiple concurrent nonreversible factors, including hypoxemia, metabolic imbalance, acidosis, toxin accumulation due to liver

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

and renal failure, adverse effects of medication, sepsis, disease-related factors, reduced cerebral perfusion, etc.

a. Decreasing Level of Consciousness

1. The usual road to death: normal, sleepy, lethargic, obtunded, semicomatose, comatose, death.
2. The difficult road to death: normal, restless, confused, tremulous, hallucinations, mumbling delirium, myoclonic jerks, seizures, semicomatose, comatose, death.
3. Absence of eyelash reflexes on physical examination indicates a profound level of coma equivalent to full anesthesia.
4. The capability for complex communication by dying patients declines, particularly if the patient is receiving high doses of opioids.
5. Patient's inability to communicate is usually very distressing to family.
6. Patient's awareness is generally greater than ability to respond, therefore one should assume the patient can hear everything.
7. In order to maximize the patient's comfort, help the family strive to create familiar environment and include the patient in conversations. They should be encouraged to give the patient permission to die, and to touch the patient.

b. Terminal Delirium

1. Delirium is characterized by fluctuating disturbances in consciousness, cognition, and perception in 28% to 83% of patients near the end of life.
2. Search for possible causes:
 - may include indirect or direct effects of another disease or treatment on the Central Nervous System
 - cause is usually multifactorial.
 - causes are often irreversible.
3. Work Up:
 - Work-up may be limited by the setting.
 - Unpleasant or painful diagnostic procedures may be avoided because the focus of care is usually more on patient comfort

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

4. Three types of terminal delirium are:
 - Hyperactive (with restlessness, agitation, and hallucinations)
 - Hypoactive (with somnolence)
 - Mixed (with alternating features of both)
5. This usually causes great distress for the family or caregiver, as it often seems as though the patient is in more pain than he is actually in.
6. Medical management: benzodiazepines (lorazepam, midazolam) and neuroleptics (haloperidol, chlorpromazine). For seizures, high doses of benzodiazepines.
6. Changes in Respiration
 - a. Breathlessness (Dyspnea). Parenteral or oral opioids relieve dypnea but there is no evidence that nebulized opioids are of benefit. Benzodiazepines may alleviate dypnea if there is an anxiety component. A fan blowing on the face stimulates the trigeminal nerve and often improves breathlessness.
 - b. Altered breathing patterns: diminishing tidal volume, periods of apnea, Cheyne- Stokes respirations and accessory respiratory muscle use may all appear; last reflex breaths may signal death.
 - c. The family usually fears suffocation, however the patient generally will not experience feelings of suffocation.
 - d. Oxygen administration likely provides no benefit but is used widely to address caregiver concerns.
7. Loss of Ability to Swallow
 - a. Loss of gag reflex and build-up of saliva and secretions may lead to gurgling, crackling, or rattling sounds sometimes referred to as “death rattle”
 - b. Once patient is unable to swallow, oral intake must be ceased or will risk aspiration.
 - c. Scopolamine to reduce production of saliva and other secretions
 - d. Postural drainage, turning patient on one side to reduce gurgling, semi-prone position (only for a few minutes)
 - e. Suctioning is *not* recommended
8. Loss of Sphincter Control: incontinence of urine, stool
 - a. Family needs knowledge, support, as this symptom often comes as a surprise

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

- b. Cleaning and skin care are very important
 - c. Absorbent pads, surfaces – can be used if incontinence is minimal
 - d. Urinary catheter – may minimize the need for frequent changing and cleaning, prevent skin breakdown, and reduce the demand on caregivers.
 - e. Rectal tube – may be useful if diarrhea is considerable and relentless
9. Loss of ability to close eyes
- a. Advanced wasting causes the loss of retro-orbital fat pad. This in turn causes the orbit to fall posteriorly within the orbital socket. Insufficient eyelid length to both extend the additional distance backward and cover the conjunctiva leads to conjunctival exposure.
 - b. Increased risk of dryness, pain.
Maintain moisture by using ophthalmic lubricants, artificial tears, or physiological saline.
- G. Psychiatric Symptoms During the Last Hours of Life
Often greatly affects the patient's quality of life as well as serve as major source of distress for family members
1. Anxiety
 - a. Symptoms: feelings of tension, apprehension, worry; signs of restlessness, an autonomic hyperactivity, hypervigilance, insomnia, distractibility, shortness of breath, tingling and numbness
 - b. Treatment: Psychotherapeutic Intervention and Pharmacotherapy: benzodiazepines, neuroleptics, antihistamines, anti-depressants, opioid analgesics
 2. Terminal Depression
 - a. Psychological/cognitive symptoms: worthlessness, hopelessness, excessive guilt, suicidal ideation, especially when pervasive and accompanied by a sense of despair or despondency
 - b. Symptoms such as fatigue, loss of energy, and other somatic symptoms are often not helpful in diagnosing cases of terminal depression, as they are generally characteristic in a dying patient.
 - c. Must take prognosis and time for treatment into consideration when deciding which drug to administer
 - d. Common treatments include tricyclic antidepressants or Selective Serotonin Reuptake Inhibitors. Ritalin may improve depression until the antidepressants take effect.
 - e. Psychotherapy may also relieve depression.

