Palliative Care

Grief and bereavement

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A diagnosis of a terminal illness has profound implications for the patient, caregivers, family, and friends. Similar to a stone thrown into a pool of water, the effects of the illness ripple throughout and change life forever. Many primary care physicians regularly care for patients and caregivers in the terminal stages of a disease process and play an important role in the grief process. Primary care physicians should be able to identify grief; develop strategies for the management of grief in patients, families, and themselves; and be able to recognize abnormal grief.¹

All human beings can expect to suffer losses during the life span and can expect to experience the process of grief. Grief is the reaction to loss, and uncomplicated grief is a normal and healthy response to loss. Grief can occur after any loss, such as losing a job, moving to a new location, or getting a divorce. Although grief may be considered a psychologic process, it encompasses all aspects of life, including physical, emotional, and social. Bereavement is the experience of a person who has lost or been deprived of a significant person or object. Three elements are common in bereavement: (1) an attachment to a person or thing that is valued, (2) a loss of that relationship, and (3) becoming a survivor of the loss. Mourning is another element of the grief process and is an active attempt to manage the loss. The process of mourning has an intrapersonal and an interpersonal component. The intrapersonal component is the private, inward struggle to cope with the loss, and the interpersonal component is the overt, shared expression of grief along with the effort to obtain social support.²

Grief in Terminally Ill Patients

Grief is a normal, expected reaction in patients and caregivers facing a life-threatening illness and needs to be acknowledged and expressed. In dealing with patients who have a life-threatening disease, grief work should be encouraged because patients who express their grief early in the disease process are more likely to cope effectively as they are dying.³

There are different theoretic approaches to coping with dying, and the task-based approach model is used most commonly because of its flexibility and principles of empowerment. Task
work represents an active process that can be undertaken in coping with dying and dealing with grief. Corr et al presented a holistic model encompassing four dimensions of task work—physical, psychologic, social, and spiritual. Physical tasks include the minimization of physical distress, such as intense physical pain and severe nausea. It often is difficult for patients under physical distress to have rich psychologic, social, or spiritual interactions. Psychologic tasks include quality-of-life issues, such as maintaining a sense of security, autonomy, and dignity. Social tasks include sustaining and enhancing interpersonal relationships valued by the dying person. Spiritual tasks include finding meaningfulness, connectedness, and transcendence and the fostering of hope.

An older model is the stage-based approach by Kubler-Ross, which included five stages of grief—denial, anger, bargaining, depression, and acceptance. Research has suggested that not all dying people go through these stages, and some dying persons never reach acceptance. There are several important premises that derive from this approach, however. The first is that people who are dying are still living and often have unfinished business that needs to be addressed. The second premise is that physicians cannot care effectively for the dying unless they listen actively and learn from those who are dying. The third premise is the importance of maintaining hope. Maintaining hope in a person who is dying can be a challenge, but without hope, patients may die sooner than their prognoses dictate. Encouragement can be given for smaller hopes, illustrated by the questions, "What are your hopes?" and "What do you hope to accomplish before you die?" Most patients have such hopes and may reply, "I hope to live until my daughter gets married" or "I hope to live until Christmas."

People who are dying also have great longings for communication. Existential issues often are questioned, such as "Why me?" Dying persons grieve the many losses they have had to endure, including the loss of security, independence, and a future. Caregivers, friends, and significant others may not be able to discuss these issues, denying the dying person an opportunity to discuss shared fears, hopes, needs, and unfinished business. At times, caregivers and patients fail to acknowledge explicitly the terminal nature of an illness to protect one another from the painful nature of separation. This conspiracy of silence only enhances the grief each person is feeling, however.

A physician can give encouragement to patients and caregivers to discuss their feelings openly and to complete unfinished business. One way to assist patients and caregivers in the completion of unfinished business and the closure of relationships is to foster the use of five salutations or phrases: (1) Forgive me, (2) I forgive you, (3) thank you, (4) I love you, and (5) goodbye. The nature of a progressive illness affords an opportunity to reconcile strained relationships and to convey a sense that nothing is left unsaid or undone. This resolution can assist survivors in their bereavement process. Validating patients' and caregivers' feelings can facilitate the grief process. Validation acknowledges and affirms their experiences in a nonjudgmental way. The physical presence of the physician can be comforting to the patient and the caregiver and communicates a caring and compassion that envelopes the principle of nonabandonment. Although there often are no answers to existential questions, silence can be therapeutic, and simply holding a hand offers solace and sympathy. The following list summarizes interventions for grief in terminally ill patients:

1. Encourage open communication.
2. Encourage completion of unfinished business.
3. Encourage and foster hope.
4. Allow an opportunity to discuss fears.
5. Validate and normalize feelings.
6. Provide a physical presence.
7. Listen empathetically.
Anticipatory Grief and Mourning

Anticipatory grief and mourning is a process that encompasses grief and mourning, coping, interaction, psychosocial reorganization, planning, balancing conflicting demands, and facilitating an appropriate death. Grief and mourning are experienced not only by the survivors, but also by the dying person. Persons diagnosed with a terminal illness may grieve over the past, present, and future losses they are forced to endure, along with the final loss of self. This time is an opportunity for the dying person to plan the future cooperatively with the survivor so that unilateral plans will not be perceived as betrayals after death.

Anticipatory grief and mourning can play an important part of the dying process of the terminally ill and the bereavement experience of the survivor. The time before a death can be used effectively by the dying person and significant others to complete unfinished business. When unfinished business is expressed, the bereaved more than likely will not have to spend time in grief counseling dealing with regrets over things that were not said when there was an opportunity. A person who has shared their thoughts and plans with the dying person, who has begun to anticipate life without this person, and who has made adequate preparation for managing affairs is in a better position to cope with bereavement than a person who has denied the illness until it was too late to prepare for the death.

Anticipatory grief does not mean that caregivers and significant others withdraw from the dying person, but rather they begin to learn to accommodate themselves to a life without the presence of the dying person. It allows for survivors to plan for the future. It also allows time for the survivor to absorb gradually the reality of impending death and to rehearse the death and its consequences.

Normal Grief

Manifestations of normal grief behavior may occur in a variety of physical sensations, cognitions, behaviors, and feelings. Physical sensations are a common occurrence among bereaved individuals and play an important role in the grieving process. Often, these physical sensations prompt a newly bereaved individual to visit the physician for an examination. Some physical sensations include hollowness in the stomach; tightness in the chest or in the throat; shortness of breath, weakness, and fatigue; hypersensitivity to noise; dry mouth; and a sense of being surreal. Common thought patterns include shock or disbelief; confusion; preoccupation with the deceased; a sense of presence of the deceased; and occasionally, auditory and visual hallucinations of the deceased. Although most of these thoughts disappear over a short period of time, it is important to acknowledge that persistent thoughts may precipitate depression or anxiety.

Grief-related behaviors include sleep disturbances, appetite disturbances (undereating and overeating), forgetfulness, social withdrawal, dreams of the deceased, restlessness, searching and calling out, crying, avoiding reminders of the deceased, sighing, treasuring or carrying objects that belonged to or remind the bereaved of the deceased, and visiting places that remind the bereaved of the deceased. These behaviors usually dissipate over time. Many different feelings occur in normal bereavement, including sadness, anger, guilt and self-reproach, anxiety, loneliness, helplessness, shock, yearning, emancipation, relief, and numbness.
Phases and Tasks of Grief and Mourning

Parkes proposed four phases of grief (Table 1).

Table 1. Stages of normal grief in adults

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<th>Phases</th>
<th>Tasks</th>
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<td>Shock/numbness</td>
<td>To accept the reality of the loss</td>
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<tr>
<td>Yearning/searching</td>
<td>To experience the pain of the grief</td>
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<td>Disorganization/despair</td>
<td>To adjust to an environment in which the deceased is missing</td>
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<tr>
<td>Reorganization</td>
<td>To relocate the deceased emotionally and to move on with life</td>
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Data from references 13, 14 and 19.

The first phase is shock and numbness, which may last for hours to days. This phase occurs immediately after the death of a loved one and is accompanied by a sense of denial and unreality. Statements sometimes heard include, "I can't believe this is real" and "I can't believe he is gone." Denial is a commonly used defense mechanism that allows the bereaved to survive until he or she is able better to handle the shock and numbness of loss. During this time, the bereaved may go through preplanned activities, such as attending the funeral, but have little recollection of what transpired during this emotionally tumultuous period.

The second phase is yearning and searching. During this phase, there is protest and separation anxiety over the loss in an attempt to search for and recover the lost person. At this time, the bereaved person often becomes irritable and anxious. Until the bereaved has gone through the painful process of searching for the lost person, he or she will not be able to let go of the attachment to the deceased and move on.

