EPEC™-O

Education In **P**alliative And **E**nd-Of-Life **C**are For **O**ncology

Self-Study Module 4:

Loss, Grief, and Bereavement

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Abstract

Cancer patients face losses from the onset of their illness, starting with the loss of their expectations for their future. Loss results in grief responses; mourning a loss and learning to live life without what is lost is part of creative adaptation. Patients can respond creatively to multiple major losses. Adverse responses to grief can occur. These include anxiety, depression, and their associated pathological manifestations. Family members, caregivers, and members of the cancer care team also experience and respond to losses. Approaches to providing support for people facing losses are described in this module. Methods for screening and assessment, as well as management of uncomplicated and complicated grief, are described. Finally, approaches to follow-up with bereaved family members are described.

Introduction

Loss is the condition of being deprived of something or someone. Loss may be anticipated, real, or perceived; primary or secondary.

Grief is the experience of a loss. **Bereavement** is the state of living with a loss. Grief is a personal and normal response to loss. It has emotional, intellectual, spiritual, physical, behavioral, and/or social components. **Mourning** is the act of grieving --the outward expression of a loss. Grief and bereavement are part of the process of adjusting to a loss. Mourning can involve private expressions of grief as well as socially or culturally defined customs such as rituals and traditions.

Cancer patients and their families experience many different losses throughout their experience of cancer. For the family, the experience of loss continues during and after the death of the patient. Loss of a sense of future, ability to function, former body image, relationships, control, independence, dignity, etc., can occur at any time. As patients' cancer progresses, the risk of losing control over fundamentally important aspects of their lives increases, often dramatically.

Each loss produces a grief response, varying in intensity with the importance of the loss as perceived by the person experiencing it. The way a person copes with and adapts to loss is key to differentiating between a complicated and an uncomplicated grief process. In an uncomplicated grief reaction, after an initial acute grief reaction, the person's emotional response is time-limited. The individual utilizes existing resources, seeking outside help to cope and adapt to the loss. There is no long-term impairment in daily functioning.

In contrast, in complicated grief reactions the emotional response does not resolve, there is little or no adaptation to the changes resulting from the loss, harmful behaviors can develop, and daily functioning is impaired.

The psychoneurophysiologic basis and somatic molecular mediators for stress of various etiologies, including loss, grief, and bereavement, are in the early stages of research, but are becoming better understood. (Ref. 1) (Ref. 2)

The impact of cancer on patients varies widely, whether the cancer has a good or poor prognosis. Each family member will experience her/his own secondary losses as well as having reactions to the patient's losses. The family system will have to cope with and adapt to the changes. Sometimes these adaptations will be constructive; sometimes not.

The emotional reactions to a loss are frequently volatile and may crescendo as everyone confronts the possibility of the end of the patient's life and the changes death will bring. Multiple coping strategies may be needed simultaneously. The likelihood of successful coping by the bereaved appears to improve with early intervention using stress-reduction techniques. (Ref. 3)

Experiencing a loved one's death can be extremely stressful. Bereavement is associated with declines in health status, inappropriate use of health services, and increased risk of death. It heightens a person's risk for depression; insomnia; increased consumption of alcohol, tobacco, and tranquilizers; suicide attempts; and death. (Ref. 4)

The time course of patients' and families' adaptation to loss varies. Assimilating the reality of a loss can take days to weeks. Adjusting to the loss can take weeks to months or even years. Interference with normal life should diminish over weeks to months, depending on the nature of the loss. While most people who are bereaved are able to reenter the world after 1 to 3 weeks, their active grieving can go on for a year or more, with sadness continuing for much longer. Although the sadness may persist, it typically does not intrude on or interfere with day-to-day activities. Over the course of a year or two, most people are able to engage in relationships that have emotional meaning in the same sphere as the relationship with the bereaved. The time course of adaptation among terminally ill patients facing losses is harder to assess but adaptation does occur over time. (Ref. 5)

In addition to challenges, each loss also presents opportunities for new perspectives on living and heightened spiritual awareness. People find greater acceptance of themselves and others. They are able to resolve conflicts with others. Often, making use of these opportunities is a part of the adaptation to the loss.

Despite the fact that patients routinely face losses due to illness, and despite the frequency with which physicians encounter bereaved patients and families, medical education has historically provided minimal training in addressing issues of loss and grief with patients and families.

All cancer patients and their families experience losses associated with having cancer. Loss, grief, and bereavement are a significant part of the cancer experience. Competence in caring for these aspects of the cancer experience is a high priority for the cancer care team. Members of the team are susceptible to counter-transference and potential burnout if they internalize the cumulative losses expressed by patients and families without coping strategies (see EPEC™-O Module 15: Cancer Doctors and Burnout). In contrast, the team can also experience satisfaction at witnessing patients' and families' enjoyment of life as they live it with meaning and value.