- H. Signs That Death Has Occurred⁴
1. Absence of heartbeat and respirations
 2. Pupils fixed
 3. Color turns to a waxy pallor as blood settles
 4. Body temperature drops
 5. Muscles and sphincters relax: release of stool and urine, jaw falls open, and body fluids may continue to trickle internally

VI. Care Of The Patient And Family Immediately Following Death

- A. Physiological Changes After Death²
1. Algor Mortis: Body temperature decreases with resultant loss of skin elasticity- Be careful removing tape to avoid skin breakdown.
 2. Liver Mortis: Bluish-purple discoloration that is the byproduct of red blood cell destruction. Occurs in dependent areas- elevate the head of the bed to prevent discoloration from the pooling of blood.
 3. Rigor Mortis: Stiffening of the body due to contraction of the smooth and skeletal muscles. To prevent disfiguring close the eyelids, insert dentures, close mouth and position the body in a natural position. After a period of hours, rigor passes and body becomes malleable.
- B. Principles of Care^{2,4}
1. Body should be clean and wrapped in clean coverings. Identify the body. Often nurses bath the body, comb the hair and put on clean covers. Remove any medical equipment or tubes. Allow family to assist in cleansing the body if they desire and to select the clothing they wish the deceased to wear.
 2. Keep normal position of features and form- eyes close, body straightened, arms at side, mouth closed, dentures replaced, folded towel used to prop up chin, raise head on one pillow. Don't use bandages to hold jaw as it may discolor or indent the skin.
 3. Find hairpieces.
 4. Before bathing remove all jewelry. Itemize all valuables and give to family and have them sign the receipt. If request to leave on wedding ring—make note and bandage.
 5. Replace soiled dressings and place waterproof plastic to prevent the escape of urine or feces. Reinforce any dressings.

**VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement**

6. May put on a mortuary gown or wrap in shroud—tag is attached to the outside bearing the same information as on the wrist.
 7. Prepare stretcher—body covered and taken to the morgue with dignity.
 8. In hospice, family and friends may stay with body and may bathe it. Muslim religious practice is to bathe the body by family.
 9. When families and friends do not assume the responsibility for funeral arrangements, the institutions may have to assume this responsibility.
 10. Local health departments have set up special regulations governing the treatment of bodies of persons who die of communicable diseases—Physician must notify any people handling the body.
 11. Evaluate the circumstances of the death. Any signs of foul play, suicide, missing medications should be reported to the appropriate authorities and/or coroner.
 12. If the patient is an organ donor, follow procedures as planned and in accordance with state, setting guidelines, policies and/or procedures.
- C. Communicating the Death and Providing Support ^{2,4}
1. Telling the family that the patient has died should be done with sensitivity.
 - Be open, honest in communication, and provide small amounts of information at the family's level of understanding.
 - Information about the death may need to be repeated due to the family feeling overwhelmed or shocked by the actual death.
 - Health professionals should have a general understanding of cultural beliefs, death rites, and rituals of the major cultures/population in their practice areas.
 - Belief systems about death may be influenced by age, race, religion, spirituality, gender, socioeconomic status, education level, traditions, rites, and rituals, beliefs about pain, suffering, death, life and after life.
 - Following the death, family members may feel numb, and confused about what to do next. Explain the process/procedures following the death.
 - If the family has planned for burial, embalming is best done within 12 hours of death.

