

Module Five

Competency 5

Loss, Grief and Bereavement Support

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Objectives:

1. To understand the family's experience of grief and loss prior to death.
2. Describe the purpose of anticipatory grief for families.
3. To understand the components of grief and factors that influence bereavement
4. Describe three major phases that occur during the grief process.
5. Demonstrate an understanding of the factors that influence the grieving process.
6. Describe the manifestations of grief.
7. Describe the influence of culture, ethnicity and religion on attitudes and beliefs about death.

Definitions

Anticipatory Grief	Phenomenon encompassing the processes of mourning, coping, interaction, planning and psychosocial reorganization that are stimulated and begin in part due to the awareness of the impending loss of a loved one and the recognition of associated losses in the past, present and future
Attitude	A state of mind or feeling, or a disposition
Belief	Something believed or accepted as true
Bereavement	State of having suffered a loss
Chronic Grief	Reaction is one that is prolonged, is excessive in duration, and never comes to a satisfactory conclusion (Complicated grief)
Conventional Grief	Post-death grief (Uncomplicated grief)
Death Accepting	View death as inevitable and natural part of the life cycle
Death Defying	Refuse to believe that death would take anything away and believe it could be overcome
Death Denying	Refuse to confront death, believe that death is antithetical to living and that is not a natural part of human existence
Delayed Grief	Reaction is one, which has been inhibited, suppressed or postponed
Developmental Losses	The necessary losses that come with physical, emotional and psychological growth and development are significant issues
Disenfranchised Grief	The grief that a person experiences when they suffer a loss that cannot be openly acknowledged (e.g., homosexual relationship)
Exaggerated Grief	Reaction occurs when feelings of fear, hopelessness, depression or other symptoms become so excessive they interfere with the daily existence of the bereaved
Functional Losses	Through loss of mobility due to paralysis, stroke, spinal cord injury loss of one or more of the five senses loss of elimination control; loss of sexual functioning; loss of health etc.

Grief	The process of psychological, social and somatic reactions to the perception of loss
Masked grief	Reactions are symptoms and behaviors experienced by a person who does not recognize the fact that these are related to a loss
Mourning	Culturally influenced responses to grief as well as the intrapsychic process which enable the bereaved to relinquish their emotional bonds to the deceased and promotes healing by helping the bereaved to learn how to live in a world without their loved one
Physical Loss	Loss of body parts or normal body functions and abilities
Secondary Loss	Losses that develop as a consequence of death of the loved one
Structural Losses	Through amputation (e.g. mastectomy, colostomy, hysterectomy, heart and kidney transplant) and through disfigurement due to congenital deformations, accidents or burns.
Values	Relative worth, utility, or importance; something (as a principle or quality) intrinsically valuable or desirable

Myths

1. People all over the world view grief in a very similar way.
2. There is a proper way to honor the dead and to grieve.
3. Children do not grieve.
4. Children should not go to funerals or other death-related rituals.
5. Children should always attend funerals or other death-related rituals.
6. People who are grieving appropriately usually get over their grief within 6 months.
7. People who don't cry following a death are avoiding dealing with their grief.
8. People who still cry about a death a year later are experiencing pathological grief.
9. Children should be protected from exposure to death, dying loss and grief or they may be permanently scarred.
10. The death of a loved one is the only major loss children and adolescents experience.
11. Children get over loss quickly.
12. It is more helpful to the bereaved person if the loss is not mentioned.
13. The goal of grief interventions is to help people get over their grief.
14. Grief is so personal that it is difficult to provide assistance to the bereaved.
15. There are no interventions to help children grieve.
16. Children should be shielded from loss.
17. Helping children and adolescents deal with loss is the family's responsibility.
18. It is best to hide your sadness from the dying person.
19. If one grieves prior to the death of a loved one then there is less grief work to do later.
20. Grieving prior to the death of a loved one means that you have given up.
21. For family and friends of a person with a terminal illness, grieving begins at the death of a loved one.