Oncologists often rely on a social worker, counselor, or pastor to assume the therapeutic responsibility for their patient's responses to loss that cannot be optimally managed within the family or the patient's community. This is a completely appropriate use of the interdisciplinary team. At the same time, patients also look to their oncologist for support. A fully effective oncologist will be able to provide support in the context of day-to-day communications with modest investments of his or her own time. Acquiring the skills to do this may entail seeking additional education beyond that which was provided in the oncologist's core training.

Objectives

After studying this module, oncologists and other members of the cancer care team will be able to:

- Define loss, grief, and bereavement.
- Facilitate creative adaptation to losses.
- Screen for and assess uncomplicated and complicated grief.
- Manage reactions to loss, including anxiety and depression.
- Follow through with bereaved family members after a patient's death.

Loss and Grief during Illness

Perceived loss also requires adaptation, whether it is in the physical, psychological, social, or existential domain. Creative adaptations to loss can sustain a person through repeated and severe losses. But creative adaptation is not easy. For those facing cancer, the demands are often repeated and severe. Assistance in achieving the adaptations that allow the patient and family to maintain a quality existence is an integral part of comprehensive cancer care.

Understanding the nature and implications of a loss, discarding exaggerated fears, and accepting unwanted realities are a necessary part of healthy adaptation. The initial emotional response to loss can be so great that comprehension is difficult. Some people need discussion and repeated "fact checking." Some need a tangible event. Others need time to let the realities sink in. Many people need to disconnect from their previous relationships while they adapt and reintegrate, emerging from this time as whole persons ready for relationships with others albeit without what has been lost.

Patient losses and adaptations

Sense of future

The first loss a cancer patient faces often is loss of confidence about the future. Even patients who do not lose hope probably confront this adjustment in some fashion. A cancer diagnosis almost inevitably raises a person's awareness of mortality and places it in a new light. This existential challenge is likely to have ramifications in the psychological and relational domain.

Function

Whether it is the cancer or the treatment that impacts function, cancer patients must accommodate a wide range of transient and permanent losses of function (i.e., onset of fatigue; inability to perform activities of daily living; or loss of normal taste, hearing acuity, or fine cognitive skills). Adaptations often involve family members in new activities such as shopping for the first time or helping the patient with toileting or other activities of daily living. The family member may have to develop new skills to perform these new activities.

Self-Image

Physical losses precipitate a changed self-image. When hair loss, weight loss, and/or breast or limb loss occur, self-image has to be adjusted.

Roles

Less tangible, and often very difficult, is the loss of social role that cancer can bring. Children temporarily or permanently stop attending school. Adults may lose their jobs. A cancer patient may become less functional in a family role, as a parent, child, or sibling. There can be losses, too, in the patient's role in the community, as an active church member, welcoming host, proud gardener, or other group participant.

The sick role and the caregiver role

In place of established roles, patients may take on the "sick" role and family members the "caregiver" role with varying degrees of personality fit for those roles. Transitions

into these new roles may develop slowly or rapidly, with varying mixes of earlier roles and varying degrees of resistance and expectations of role definitions.

In the sick role, the person with cancer may take on an identity of being dependent. He or she expects and is expected to be cared for by others who tend to needs that he or she cannot fulfill alone. (Ref. 6) (Ref. 7) Family members may adopt different caregiving activities and corresponding identities as they settle into expectations for the activities and resulting relationships.

Role transitions can be difficult. For instance, as the patient becomes unable to perform activities of daily living, the caregiver must learn how to help with personal function. This type of intimacy may not be welcome, involving as it does different self-images and relational boundaries. A sense of loss for one's former self may exist for the patient and the caregiver. It may be necessary for each party to experiment with various ways of performing the roles.

The physician can help by acknowledging and normalizing the attention these transitions need, emphasizing that they do not always go smoothly and may require the types of relational coping skills that family members have found helpful in other stressful adaptations.

With adjustment, the caregiving role can yield gratification. (Ref. 8) It can also be accompanied by significant burdens. (Ref. 9) Caregivers experience worse health outcomes than their matched counterparts. (Ref. 10)

The dying role and successor roles

Society assigns a different role for people who are expected to die soon. They are no longer expected to struggle for cure and recovery. They are encouraged to reach a peaceful state with others and offer parting gestures. They are expected to reach some type of conclusion to their life story or personal legacy. They may be encouraged to make practical arrangements for material gifts and sometimes for their own death-related events, such as a funeral. They may be expected to offer designations for successors to the roles they have held in their lifetime, such as asking a child to "look after mother for me" or a friend to "see to the finances for my child."