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

- In most settings, the funeral home will require a time of death, social security number, diagnosis, physician, and survivor contact.
- Family members may need time to adjust to the immediate loss before they are able to make phone calls. Some family members, however, find healing in immediately telling the story of the death to family, friends. Offer to assist with phone calls and assist per family request. Notifications: Assist with notifying the physician, co-workers, and other involved health care agencies.
- Pastoral care can assist with services and help facilitate decision-making about funeral/memorial services.
- Following the death, the practitioner should initiate bereavement support by providing compassion, active listening, and presence. In addition, the practitioner should assess grief reactions and assess bereavement risk factors. Follow-up bereavement support through phone calls, cards, attending funeral/memorial service and visits are helpful for the family and nurse's closure with the deceased.

VII. Grief And Bereavement

A. Introduction ¹

1. Grief is a process. Grief begins before the death for the patient and survivor as they anticipate and experience loss. Grief continues for the survivor with the loss of the patient.
2. The grief process is not always orderly and predictable. Usually the grief process includes a series of stages and/or tasks that the survivor moves through to help resolve grief. This is sometimes referred to as "grief work."
3. No one really "gets over" a loss, but he/she can heal and learn to live with a loss and/or live without the deceased.

B. Definitions: ^{1,2}

1. Loss

The absence of a possession or future possession. The value of the possession is determined by and unique to the individual experiencing the loss. Losses are experienced in daily life such as through divorce or children leaving home. Losses may also occur before the death for the patient and significant others as they anticipate and experience loss of health, changes in relationships and roles and loss of life. After a death, the survivor experiences loss of the loved one. Most losses will trigger mourning and grief and accompanying feelings, behaviors and reactions to the loss. Patients, family members and survivors experience loss.

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

2. Grief
The emotional response to a loss. Grief is the individualized and personalized feelings and responses that an individual makes to real, perceived, or anticipated loss.
 3. Bereavement
Both the situation and the long-term process of adjusting to the death of someone to whom a person feels close.
 4. Mourning
The outward, social expression of a loss. How one outwardly expresses a loss may be dictated by cultural norms, customs, practices including rituals and traditions. Some cultures may be very emotional and verbal in their expression of loss, some may show little reaction to loss, others may wail or cry loudly, and some may appear stoic and businesslike. Religious and cultural beliefs may also dictate how long one mourns and how the survivor "should" act during the bereavement period. In addition, outward expression of loss may be influenced by the individual's personality and life experiences
 5. Anticipatory Grief
Occurs with loss associated with diagnosis, acute and chronic illness and terminal illness experienced by patient, family and caregivers.
Examples: actual or fear of potential loss of health, loss of independence, loss of body part, loss of financial stability, loss of choice, loss of mental function
 6. Disenfranchised Grief
Encountered when a loss is experienced and cannot be openly acknowledged, socially sanctioned or publicly shared. Those at risk include partners of HIV/AIDS patients, ex-spouses, ex-partners, fiancées, friends, lovers, mistresses, co-workers, children experiencing the death of a stepparent, the mother of a stillborn delivery, terminated pregnancy.
- C. Factors Influencing the Grief Reaction ^{1,2,3}
1. Psychological Factors
 - The unique nature and meaning of the loss sustained or relationship severed.
 - The individual qualities of the relationship lost—strength of the attachment—hard to resolve ambivalent relationships—if small degree of attachment easier to deal with loss.
 - Role the deceased played in the family can reveal primary and secondary losses.
 - Individual's coping behaviors, personality and mental health. Usual coping mechanisms of grief.

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

- Avoidance of painful stimuli (not talking about deceased, Hiding pictures or mementos).
- Distraction with work, school etc.
- Food, alcohol or drugs.
- Obsession rumination—preoccupation with the cognitive details of loss.
- Impulsive behavior or escape—sell house—become deeply involved with another person.
- Prayer—offers hope, allows for relief of guilt and suffering.
- Rationalization and intellectualization—put loss in a less painful perspective.
- Contact with people—mitigates the intense feelings of loneliness and despair.
- Individual's level of intelligence and maturity.
- Individual's past experience with death and loss.
- Individual's social, cultural, ethnic and religious backgrounds.
- Individual's sex role conditioning.
- Individual's age—younger widows under 40 more at risk.
- Age and characteristics of the deceased.
- Death parent--lose past.
- Death spouse--lose present.
- Death child--lose future –hardest death to handle.
- Amount of unfinished business between the griever and the deceased.
- Individual's perception of the deceased's fulfillment in life.
- Immediate circumstances of death—location, type, reason, degree of preparation.
- Timeliness of death—psychological acceptability of death for this person at this time. Death of young is untimely.
- Individual's perception of preventability.