The third phase is disorganization and despair. During this phase, the bereaved person may feel lonely, isolated, and depressed and is likely to have difficulty concentrating and problem solving. Another common experience during this phase is a strong sense of the deceased person being near at hand. The fourth phase is reorganization. During this phase, the bereaved attempts to adapt to the changes that have taken place and to move on and reinvest energy in new relationships. A resurgence of interest in the world and a willingness to plan for the future emerge.

Worden proposed four tasks of mourning (see Table 1) and asserted that when these tasks are completed, the bereaved person is on the way to healing. The first task is to accept the reality of the loss: that the loss is real, the person is dead, and reunion in this life is impossible. Coming to this acceptance takes time because the reality of loss includes intellectual and emotional acceptance. Funerals and other rituals often help the bereaved person move toward acceptance. The second task is to experience the pain of the grief. It is almost impossible to lose someone you have loved and cared for deeply without experiencing some level of pain. To suppress the pain can prolong or delay the course of mourning; to experience the grief leads to pain but eventual healing. Bowlby indicated that persons who do not address their grief consciously eventually become depressed. Not everyone experiences the pain of grief with the same intensity or feelings, and for some, the intensity is overwhelming. The level of pain decreases as healthy mourning progresses, however. The third task is to adjust to an environment in which the deceased is missing. This task involves identifying the various roles that the deceased person played in the relationship with the bereaved person and to adjust to the fact that the deceased no longer will perform these
roles. Sometimes the bereaved person regresses and feels helpless with lowered self-esteem. Most bereaved persons develop new skills, however, and learn to take on different tasks formerly occupied by the deceased. The fourth task is to relocate the deceased emotionally and to move on with life. This does not mean that the bereaved person forgets about the deceased person, but rather that the bereaved finds an appropriate place for the deceased in his or her emotional life. The bereaved person is able to think about the deceased person with sadness but not with the overwhelming intensity of pain previously experienced. After completion of this task, bereaved persons are able to reinvest their emotions back into life and living.

As with the terminally ill, validation is an important part of bereavement. The bereaved needs the reassurance that how he or she is responding to grief is normal and natural and that there is no set length of time for the process of mourning. The first year of bereavement is a challenging time for the bereaved with all of the anniversaries and holidays; however, the second and third year often can be just as difficult. Generally, when the bereaved regains an interest in living, is feeling hopeful, has adapted to new roles, and is able to experience gratification, mourning has been managed appropriately.

**Interventions for Grief in Adults**

Primary care physicians, because they are likely to have cared for the deceased person during the illness and to have helped family members prepare for the loss, are in a good position to offer psychologic support. Initially after the death, it is beneficial for physicians to make a bereavement telephone call to the family to offer condolences. Family members appreciate the expression of sympathy, and it offers the physician an opportunity to elicit the bereaved person's social support network. If a phone call is not possible it is helpful to send a sympathy card, perhaps also signed by the office staff. Although most physicians do not have the time to attend funerals, it is a nice gesture and offers the physician an opportunity for closure. Also, because emotional support is important in the mourning process, many newly bereaved individuals often consult their physician for relief of emotional symptoms. It may be helpful for the physician to offer a follow-up appointment several weeks after the death, especially for spouses and for parents with young children, to inquire about the person's health and to deal with any unanswered questions.

Validation is an important aspect of dealing with a bereaved person's grief. The physician can assist the bereaved by acknowledging his or her feelings and by encouraging the bereaved to create a steady routine. The physician also can caution the bereaved to avoid making significant lifestyle changes or other major personal decisions during this difficult period. The physician can assist the bereaved by helping him or her to recognize that grief is a painful process and that the symptoms in which grief is manifested must be seen in perspective. A primary care physician can offer reassurance to a distressed spouse that feelings of anger and dreams of the deceased spouse are a normal reaction to loss. Physicians can encourage participation in bereavement support groups that are offered by many hospices. Such groups provide bereaved persons an opportunity to share their experiences with other people who have suffered similar losses and assist one another in learning to cope.