As the patient enters the dying role, family members, friends, and colleagues begin to take on the role of successors. They accept the role of guarding the person's personal and material legacies, sometimes finishing an unfinished project or recording the dying person's story so that it can be passed down through the generations.

Negotiating timely role transitions

Although important, new roles can be detrimental if they are entered prematurely. Patients can feel discarded before their time, and future caregivers or successors can feel that they have made serious errors in a role they cared deeply about.

Patients and families can be encouraged to settle their differences when possible and to enjoy the peace that results. Suggestions can be offered about making practical arrangements early, with the explicit acknowledgement that it is intended to "get them squared away," rather than to usher in an expected death. The notion of planning for the eventuality while living for quality relationships can be helpful. Preparations for the future may be especially helpful for close caregivers, who may have difficulty with transitioning out of an all-consuming role. (Ref. 11) (Ref. 12)

Relationships

Along with changing social roles, personal relationships are often in transition. Personal needs change. Capacities for relating in previously habitual ways change. The patient can feel abandoned when it emerges that his or her significant other is not well-suited to the caregiver role. The family member can feel abandoned when it emerges that the patient can no longer perform in the ways he or she did in the past. Sexual drive and capacity may change, and the meaning and emotional needs associated with it may change. Favorite recipes may taste different, taking away the gratifications of cooking and eating together. The bathroom, bedroom, and living areas may be transformed by medical equipment that reminds people of sickness or death. The physician has a great deal of power to normalize the feelings associated with these changes and will want to remain alert to the possible need for counseling.

Material losses

As personal challenges mount and personal resources are expended in response, material losses also accumulate. Financial losses occur due to lost income, medical bills, and practical life changes such as relocating or paying for caregiving. (Ref. 13) These material losses also induce emotional reactions and drain a person's coping resources. The physician can be alert to the need for intervention by a social worker or for mobilization of community support to assist with these adaptations.

Family losses and adaptation

Patient losses result in family losses. As the patient loses function, the family tends to take up the slack. This may entail gains in roles or relationships, but there are usually losses as well. Family members may have to give up work; modify their expectations of a mother, spouse, or child; make time to perform domestic functions; and so on. Adaptations by family members are an integral part of the process of living with cancer, adjusting to losses, and coping with eventual bereavement. Comprehensive cancer care requires awareness of adjustments by family members and interventions to aid the process. The patient is not likely to do as well if his or her family is failing to cope.

The health care team and loss

The cumulative effect of loss on the physician and the health care team can be overwhelming. To enhance their own effectiveness, those in the helping professions

need to be keenly aware of their own vulnerability and take the necessary steps to protect themselves. Feelings of powerlessness, inadequacy, and isolation can be mitigated by self-care approaches that incorporate mental, physical, emotional, and spiritual dimensions. (Ref. 14) Balancing work life with other activities will assist the health care team in responding to the emotional needs of patients and their families. (see also EPEC™-O Module 15: Cancer Doctors and Burnout).

Loss, Grief, and Adaptation among Survivors

Among cancer survivors with an excellent prognosis, quality of life appears to be high, suggesting that patients adapt well to their cancer experience. (Ref. 15) Survivors who live with cancers that have a poor prognosis experience continuing stress. But even among cancer survivors who are currently cancer free, symptoms such as fatigue can cause significant stress. One study looked at breast cancer survivors with persistent fatigue and noted that they had altered cortisol responses to psychologic stress. (Ref. 16) However, the quality of studies is limited. (Ref. 17) This topic is further discussed in EPEC™-O Module 5: Survivorship.

Module 4 - Video 1

Loss and Grief after the Death

The grief process

Immediately after a death, those who are bereaved will need time to recover from their acute stress and fatigue and restore their environments to normal. As they begin to live with the significance of their loss, they will likely experience an intense grief reaction with multiple cognitive, emotional, and physical responses and require considerable ongoing support to help them deal with all the changes to their lives. (Ref. 18) (Ref. 19) (Ref. 20) (Ref. 21) (Ref. 22) Some people who are bereaved will make a conscious effort to deal with the loss, emotions, and changes that follow the death of a loved one. They may seek ongoing assistance from their physicians to help address their feelings of loss. Others will deny what is happening and avoid dealing with any of these issues. They will be at high risk for a prolonged, complicated grieving process.