Loss, Grief and Bereavement

We are continuously letting go of people, things and experiences. Although it is natural, it can be challenging. To no longer have something, to lose or let go of someone or something, triggers a reaction we call grief. Understanding loss and grief is important to assess because it influences the responses (bereavement) of your patient and families. Despite the individual nature of grief work, complicated grief reactions can sometimes occur in the form of chronic grief, delayed grief, exaggerated grief and masked grief. In addition, children express and deal with grief in different ways, which can lead to miscommunication in the family unit. The death of a child is very traumatic since a death of a child is not expected in our society.

Grief

Purpose of Grief

Grief evolved in order to encourage our species to maintain social bonds and make attachments critical for survival (individuals could not survive alone). Certain emotions serve particular purposes:

- Grief = transition and growth
- Shock = protection
- Anger = protection and change
- Fear = caution and protection
- Love = giving, joy and delight

Grief in particular offers the opportunity for individual to grow as it disrupts and sometimes shatters one's way of viewing or making sense of their world.

Rando's Three Broad Categories of Grief

AVOIDANCE: shock, denial, disbelief, confusion, emotional anesthesia, numbness, disorganization, intellectualized acceptance of death

CONFRONTATION: highly emotional state wherein the grief is most intense and the psychological reactions to loss are felt more acutely (specific thoughts, feelings, behaviors, symptoms such as; anger and sadness)

REESTABLISHMENT: gradual decline of the grief and marks the beginning of an emotional and social reentry back into the everyday world (thoughts, feelings, behaviors, symptoms become less intense and increasingly intermittent)

Manifestations of Grief

Physical	Cognitive	Emotional	Behavioral
-Headaches -Dizziness -Exhaustion -Muscular aches -Sexual impotency -Loss of appetite -Insomnia -Feelings of hollowness -Breathlessness -Tremors -Shakes -Oversensitivity to noise	- Sense of depersonalization - sense of disbelief -confusion -idealization of the deceased -search for meaning of life and death -dreams of the deceased preoccupation with image of deceased -fleeting visual, tactile, olfactory, auditory, hallucinatory experiences	-anger -guilt -anxiety -sense of helplessness -sadness -shock -yearning -numbness -self-blame -relief	-impaired work performance -crying -withdrawal -avoiding reminders of the deceased -seeking or carrying reminders of the deceased -over reacting -changed relationships

Anticipatory Grief

During the period of anticipatory grief, families and significant others must cope with a multitude of losses ranging from the dying person's decreased ability to contribute to the work of the family, to the probability of the impending death of their loved one. Anticipatory grieving involves mourning, coping, interaction planning and psychosocial reorganization. Anticipatory grieving is stimulated and begins in part due to the awareness of the impending loss of a loved one and the recognition of associated losses in the past, present and future. Examples of the tasks of anticipatory grief include; focusing on the patient as a living person versus remembering that the person is dying; and rushing to create memorable experiences in the person's last days, pushing for as much meaning as possible in the time remaining versus allowing nature to take its course, reminiscing and just passively being present with the patient. Finally, the reality their loved one is dying is one of the most difficult challenges for many families. Conducting a family assessment and intervening with families and significant others as they care for and anticipate the death of their loved one, can help families maximize the opportunities present during this time and decrease problems during bereavement.

Sociocultural Aspects of Grief

Death is universal, yet the grief response that death elicits is cultural. How individuals grieve is first determined by cultural norms, expectations and practices and then by family traditions and individual preferences. Because death is universal, for centuries all societies have struggled with the reality of death and created a wide variety of responses to dealing with loss. Our beliefs, attitudes, values about death, dying, grief, and loss are initially molded by these societal dictates. Within societies, various religious, philosophical and ethnic groups further determine and refine the range of appropriate responses, feelings behaviors and rituals.