Sudden versus expected death

Anticipatory grieving doesn't lessen the grief but unexpected overwhelms people and severely reduces their functioning.

Length of the illness prior to death—too long can lead to poor bereavement outcomes. —Because of length of social isolation in caring for dying, physical debilitation from caring, and emotional exhaustion—remissions and relapse can lead to death wishes, which cause guilt. Better adjustment is short-term chronic illness less than six months rather than long term or sudden death.

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

- Number and types and quality of secondary losses.
 - Presence of concurrent stresses or crises.
2. Social Factors
- Individuals support system and acceptance of support—as well as timing of support—and support over time.
 - Religious, cultural and philosophical backgrounds.
 - Educational, economic and occupational status of bereaved.
 - Funeral rituals.
3. Physiological Factors
- Use of sedatives harmful—need to vent their feelings.
 - Need for nutrition, sleep and rest, exercise, and physical health.

VIII. Psychological, Physical, And Social Manifestations Of Grief ¹

A. Psychological Manifestations:

1. Avoidance Phase

- Characterized by shock, denial, disbelief, and intellectualization and making funeral arrangements, loss recognized but emotions denied. Difference between denying the death and denying the feelings stimulated by the death.

2. Confrontation Phase

- Characterized as full pain of grief—angry sadness—feeling indifferent to others—anxiety or panic—anger at deceased, God, others, self—mixture of negative and positive feelings toward deceased may lead to feelings of guilt (normal)—guilt at still being alive—guilt from unrealistic expectations of self—failure to protect—self reproach or worthlessness may be pathological if extreme. Depression and despair are normal.
- Feelings of loss of control—fleeting ideas of suicide.
- Heightened psychological arousal—irritability, anxiety, tension.
- Preoccupation with deceased—hugging tightly before saying goodbye— involves dreaming about the deceased, thinking he has seen her, or actively searching for her.
- To gain control—there may be an obsessive review of the circumstances of death.
- Grief attacks—come on unexpectedly with physical sensations- must stop activities to gain control.

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

- Identification with the deceased—take on their habits or hobbies.
 - Sense of relief—termination of responsibilities.
3. Reestablishment phase
- Beginning decline in grief and beginning of social and emotional reentry into the everyday world. Loss is not forgotten but put in a special place. Waxes and wanes with confrontation phase—it never arrives all at once.
- B. Social Manifestations of Grief
- Restlessness and inability to sit still.
 - Lack of ability to initiate and maintain a pattern of activity.
 - Social withdrawal behavior—pain of seeing others with their loved ones.
- C. Physical Manifestations of Grief
- Anorexia or GI problems.
 - Loss of weight.
 - Inability to sleep.
 - Crying.
 - Sighing.
 - Lack of strength, exhaustion.
 - Feelings of emptiness or heaviness.
 - Something in the throat.
 - Nervous.
 - Heart palpitations.
 - Loss of sexual drive or hyper sexuality.
 - Psychomotor retardation.
 - Restlessness.
 - Short of breath.
- D. Rando's 6 Processes of Mourning or Grief Work¹
1. Recognize the loss—acknowledge and accept the death.
 2. React to the separation—experience the pain, feel, identify, accept.
 3. Recollect and re-experience the deceased and the relationship. Review and remember realistically.
 4. Relinquish old attachments to the deceased and the assumptive world.

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

5. Readjust to move adaptively in the new world without forgetting the old. Develop new relationships with the deceased and form a new identity.
6. Reinvest.

Rando¹ defined **Complicated Grief** as grief that is present whenever, taking into consideration the amount of time since death, there is some compromise, distortion or failure of one or more of the six “R” processes.