Families with a member who has terminal cancer are in a nonlinear transition from living with cancer to experiencing a death from cancer. (Ref. 23)

Theoretical perspectives have offered frameworks for understanding why we grieve. Bowlby (Ref. 24) suggests that grief occurs when an attachment necessary to one's

safety and security is disrupted. Others conceive grief as a part of the healing process, reestablishing equilibrium in a person's life after the loss of a loved one.

Most theories conceptualize grief after a death as encompassing multiple sensations and experiences, including:

- Emotional (e.g., sadness, anxiety, anger)
- Physical (e.g., loss of appetite, fatigue)
- Cognitive (e.g., preoccupation, confusion)
- Behavioral (e.g., restlessness, searching)
- Spiritual (e.g., questioning beliefs, anger at God)

Uncomplicated grief

Uncomplicated grief reactions include a wide range of physical, emotional, spiritual, and cognitive behaviors. The bereaved may note feelings of hollowness in the stomach, tightness in the chest, heart palpitations, weakness, lack of energy, gastrointestinal disturbances, weight gain or loss, or skin reactions. Many say they feel emotional numbness, relief, sadness, fear, anger, guilt, loneliness, abandonment, despair, or ambivalence. The bereaved may be concerned about cognitive symptoms such as disbelief, confusion, inability to concentrate, and preoccupation with or dreams of the deceased. All of these are expected grief reactions to a loss.

Worden suggests four tasks of grief:

1. Accepting the reality of the loss
2. Experiencing the pain of grief
3. Adjusting to an environment in which the deceased is missing
4. Withdrawing emotional energy from the deceased and reinvesting in other relationships

These tasks should be seen as guides for what the bereaved may experience. The bereaved do not go through these in a scripted manner, but in a variety of ways and with different timing for each person.

Worden and others have defined benchmarks from which to judge the resolution of the grief process, when:

- The bereaved is able to talk about the deceased without intense, fresh feelings of loss.

- The survivor is able to invest energy in new relationships, roles, and responsibilities, without disabling guilt and feelings of disloyalty toward the deceased.

Complicated grief

Some people who are bereaved continue to experience intense cognitive, emotional, and physical grief reactions over long periods of time that interfere with their physical or emotional well-being. When this occurs, it suggests that the person is experiencing complicated grieving that needs more attention. (Ref. 25) (Ref. 26)

There are four categories of complicated grief reactions:

Chronic grief is characterized by normal grief reactions that do not subside and continue over very long periods of time.

Delayed grief is characterized by normal grief reactions that are suppressed or postponed. The person consciously or unconsciously avoids the pain of the loss.

Exaggerated grief is characterized by coping strategies that accelerate and even become destructive, especially in the face of a seemingly insurmountable loss (i.e., increased smoking/alcohol/medication intake, overworking, even suicidal ideation).

Masked grief is characterized by oblivion that the behaviors that interfere with normal functioning are a result of the loss.

Both uncomplicated and complicated grief can continue for several months to several years. Grief may continue longer in some situations. Mediating factors include:

- Mode of death (e.g., natural, traumatic)
- Preexisting emotional states (e.g., depression, stress)
- Personality variables (e.g., coping, resilience)
- Social and cultural context (e.g., traditions, rituals, social network)
- Relationship(s) to the deceased (e.g., close, conflicted, or ambivalent; loss of a child or loss of a long-term marital partner)

It is the duration as well as the intensity of the symptoms, coupled with a diminished ability to function, that help to distinguish uncomplicated from complicated grief. Worden provides clues to diagnosing complicated grief:

- Inability to speak about the loss without experiencing intense and fresh grief
- Relatively minor events trigger intense grief reactions
- Themes of loss permeate clinician's interview

- Unwilling to move material possessions
- Physical symptoms similar to those of the deceased
- Radical changes of lifestyle
- History of subclinical depression, often with persistent guilt and lowered self-esteem, or the opposite, false euphoria
- Compulsion to imitate the deceased
- Self-destructive impulses
- Unaccountable sadness occurring at a certain time each year (although anniversary reactions, or increased intensity of grief during holidays, birthdays, etc., are a normal part of the uncomplicated grief process).
- Phobia about illness or about death

Bonanno and others have found that psychological resilience is more common during bereavement than previously thought. (Ref. 27) These works suggest that there are multiple trajectories for the grief process, including those involving intense, negative emotional experiences throughout the course as well as those involving psychological growth.

Exaggerated grief responses include major psychiatric disorders that develop following a loss and include recognized diagnoses in the American Psychiatric Association's Diagnostic and Statistical Manual (DSM). Clinical depression is one example.