Age Differences in Grieving of Children

1. Babies- may withdraw and stop eating, or be listless and fussing.
2. Toddlers- Toddlers sense of what they want guides how they see the situation around them. They believe that people can read their minds and that wishing for something will make it happen. Frequently they will blame themselves for what does happen including the death of a family member. Toddlers may not distinguish between going away and death. They may show their distress in nonverbal ways as agitated behaviors, body language or in dreams. Some times in play situation. Toddler may cry one moment and run outside to play in the next.
3. Preschool-Kindergarten Age- Children between the ages of 3-6 years begin to recognize their own behavior even though they may not be able to fully control their feelings and actions. By age 4 children may have a limited understanding of the word death. They may think the dead may come back to life. There is an interaction with the social environment. For example, if the mother died when the child was 2 years old and the father remarries the child at the age of 4 feels cared by this second mother but still may want to visit the grave of his mother.
4. Elementary School Age- Children are on a continuum of development and they learn quickly not only about relationships but also how to read and develop more resources for themselves. These children are able to separate their point of view from that of others. Elementary school age children realize there is a connection between events and that their father being sick led to his death. They have concerns as to who will take their father's place? These children understand death as the cessation of functions. Death processes and funerals are very much on their minds. Older children know that death is universal. There can be emotional disturbances such as poor school performance, appetite change, shortened attention span, depression, guilt and fear. They may complain of stomachache and other somatic symptoms. They frequently will not bring up their concerns.
5. Adolescence- This period of time is one of rapid cognitive, emotional and physical development. They act more independently and are able to think abstractly, to also recognize their own feelings and point of view as well as other's feelings and points of view. Maintaining relationships and receiving approval from their peers are vitally important to them. When death occurs in the family they can talk about their feelings. Questions about death are natural and an integral part of an attempt to reach a new understanding of life. Initial response to death may be shock, confusion, depression, anger, fear, blaming, lethargy and guilt, which decrease over time. Acting out behavior such as driving fast or talking risks may be seen.

The Process of Bereavement

Bereavement takes many forms and is influenced by culture, religious practices, the relationship that existed with the deceased, the age of the deceased and the manner of the death. Loss involves disruption of the multiple spheres of the individual's life.

Bereavement involves adjustment to these disruptions. The process of bereavement can be categorized by asking three main questions of the bereaved person:

1. Do you think about “X”? (names, images and thoughts)
2. Do you find yourself missing “X”? (acute separation)
3. Do reminders of “X” such as photos, situations, music, places etc., cause you to cry about “X”? (grief)

These questions can be used to assess the intensities of the bereavement reaction.

Bereaved persons can experience considerable pain but cope adaptively. However, symptomatic depressions are frequently seen as complications of bereavement that may be chronic.

Grief Compared to Depression in the Terminally Ill

Characteristics of Grief	Characteristics of Depression
Patients experience feelings, emotions and behaviors that result from a particular loss	Patients experience feelings, emotions and behaviors that fulfill criteria for a major psychiatric disorder; distress is usually generalized to all facts of life
Patients may cope with distress on their own	Medical or psychiatric intervention is usually necessary
Patients experience somatic distress, loss of usual patterns of behavior, agitation, sleep and appetite disturbances, decreased concentration, social withdrawal	Patient experience similar symptoms, plus hopelessness, helplessness, worthlessness, guilt, and suicidal ideation
Grief is associated with disease progression	Depression has an increased prevalence (to almost 80%) in patients with advanced disease; pain is a major risk factor
Patients retain the capacity for pleasure	Patients enjoy nothing
Grief comes in waves	Depression is constant and unremitting
Patients express passive wishes for death to come quickly (45% have fleeting suicidal thoughts)	Patient express intense and persistent suicidal ideation
Patients are able to look forward to the future	Patients have no sense of a positive future

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Study Questions

1. Appropriate anticipatory guidance for the bereaved includes which of the following:
 - a. Help the griever understand that their grief reaction will be unique
 - b. Let the griever know that the process of grief will affect all areas of their life
 - c. Help the griever recognize that they must yield to the painful process of grief