**Grief in Children**

Many factors can influence a child's reaction to the loss of a loved one. The length of the patient's illness, the relationship to the patient, and how open and honest the family was with the child during the illness should be considered. Children express their feelings of grief and bereavement differently than adults. Children often do not display their feelings as openly as bereaved adults do. It is sometimes puzzling to adults, who are openly grieving, how children can immerse themselves in activities of everyday life. This retreat is simply a defense mechanism to protect children from being overwhelmed. It is common for bereaved children to have strong feelings of anger and fears of abandonment or death, and they often play death games as a way of working out these issues in a safe environment. Although a child's
grief may appear more intermittent and brief than an adult's grief, it usually lasts longer. As children grow and develop, they often revisit their grief in significant life events, such as graduation from school and marriage. Additionally, children often have difficulty articulating their feelings and commonly express their grief through behaviors, such as aggressive or destructive actions, school phobias, or overly attention-seeking actions.\[1\]

Children respond to bereavement experiences based on their age and developmental level. Generally, infants and toddlers are not cognizant of death; however, infants separated from their mothers have shown physical and emotional changes, such as listlessness, weight loss, lack of sleep, and a decrease in activity. Toddlers often confuse death with sleep and have shown signs of anxiety after a death. Children age 3 to 6 often consider death a temporary event. They consider death reversible and often ask questions about the physical activities of the deceased person. Also, children in this age group often partake of magical thinking whereby they consider their thoughts or actions as directly causing the person's death. Such children may say to a parent or sibling, "I hate you and wish you were dead," and if this parent or sibling later dies of an illness or accident may believe that they were responsible for the death. Behaviorally, children in this age group often regress and may show disturbances in eating, sleeping, and toileting. Children in the 6 to 9 age group start to comprehend that death is final; however, they believe it is not universal. Behaviorally, children often act out and become aggressive, or they may become overly clingy. By age 9 or 10, most children understand death as final and universal.\[8\]

In bereaved children, there are three prominent concerns: (1) Did I cause the death to happen? (2) Is the same fate going to happen to me? (3) Who will take care of me? Children often worry if they caused the death. As mentioned earlier, if a child says to the parent or sibling, "I hate you and wish you were dead," and this parent or sibling later dies, a child may believe he or she was the cause of the death. In palliative care, when there may have been an extended illness followed by a death, it is common for a child to believe he or she will suffer the same fate or wonder who will care for him or her if a parent dies. Children who have experienced the death of a parent often try to maintain some type of connection to the deceased parent and often hold onto objects such as photos and other mementos of the deceased parent.\[7\]

Similar to adults, children process mourning tasks. Fox\[9\] identified four productive mourning tasks for bereaved children. The first task is to understand and make sense out of the death. During this task, children seek out information about the circumstances surrounding the death and attempt to come to an understanding regarding the loss of a loved one. The second task is to express emotional responses to the present or anticipated loss. This task involves identifying and validating the strong responses to a loss that a child may be experiencing and to find appropriate ways to respond that are not harmful to the child or to others. The third task is to commemorate the loss through some formal or informal remembrance. This commemoration may include funerals, memorials, or other types of services and assists the child in accepting the reality and finality of the death. The fourth task is to learn how to go on living and loving and involves successfully integrating the loss emotionally and being able to move forward.

With the terminal illness of a family member, children should be involved so that they can begin grief work before death. It is common for parents to try to protect children by not informing them of the terminal nature of a loved one's illness. By letting the child know of the seriousness of the illness and the possibility of death, however, the child is provided with an opportunity to begin grief work before death. Primary care physicians can encourage open communication between family members and the child. After the person has died, explanations of the death should be kept simple. Questions should be addressed with as much truth and detail as the child is able to comprehend, and reassurance should be provided that the child is loved and will not be abandoned. It is important to forgo the use of euphemisms, such as "we lost him" or "he is sleeping," because these are confusing to children who take translations literally. It is better to use proper words, such as "he died" and "he had cancer." Some parents ignore their child's questions and do not discuss the details of the death. Silence indicates to children that something is wrong and does not help them to
deal with loss in a healthy manner. The child should be informed that he or she may have different feelings, such as sadness or anger, and that these feelings are normal and will not last forever. Stress in children often is exhibited by somatic complaints, such as abdominal pain and malaise; consequently, physicians should be cognizant that somatic complaints may be a disguise for reactions to grief and obscure emotional feelings regarding the death of a loved one. The following list summarizes interventions for grieving children:

2. Answer all questions honestly and with as much detail as the child can comprehend.
3. Use correct language, such as "cancer" and "died," and not euphemisms, which are confusing.
4. Include the child in the planning of remembrances, such as funerals or other memorial services.
5. Encourage the child to participate in funerals or memorial services according to his or her level of comfort.
6. Inform the child of the different feelings he or she may have, such as anger or sadness, and make sure the child knows these feelings are normal.
7. Provide reassurance that the child is loved and will be taken care of.