Assessment

Indicators of uncomplicated grief include incorporating the loss into one's life and beginning to enter into meaningful relationships and activities again. Even in uncomplicated grief, this movement forward is painful.

Effectively anticipating and reducing the severity of the grief reactions of patients and families begins early in the process and involves repeated assessment of anticipated and actual losses, emotional responses, and coping strategies. Cognitive, emotional, and physical reactions to grief, and the need for bereavement support, can be ongoing for months.

Recognition that grief may be the underlying cause of a patient's physical complaints is important if useless or misleading investigations or medication trials are to be avoided. To effectively anticipate and reduce the intensity of grief reactions, assess each patient's anticipated and actual losses, emotional responses, and coping strategies frequently during the first months following a death. Gentle inquiry can help the physician understand how the survivor is coping and provide support.

When religion is an important component of coping, engage a chaplain or pastoral care professional to help determine and understand the religious background and framework held by each family member.

Try to identify individuals who are at particular risk early. Physicians and health care workers need to be skilled at assessing grief reactions, providing basic supportive care, and referring individuals to bereavement experts expeditiously when grief reactions become complicated.

Some people will make a conscious effort to manage the loss. Others will deny what is happening and avoid dealing with the loss. Some coping strategies (e.g., increased smoking/alcohol/medication intake, overworking, and suicidal ideation) may accelerate and even become destructive, especially in the face of seemingly insurmountable loss.

Physicians and other health care providers need to be attuned to behaviors that might indicate complicated grief, especially if these continue beyond 6 to 12 months. (Ref. 28) The survivor may not be able to speak of the deceased without experiencing intense sadness. Themes of loss may continue to occur in every topic during a clinical interview. Minor events may unexpectedly trigger intense grief and sadness. The survivor may be unwilling to move possessions belonging to the deceased. Sometimes the survivor will develop symptoms similar to those of the deceased.

Ongoing assessment will help the clinician distinguish uncomplicated from complicated grief reactions. Understanding the bereaved person's preexisting conditions is beneficial as those conditions may complicate the grief process. Preexisting clinical depression, for instance, can predispose someone to a complicated grief process. Many symptoms of normal grief are similar to those of mental health disorders. Differentiating normal grief from mental health disorders is helped by factoring in the intensity, duration, and impact on functioning for the bereaved. Clinical depression is a good example because both grief and depression are associated with intense low mood, difficulty experiencing pleasure, sleep disturbance, and appetite loss, making it difficult to distinguish among them.

Table 1, adapted from Cook and Dworkin (1992), contrasts uncomplicated grief with clinical depression. It is important to note that while a full depressive reaction may accompany a normal grief response, grief typically does not include the loss of self-esteem, worthlessness, or overall sense of guilt that characterizes depression. The depressed person has a consistently low mood or an absence of emotion, has little enthusiasm for previously enjoyable activities, and has little interest in others. In contrast, the grieving person has variable emotions and is likely to shift from being able to enjoy some activities to refusing activities and from wanting to be with others to preferring to be alone. Hence, a low threshold for inquiring about depression is appropriate when treating patients with cancer and their families.

Table 1. Uncomplicated Grief vs Clinical Depression (adapted from Cook & Dworkin, 1992)

	Uncomplicated Grief	Clinical Depression
Loss	Recognizable and current	May be associated with a loss; loss is not always recognizable, and may be symbolic
Reactions	Initially intense, then variable	Intense and persistent
Mood	Labile, acute, heightened when thinking about loss	Consistent low, pervasive, chronic, absence of emotion
Behavior	Variable, shifts from being able to share pain to wanting to be alone, variable refusals of enjoyable activities	Refusals of most previously enjoyed activities, no enthusiasm, consistent difficulty enjoying activity
Anger	Often expressed	Self-directed
Sadness	Periodic weeping or crying	Little variability (inhibited or uncontrolled expression)
Cognition	Preoccupied with loss, confusion	Preoccupied with self, worthlessness, self-blame, hopelessness
History	Little history of psychiatric disorder	Previous history of depression or other psychiatric disorder
Sleep	Periodic difficulties falling asleep and with early morning awakening	Regular early morning awakening
Imagery	Vivid dreams, capacity for imagery and fantasy	Self-punitive imagery
Responsiveness	Responds to warmth and assurance	Limited responsiveness to others

Screening questions

Some inquiries to initiate assessment include:

- "What comforts you?"
- "What concerns you most today?"
- "What else is going on in your life at this time?"
- "Tell me about your life since the death."
- "Who do you have that you can talk with? Are they available when you need them?"
- "What physical sensations do you notice when your grief is most intense?"