- d. Reassure the griever that experiencing deep feelings of sadness will prevent the need expressing other kinds of emotions like anger and sadness
 - e. All of the above
 - f. None of the above
 - g. a, b, c
 - h. a, d
 - i. b, c, d
 - i. Answer G
2. Being present physically or sitting quietly with the family without talking will make the family feel more uncomfortable, so it is best to leave the family alone and respect their privacy once you have finished caring for the patient.
- a. True
 - b. False
 - i. Answer F
3. Grievers should be discouraged from writing poetry or music until they have resolved their grief because the sadness and tears that may arise from these activities will impair their grieving process.
- a. True
 - b. False
 - i. Answer F
4. When writing a letter of condolence it is appropriate to recount a memory about the deceased and describe special qualities of bereaved person
- a. True
 - b. False
 - i. Answer T
5. It is best to wait for the person to ask for help so that you can do the “right” thing.
- a. True
 - b. False
 - i. Answer F
6. When people repeatedly discuss and review their experiences with the deceased, it slows their recovery process.
- a. True
 - b. False
 - i. Answer F
7. Bring up the loss makes people cry and is detrimental to resolving the grief
- a. True
 - b. False
 - i. Answer F

8. It will make the griever feel better if you remind them that there are other loved ones still alive.
 - a. True
 - b. False
 - i. Answer F

9. The goal of nursing interventions for the bereaved is to take away the pain of their loss.
 - a. True
 - b. False
 - i. Answer F

10. Knowing the cultural norms of a society provides some but not all of the information about death rituals that are important to grieving patients.
 - a. True
 - b. False
 - i. Answer T

11. Death-related rituals are usually an important part of how individuals process a death.
 - a. True
 - b. False
 - i. Answer T

12. There is a predictable pattern in the way all people grieve.
 - a. True
 - b. False
 - i. Answer F

13. People who are grieving appropriately usually get over their grief within 6 months.
 - a. True
 - b. False
 - i. Answer F

14. Grief is mainly comprised of crying and sadness
 - a. True
 - b. False
 - i. Answer F

15. People who still cry about a death a year afterwards are experiencing pathological grief
 - a. True
 - b. False
 - i. Answer F

16. Children express grief similarly to adults
 - a. True
 - b. False
 - i. Answer F

17. All children grieve. Even infants react to the absence of familiar voices
- True
 - False
- i. Answer T
18. Most conceptualizations of grief would fit in the three broad categories of:
- Anger, sadness and acceptance
 - Confrontation, numbness, completion
 - Avoidance, confrontation, reestablishment
- i. Answer C
19. Recollecting and re-experiencing the relationship with the deceased can lead to abnormal grieving patterns
- True
 - False
- i. Answer F
20. Individuals who experience numbness and disbelief immediately after a death are more likely to have pathological grief reactions.
- True
 - False
- i. Answer F
21. The feelings of disorientation and fear of “going crazy” are common aspects of the grief experience
- True
 - False
- i. Answer T
22. The age of the grieving child affects the behaviors demonstrated
- True
 - False
- i. Answer T
23. Which of the following are common responses during grief?
- Crying
 - Gastrointestinal symptoms
 - Forgetfulness
 - Difficulty concentrating
 - Preoccupation with the deceased
 - Sleep disturbances
- 3, 5
 - 2, 6, 7,
 - 1, 4
 - all of the above
 - none of the above
1. D

Case Study One

Tom, age 51 is now hospitalized with metastatic colon cancer so that his ascities can be relieved. He sleeps at least half the time although his mind is relatively clear. He has been married to his wife Susan for 4 years and each brought two children into the marriage, 3 of whom live with them. Tom's son James age 17 and Susan's children Scott age 15, and Simone age 9. Tom's daughter Jennifer age 18 lives with her mother, but visits frequently. When her dad was first diagnosed Jennifer was very involved in cross-country track team, which often interfered with her scheduled weekends at her father's house. As time progressed she began to absorb the seriousness of his illness and modified her visiting patterns and began spending 3-4 evenings a week at her father's house doing her homework. Recently she started skipping track team practices to be closer to him. Jennifer's mother is now concerned that she is "getting too attached" to her father and it will make it harder for her after he dies.