Complicated Grief

Complicated grief (or complicated mourning) refers to grief reactions or mourning processes that are abnormal and unhealthy. Usually, these unproductive behaviors overwhelm the bereaved and lead to maladaptive behaviors and a failure to move toward a satisfactory outcome in the mourning process. Complications in grief may arise from many different factors. A person's mental health history and personality traits can indicate the ability to cope with emotional distress. People with a history of depressive disorders run a higher risk of complicated grief reactions. Other risk factors include an ambivalent, overly close, or intense relationship with the deceased; multiple, recent losses; and loss of a parent or significant person during childhood.

Another factor in the development of complicated grief reactions involves social factors. Grief is a social process and is dealt with best in social settings. Lack of a social support network and social isolation can contribute to complicated grief. Some people experience disenfranchised grief, whereby the loss they experience cannot be acknowledged openly, supported socially, or mourned publicly. Examples of disenfranchised grief may include deaths from suicide or acquired immunodeficiency disease syndrome (AIDS).

Risk factors for complicated grief are summarized as follows:

1. Previous history of psychiatric disorders.
2. Ambivalent, overly close, or intense relationship with the deceased.
3. A history of multiple, recent losses.
4. Loss of a parent or a significant person during childhood.
5. Lack of social support.
6. Deaths by suicide, AIDS, murder, or other unexpected deaths.

There are four types of complicated grief reactions: (1) chronic grief reactions, (2) delayed grief reactions, (3) exaggerated grief reactions, and (4) masked grief reactions. Chronic grief reactions are excessive in duration and do not lead to an appropriate conclusion. Often people with chronic grief reactions had confused or ambivalent relationships with the deceased, and there may have been issues related to alcoholism and abuse. Delayed grief reactions are inhibited, suppressed, or postponed responses to a loss that tend to resurface at a later date and often appear as an excessive reaction to a subsequent loss or event. Exaggerated grief reactions are excessive and disabling responses to a loss in which the bereaved feels overwhelmed and resorts to maladaptive behavior. Often, such responses include depression, anxiety, various phobias, and panic attacks. Masked grief reactions occur when individuals experience symptoms and behaviors that cause them difficulty but fail to see they are related to the loss. Masked grief often is expressed in psychosomatic or physical symptoms.
Because many bereaved individuals initially present with somatic complaints, primary care physicians generally are in a position to recognize complicated patterns of grieving. Persons who are at risk for complicated grief or those who show early signs of abnormal mourning may be referred for grief counseling or for psychiatric evaluation. Appropriate intervention techniques include identifying the feelings associated with the death, allowing the bereaved to cry, and encouraging the bereaved to express his or her feelings. By bringing latent anger and guilt to consciousness, the physician may enable the bereaved to deal with conflicted feelings in a more realistic manner. Physicians should be aware of bereaved individuals at risk for neglect or suicide. Abnormal grief, accompanied by depression, suicidal ideation, or both may necessitate a referral for psychiatric evaluation, drug therapy, and possible hospitalization.

**Grief in Physicians**

To assist the terminally ill, physicians should be prepared to share the patient's grief, losses, and fears. Sometimes, there is a satisfaction in knowing that, despite the pain and suffering a patient endured, he or she had a peaceful death. There are times, however, when the patient does not have a peaceful death, and at times, physicians may feel responsible for their suffering and death. Primary care physicians are at risk for patient-related grief because they often care for elderly patients and cancer patients in their practices, and it is common for physicians to feel a sense of loss after the death of a patient known to the physician for a long time. Physicians and other health care professionals often deny their own need to grieve and find it difficult to acknowledge their own emotional needs. It is expected and deemed appropriate that patients and families should express their grief; why should physicians and other professional caregivers not be expected to do the same? Physicians who find ways to meet their needs for emotional expression and support are likely to find greater satisfaction in their work and are more likely to achieve a successful balance between meeting the needs of their patients and maintaining their own resources of energy and commitment.

**References**