Module 4 - Video 2

Management

Interventions for clinical depression occurring during grief may include antidepressant ± anxiolytic medication and psychotherapy. Supportive therapy and cognitive behavioral therapy are two psycotherapeutic approaches that are used to treat depression occurring with grief. When the clinician suspects depression or other psychopathology, it may be helpful to explain to the dying or bereaved person that stress may precipitate these disorders and to emphasize that the associated suffering can be treated or managed.

The patient and family during the course of cancer

As the patient takes in the diagnosis, he or she will experience stress. (Ref. 29) Acknowledge the loss of a sense of the future. This will likely facilitate more candid discussions and help newly diagnosed patients gain insight into the reality of having cancer. The result will hopefully be a supportive transition to living with cancer. Counseling may be necessary, particularly if patients and family members have differing expectations. As the patient begins to experience loss of function, practical strategies and psychological support from interdisciplinary members of the care team, support groups, a pastor, or community members may all be beneficial. For the patient suffering from altered self-image, cosmetic approaches may be appropriate in addition to counseling. Adaptation by patients and families is particularly difficult if symptoms go unrelieved; careful attention to symptom relief is also an essential part of adaptation to loss. (Ref. 30) See EPEC™-O Module 3: Symptom Management.

Reassess frequently

As cancer progresses, responses to challenges may trigger rapid change in the patient's emotions. Frequent reassessment is essential. As family members are aware of the patient's impending death, anxiety rises and psychological and cognitive functioning may decline. Psychological support is helpful and may prevent needless long-term anxiety. (Ref. 31) Indeed, experience of traumatic grief predicts mental and physical morbidity more than bereavement alone. (Ref. 32)

The bereaved family

Acknowledge the loss

The clinician's respect for the grief process may make a difference in the ability of the dying person and bereaved family members to move toward their life goals. For the dying person, this may involve dying in his/her chosen way, with an intact personal identity and opportunities to complete important remaining goals. For the bereaved, this may involve appreciation of a significant relationship, acceptance of change, and development of new life patterns and relationships.

Finding adaptive responses and reintegrating into society is a significant accomplishment. If the physician perceives that the patient or family has achieved this, or even begun the process, it is important to acknowledge and affirm the achievement. This will reinforce the process and foster development of skills that may be necessary each time the patient and family face a new loss.

Encourage participatory activities

Encourage the bereaved person to talk about what it is like to live without the deceased. Encourage her/him to attend the funeral or memorial service, participate in personal rituals, and write letters to family and friends, recounting the story and feelings. After a period of time, during which introspection has allowed the bereaved person to acknowledge the loss, suggest that he/she begin to participate in activities with family, friends, and community. Initially, these activities may seem meaningless, but encourage the bereaved person to remain engaged until meaning can be recreated.

Treat anxiety, depression, insomnia

If the grief reactions and coping strategies appear to be appropriate and effective, the situation can be monitored and supportive counseling provided. When bereaved survivors feel they are "going crazy" or "losing their mind," give them time to discuss their feelings. It may also help to explain that grief is painful and prolonged, but normal. The length of time needed for the grief process will vary with each person and situation. There is no "right" way to grieve and each person will have his/her own way. If counseling is insufficient, medical management of anxiety, depression, insomnia, or other common grief reactions can be helpful for short periods of time (weeks to months).

Refer to resources

Immediately after a death, those who are bereaved will need time to recover from their acute stress and fatigue, and restore their environments back to normal. As they begin to realize the significance of the loss to their lives, they will likely experience an intense grief reaction with multiple cognitive, emotional, and physical responses (see Table 1) and require considerable ongoing support to help them deal with all the changes to their lives. (Ref. 18) (Ref. 19) (Ref. 20) (Ref. 21) (Ref. 22)

If loss, grief reactions, and coping strategies appear to be inappropriate, ineffective, or prolonged and/or they have the potential to cause harm (e.g., destructive behaviors or suicide), they will need to be assessed and managed aggressively. Some people will need ongoing support, psychotherapy, and/or medication to manage their symptoms and reduce the intensity and protracted course of their suffering as they struggle to adapt to the profound changes to their lives. Consult a psychiatrist, psychologist, or another specialist who is skilled in complicated loss, grief, and bereavement care so that therapy can be instigated rapidly to reduce the risk of harmful/destructive activities.