1. What would the most appropriate nursing response to this concern be?
 - a. Suggest to Jennifer's mother that she encourage her daughter to become more involved in her track team to help take her mind off her father's dying and suggest she make her visits briefer and less frequent.
 - b. Talk with Jennifer about how she is thinking and feeling about the evenings she spends with her father and how being with her dad is fitting into her life.
 - c. Encourage Tom to talk with Jennifer about her boyfriend to see if there is some problems in the relationship that she is avoiding him.
 - d. Suggest to Susan, the stepmother, that she find tasks for Jennifer to do while she is visiting her father.
 - i. Answer B

2. James had a difficult sophomore year, was picked up with a DUI and fought continuously with his father (Tom) who did not allow him to transfer to an alternative high school that emphasized creative arts so that he could pursue his love of painting. Aware that his father was becoming more ill, James spend time reviewing possible college choices with his father and reading his Dad's favorite books to him. They joked about the names of the professors at several of the creative arts colleges and the names of the courses that were required for freshmen and have had brief exchanges about the conflict that occurred around the high school issues. Susan has encouraged James to apologize to his father for all his difficult behavior as a teenager. How could the nurse respond to this?
 - a. Support Susan's request and help James understand that he will feel terrible after his father dies if he does not apologize
 - b. Suggest that Susan talk with Tom (or the nurse talk with Tom) and encourage him to let James know that he knows James loves and cares for him and that conflict is just normal in any relationship
 - c. Ask James if he feels any unfinished business with his father and encourage him to talk about all his current school problems.

- d. Tell Susan to mind her own business and that the guys are doing fine using guy talk and beating around the bush to settle something between them.
 - i. Answer B
3. Over the past six months both Jennifer and James have become involved in steady boy/girlfriend relationships. They feel that those relationships have provided them a lot of comfort and served as a good source of “escape” when they just couldn’t deal with the family’s constant focus on illness. Both the mothers are very worried that the teenagers will “get into trouble” with their boy/girlfriends to escape dealing with their pain about their father’s impending death. Possible responses from the nurse might include:
- a. Having a boy/girlfriend could be viewed as a positive coping mechanism as a strategy for balancing the inward focus of the family on the illness with staying connected with other aspects of life.
 - b. Because all the family members are dealing with their own anticipatory grieving, it can be more difficult for them to support each other, the teenagers’ relationships could provide importance source of support.
 - c. Evaluate all the family members levels of stress and coping strategies, provide anticipatory guidance about common difficulties faced by families and offer counseling about how to help each family member identify effective and ineffective approaches to managing their stress.
 - d. All of the above
 - i. Answer D
4. Which of the following is NOT a common task or competing agenda for families facing a terminal illness?
- a. Coping with terminal illness of their loved one, while continuing to take care of the family unit
 - b. Remaining involved with the patient vs. separating from the patient
 - c. Planning for life after the death of the patient vs. not wanting to betray the patient by considering life in his or her absence
 - d. Communicating feelings to the patient vs. not wanting to make the patient feel guilty for dying or bound to this world when the patient needs to let go.
 - e. Rushing to create memorable experiences in the patient’s last days and pushing for as much meaning as possible in the time remaining vs. allowing nature to take its course, reminiscing, and just passively being present with patient.
 - f. Talking with all the extended family members and keeping them up to date on the patient health vs. staying focused on the nuclear family members closest to the dying patient.
 - i. Answer F

Case Study 2

Mr. Moss has been hospitalized off and on for the past two years with metastatic cancer and now has returned to the unit because he has become nonresponsive and comatose. The family are more subdued than they have been in the past and they take turns with a bedside vigil, singing to him and saying the rosary. It would be appropriate for you to:

- a. Upon admission ask the family to please limit any family, religious or cultural rituals that will interfere with Mr. Moss's care
 - a. True
 - b. False
 - i. Answer F

- b. After you talk with them about their awareness that Mr. Moss is dying, ask the family about their traditions, rituals, typical responses and behaviors surrounding the actual dying process (before, during and after) and how you could best facilitate them.
 - a. True
 - b. False
 - i. Answer T

- c. A few minutes after death, you should encourage the family to go home and rest and begin to implement the post mortem hospital procedure.
 - a. True
 - b. False
 - i. Answer F

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