IX. Assessment Of Loss And Grief ^{1,2,3}

A. General Considerations

1. Grief assessment begins at the time the patient is admitted to a hospital, nursing facility, assisted living facility, time of diagnosis of acute or chronic illness, terminal illness.
2. Grief assessment is on going throughout the course of an illness for the patient, family members and significant others and for the bereavement period after the death for the survivors. Grief should be assessed frequently during the bereavement period to alert the nurse to possible signs/symptoms/reactions of complicated grief.
3. The survivor’s anticipated and actual losses, emotional responses, and coping strategies must be repeatedly assessed. The interdisciplinary team, including the hospice nurses, social workers, and chaplains are particularly important in assessing and monitoring grief.
4. Many caregiver survivors do not care for themselves when caring for the deceased. As such, an assessment should also include:
 - A general health check-up and assessment of somatic symptoms;
 - A dental visit
 - An eye check-up as appropriate
 - Nutritional evaluation
 - Sleep assessment
 - Examination of ability to maintain work and family roles
 - Determination of whether there are major changes in presentation of self
Assessment of changes resulting from the death and the difficulties with these changes
 - Determine survivor's cultural practices in mourning and grief reaction.

B. Conduct a Grief Assessment by: ¹

Asking questions such as:

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

- Can you tell me about the death? What happened?
- Tell me about him about your relationship from the beginning?
- What has been happening since the time of death?
- Have you been through other bad times like this?

Identify:

- Illogical or magical thinking.
- Increased guilt and responsibility.
- What loss means to the mourner.
- All factors influencing grief.
- History of prior losses.
- Determine which tasks of grief are incomplete.

X. Intervention Strategies For Loss And Grief ^{1,2,3,}

- Need acceptance and nonjudgmental listening.
- Establish a relationship and be physically present especially during shock and disorganization and weeks and months later when the loss sinks in.
- Reach out in concrete ways- don't just say call me if you need me.
- Minimize the tendency for the bereaved to be overwhelmed. Remind to eat—get rest—suggest priorities—help with funeral decisions—help focus on problems one at a time.
- Give permission to grieve.
- Do not allow the griever to remain isolated. Absence of support creates complicated grief. Suggest self help groups or psychotherapy.
- Maintain family system perspective.
- Medical evaluation when symptoms warrant.
- Be realistic: You can't take away pain.
- Overcome your own sense of helplessness—don't pull back.
- Expect volatile emotions—especially early.
- Gift of presence—willingness to remain present—suspend judgment.
- Show care and concern.
- Don't let your own needs determine the experience of the mourner.
- Don't try to explain the loss—or pretty up the situation.

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

- Plant the seeds of hope—life will someday have meaning again—someday they will be in less pain allows them to carry on.
- Don't tell the griever not to cry.
- Help realize that he deals with his grief he can look forward to overcoming the pain and carrying on with life.
- Encourage verbalization and recollection of the deceased.
- Help the bereaved actualize and accept the loss.
- Assist griever in identifying the feelings such as anger sorrow, depression and relief, helplessness, anxiety.
- Help the griever own the feelings.
- Explore the griever's defenses if resisting the grief process such as excessive dependency, anger or guilt.
- Balance positive and negative—what do you miss about him—what don't you miss.
- Allow crying, talking, and reviewing –may go over situation or memory repeatedly.
- Don't be afraid to mention the dead person to the griever. Encourage the griever to realistically review the relationship.
- Help identify and resolve secondary losses and unfinished business such as loss of time with children due to second job, loss of sex partner, loss of social life, and loss of dreams hopes and fantasies.

XI. Worden's Counseling Principles ¹

Principle One: Help the Survivor Actualize the Loss

- Help the survivor come to a more complete awareness that the loss has actually occurred by:
- Talking about the loss—when, where, how did the death occur; what was the funeral like—reviewing the loss over and over is normal.
- Visiting the gravesite.

Principle Two: Help the Survivor to Identify and Express Feelings

- Anger—directed toward the deceased or displaced to others is normal. Anger that is directed toward self may lead to depression and suicide. Ask the individual such questions as:

“Has it been so bad that you thought of hurting yourself?”

“What do you miss about him?”

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

“What don’t you miss about him?”

- Holding on to only negative feelings may be a way of trying to avoid the sadness.
- Guilt is also a common reaction. Individuals question whether they obtained adequate medical care or what else could have been done?
- Anxiety, helplessness, and fear of their own death are often manifested. As professionals you can help them articulate these fears. By asking individuals how they managed on their own before the loss, you can help put feelings of anxiety and helplessness into perspective.
- Sadness is a common reaction. Suggest that they give themselves permission to cry.