Follow-up

Write a condolence note

A note or letter from the doctor after the death has been widely reported to be helpful to the bereaved. (Ref. 33) Such a note has two goals: offer tribute to the deceased as someone who was important and be a source of comfort to the survivors. Mourners will appreciate that you took the time to sit and compose a personal message to them or share a memory of the deceased. A promptly sent letter, generally within 2 weeks after the death, will be far more effective than a late one. Use any standard stationery and write it by hand. Some specific guidelines for writing a good condolence note include:

- Acknowledge the loss and name the deceased. This sets the purpose and tone of the letter. Let the bereaved know how you learned of the death and how you felt upon hearing the news. Use the name of the deceased. "The hospice called to let me know that your mother, Mary Smith, died on Thursday."
- Express your sympathy. Use words of sympathy that remind the bereaved that they are not alone in their feelings of sadness and loss, such as "I was so sad to hear the news."
- Note special qualities of the deceased. Acknowledge those characteristics that you observed about the person who has died. These might be qualities of personality (courage, sensitivity), or attributes (funny, affable), or ways the person related to the world (religious, devoted to community welfare). Say something like, "I will miss her sense of humor."
- Recall a memory about the deceased. Talk about how the deceased touched your life. Try to capture what it was about the person in the story that you admired, appreciated, or respected. You may use humor. Funny stories are often

the most appreciated by the bereaved. Say something like, "I particularly remember when she had all of us in the office laughing at one of her jokes about the examination gown."

- Remind the bereaved of their personal strengths. Bereavement often brings with it self-doubt and anxiety about one's own personal worth. By reminding the bereaved of the qualities he or she possesses that will help him/her through this period, you reinforce his/her ability to cope. Qualities to mention might be patience, optimism, religious belief, resilience, and competence. If you can recall something the deceased used to say about the mourner in this regard, you will be giving the bereaved a very real gift.
- Offer help, but be specific. Don't say, "If there is anything I can do, please call." That puts a burden on those in grief who may be totally at a loss about what needs to be done. A definite offer of help is more appreciated (e.g., "I'd be happy to answer any questions you or your family might have about her illness and her care. Just make an appointment with the office-no charge."). Whatever you offer, do it! Don't make an offer you cannot fulfill.
- End with a word or phrase of sympathy, such as "I'll never forget your mother or the care you gave her."

Help from the interdisciplinary team

Professional members of the interdisciplinary team can also offer to assist family members, when ready, to deal with outstanding practical matters, secure documents to redeem insurance, find legal counsel to execute the will, meet financial obligations, close the estate, etc.

Bereavement visit

The physician can assist the family with uncomplicated grief by listening to how the bereaved family member is doing, educating about the grief process, and normalizing the experience. Simply offering a bereavement visit as a routine matter will help to normalize the experience.

Grief counseling and support may be helpful for persons experiencing uncomplicated grief. Although these individuals may not need professional intervention, they may benefit from opportunities to receive education about the grief process, express emotions with others having similar feelings, and receive guidance with problem solving during adjustment to life without the deceased.

Hospice and palliative care programs typically provide a wide range of bereavement services, including individual, general, and specialty group counseling; support newsletters; memorial celebrations; and specific strategies to help cope with holidays and particular types of loss. If the patient was enrolled in hospice care, family members may be eligible for bereavement support services through that hospice without charge. Other bereaved individuals may be able to access those services for a fee.

Summary

Care of patients' and families' response to cancer is part of comprehensive cancer care. Patients respond first to the loss of their expectations for their future, and the process continues throughout the course of their cancer experience. Family members have counterpart responses, and many face bereavement.

Understanding the processes of adaptive and maladaptive responses is essential. Acknowledging loss, and teaching the patient and family about the process of responding to loss, can help them in their adjustments to illness-related losses and to the last stages of living and bereavement. Each loss results in a need to assimilate the reality of the loss, creatively adapt, and reintegrate into society. Each loss and adaptation can involve experiments with coping that fail or cause stress. They can also result in deep and meaningful relationships. These important stages often leave lasting memories for families, as well as for caregivers and professionals.

Care does not end until the physician has helped the family with their grief reactions and helped those with complicated grief to get care. Interventions for depression during grief and assistance with developing coping mechanisms for adapting to loss may be best administered by a social worker, pastor, or other counseling professional.

Key Take-Home Points

1. Cancer patients and their families experience a variety of losses throughout the progression of the illness and after the death of the patient. The physician is instrumental in assisting with the adaptations and reactions that accompany a loss.
2. A thorough history and assessment of the physical, emotional, and mental health of the patient suffering a loss will allow the physician to appropriately intervene or refer the patient for further professional support.
3. Grief is a continuum. Consider intensity and duration of symptoms and level of functioning as initial monitors that may reveal clinical depression, adjustment disorders, generalized anxiety, or other pathologic responses.
4. Involvement of other key team members and appropriate referrals early in the process can be beneficial to patients, families, and physicians as they integrate their experience of cancer, and sometimes the death of the patient, into their lives.

Pearls

1. Introduce the idea of loss and creative adaptation early in the illness to assist patients and families with coping resources during each transition.

2. Acknowledge each loss and adaptation, including the attainability of a good quality of life despite each loss.
3. Maintain awareness of depression or maladaptive coping mechanisms.
4. Involve a professional counselor early, possibly from the time of diagnosis, for the patient and relevant family members.
5. Make a partnership with your patient and the family caregiver; draw them into the interdisciplinary team and foster their active participation in the care plan.
6. Additional information can be found in the Health Professional Resources and Patient Resources section of this module.

Pitfalls

1. Forgetting the importance and energy-consuming nature of loss and adaptation.
2. Being inhibited about acknowledging or addressing the issues.
3. Failing to involve a professional counselor.
4. Missing the diagnosis of depression in either the patient or a family member.
5. Failing to follow through with the bereaved family member after the death of the patient.
6. Missing the diagnosis of depression in a bereaved family member.

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Module 4: Loss, Grief, and Bereavement

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A condolence letter has two goals: to offer tribute to the deceased and to be a source of comfort to the survivors. The authors provide specific guidelines for writing a good condolence letter.

Self-Assessment

Module 4: Loss, Grief, and Bereavement

1. Mr. Larson, a 48-year-old man with a history of stage I colon cancer 4 years ago returns to the office concerned that his cancer has returned. His daughter, age 11, died from acute lymphocytic leukemia 2 months ago. He comes to the office complaining of tightness in the chest, palpitations, lack of energy, a 4-pound weight loss, and difficulty sleeping. He seems “flat” and confirms that he feels emotionally “numb.” He is working and does report the ability to experience pleasure when playing golf or going out to dinner with his wife. The most likely diagnosis in this man is:

   - a). coronary artery disease
   - b). grief
   - c). recurrent cancer
   - d). major depression

2. The most useful thing the oncologist can do to support Mr. Larson is:

   - a). educate him about normal grief
   - b). not reschedule any visits so as not to remind him of cancer
   - c). tell him his daughter is in a better place
   - d). perform coronary angiography

3. Mr. Larson is seen again, 1 year later. He can talk about his daughter without intense feelings of loss. He reports his sleep is normal, and he has started volunteering for the leukemia society. This most likely represents:

   - a). repressed grief
   - b). resolving grief
   - c). complicated grief
   - d). disenfranchised grief

4. Mr. Larson returns 18 months after his daughter's death for follow-up. He again thinks his cancer has returned. He reports feeling "low." He has stopped playing golf or going out. He stays home "sick" from work frequently. He expresses no enthusiasm for any of his work or family activities which previously gave him pleasure. The best approach would be to:

- ☐ a). refer to psychiatry for medication and therapy
- ☐ b). reassure that grief is episodic, sometimes for years
- ☐ c). plan restaging for cancer
- ☐ d). schedule return visit in 2 weeks to reassess

Self-Assessment Answers

Question 1. The correct answer is: b)

Normal grief reactions include a range of physical, emotional, and cognitive behaviors. The bereaved may note feelings of hollowness in the stomach, tightness in the chest, heart palpitations, weakness, lack of energy, gastrointestinal disturbances, weight gain or loss, or skin reactions. Many say they feel emotional numbness, relief, sadness, fear, anger, guilt, loneliness, abandonment, despair, or ambivalence. They may be concerned about cognitive symptoms such as disbelief, confusion, inability to concentrate, and preoccupation with or dreams of the deceased. The other diagnoses, while possible, are less likely.

Question 2. The correct answer is: a)

Clinicians can provide education, communicating that painful feelings about a loss, such as sadness and anxiety, are understandable. It may be valuable to confirm that ambivalent feelings (e.g., sorrow and anger, anxiety and relief) in grief are common as most relationships have their difficult as well as their wonderful moments.

Question 3. The correct answer is: b)

Worden and others have defined benchmarks from which to judge the resolution of the grief process. One indication is when the bereaved is able to talk about the deceased without intense, fresh feelings of loss. Another is when the survivor is able to invest energy in new relationships, roles, and responsibilities, without disabling guilt and feelings of disloyalty toward the deceased.

Question 4. The correct answer is: a)

Interventions for clinical depression occurring during grief may include antidepressant or anxiolytic medication and psychotherapy. Supportive therapy and cognitive behavioral therapy are two psychotherapeutic approaches that are used to treat depression occurring with grief. The global nature of his complaints argues against grief. Cancer recurrence is unlikely.