Principle Three: Assist Living Without the Deceased

- Facilitating their ability to live without the deceased and to make decisions independently, involves using a problem solving approach. What are the problems that the survivor faces and how can they be solved?
- Help the person deal with the loss of their sexual partner. Recognize that the need to be held and touched is normal.
- Encourage bereaved not to make major life changing decisions in the first year.

Principle Four: Facilitate the Emotional Relocation of the Deceased

- Reminiscing helps to establish new relationships with the deceased. Encourage them not to jump into new relationships within the first year.

Principle Five: Provide Time to Grieve

- Critical time points are three months after the death when the support systems have pulled back, during anniversaries of the death, birthdays of the deceased, and holidays.

Principle Six: Interpret Normal Behavior

- People may feel that they are going crazy. Yet, hallucinations, distractibility, and a preoccupation with the deceased are normal.

Principle Seven: Allow for Individual Differences

- There is a wide range of behavioral responses.

Principle Eight: Provide Continuing Support

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

- Make yourself available to the griever over the most critical periods for the first year.

Principle Nine: Examine Defenses and Coping Styles

- Be alert to coping with drugs and alcohol, which can intensify the experience of grief and depression.
- Try to figure out why an individual refuses to look at pictures of the deceased or refuses to keep anything around as a reminder.

Principle Ten: Identify Pathology and Refer

Useful Techniques for Counseling

- Evocative language: “Your son died versus you lost your son”. Speaking of the deceased in the past tense: “Your husband was”.
- Use of symbols: bring in photos of the deceased, videos of the deceased, articles of clothing and allow the person to speak about their feelings.
- Writing: have the survivor write a letter to the deceased expressing thoughts and feelings- keep a journal of one’s grief experience or suggest writing poetry.
- Drawing: reflects ideas and feelings.
- Role playing: help model new behaviors.
- Cognitive restructuring—our thoughts influence our feelings—help clients identify those thoughts and reality test them such as the thought “no one will ever love me again.” Instead, have the individual say often “I am loved by others.”
- Memory book of photos, or mementos can help an individual create a new relationship with the deceased.
- Direct imagery—help people imagine the deceased and encourage them to say what they need to say to him or her talking to the person rather than talking about the person.

XII. Complicated Grief Reactions ¹

- A. Chronic grief: characterized by normal grief reactions that do not subside and continue over very long periods of time
- B. Delayed grief: characterized by normal grief reactions are suppressed or postponed. The survivor consciously or unconsciously avoids the pain of the loss
- C. Exaggerated grief: the survivor may resort to self-destructive behaviors such as suicide

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

- D. Masked grief: the survivor is not aware that behaviors that interfere with normal functioning are a result of the loss

XIII. Conclusion

- A. No one can predict when the grief work will be complete.
- B. Grief work is never completely finished as there will always be times when a memory, object, anniversary of the death or feelings of loss occur.
- C. Grief can diminish and healing occur as characterized by: the pain of the loss is less, the survivor has adapted to life without the deceased, the survivor has physically, psychologically and socially "let go." The survivor, however, will continue to experience memories of the deceased.

VISN 3 Geriatric Research, Education & Clinical Center (GRECC)
Geriatrics, Palliative Care & Interprofessional Teamwork Curriculum
Module # 20: Grief and Bereavement

XIV. References

1. Rando, T. (1984). *Grief, dying, and death: Clinical interventions for caregivers*. Champaign, IL.
 2. Corr, C., Nabe, C., & Corr, D. (1997). *Death & dying: Life & living*. CA: Brooks/Cole Publishing.
 3. Doka, K., & Morgan, J. (1993). *Death and spirituality*. New York: Baywood Publishing Company.
 4. American Association of Colleges of Nursing & City of Hope National Medical Center. (2005). *End-of-Life Nursing Education Consortium (ELNEC) Training Program*. (Module 9). Available from the American Association of Colleges of Nursing: www.aacn.nche.edu/elneec
 5. American Medical Association. (2005). *Education for Physicians on End-of-Life Care (EPEC) Trainers Guide*. Available from the American Medical Association: www.ama-assn.org
 6. Plonk, W., & Arnold, R. (2005). Terminal care: The last weeks of life. *Journal of Palliative Medicine*, 8(5), 1042-1054.
-