EPEC-O

Education in **P**alliative and **E**nd-of-life **C**are - **O**ncology

Participant's Handbook

Module 4

Loss, Grief and Bereavement

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Abstract

Cancer patients face losses from the onset of their illness, starting with loss of their expectations for their future. Loss results in grief responses; mourning a loss and creatively adapting to life without what is lost is part of creative adaptation. Patients can respond creatively to multiple, major losses. Adverse responses include anxiety, depression, and their associated pathological manifestations. Family, caregivers and the members of the cancer care team also 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 also described. Lastly, approaches to follow-up with bereaved family members are described.

Key words

Loss, grief, complicated grief, uncomplicated grief, bereavement, adaptation, creative adaptation, self image, roles, sick role, dying role, economic hardship, acknowledgement, listening, condolence note, professionals responses to patient losses

Objectives

After reading this module, oncologists and 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.

Clinical case on trigger tape

T.S. is a 68-year-old recently bereaved man who comes into the office at the insistence of his daughter. He has been finding it difficult to enjoy or find meaning in life since his wife passed away. He has been loosing weight. He has a history of colon cancer 8 years ago, and his daughter is worried that he may have a recurrence.

Introduction

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

Grief is a personal and normal response to a loss. It can be emotional, intellectual, spiritual, physical, behavioral, and/or social. *Grief is the experience of a loss.* Mourning is the act of grieving. It can involve private expressions and experiences of grief, and socially and culturally defined customs such as rituals and traditions. Mourning is the

outward experience of a loss; grief and bereavement are components of the process of accommodating a loss.

Bereavement is the *state of living with a loss*.

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

Each loss produces a grief response, the intensity of which will vary with the importance of the loss to the person experiencing it. The way that a person copes and adapts to loss and their grief response is key to differentiating between a complicated and an uncomplicated grief process. In *uncomplicated grief reaction,* after an initial acute grief reaction the emotional response is time-limited, the individual utilizes existing resources and seeks outside help to cope and adapt to the loss, and 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 early stages of research, but are becoming better understood.[1,2]

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

Those caring for the patient also suffer their own losses as their lives change and they share the experience with the patient.

Experiencing a loved one's death can be extremely stressful. Bereavement is associated with declines in health; inappropriate health services use, 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.[3]

With such a high prevalence of loss and grief amongst their patients and families, oncologists and other members of the cancer care team are susceptible to counter transference and potential burnout if the cumulative losses expressed by patients and families are internalized without recognition or strategies for coping (see EPEC-O Module 15: Cancer Doctors and Burnout). In contrast, they can also experience satisfaction at witnessing the patients and family's enjoyment of life as they live to the fullest with meaning and value.

Since all cancer patients and their families experience the losses associated with having a cancer, and since all families who lose a patient to cancer face loss, grief, and bereavement, these forces are a significant part of the cancer experience. Competence to provide care for these components of the cancer experience is therefore a high priority for oncologists.

The time course of adaptation to loss varies. Taking in 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 reduce over weeks to months, depending on the nature of the loss. While most people who are bereaved are able to reenter the world after one to three weeks, their active grieving can go on for a year or more and sadness can continue for much longer but typically does not intrude on or prevent new life. Over a period 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.[4]

In addition to challenges, each loss also presents opportunities for new perspectives on living, heightened spiritual awareness, and chances to resolve conflicts and find greater acceptance of oneself, others, and the world. Often, people find ways to make these opportunities part of the adaptation to loss.

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.[5]

Despite the ubiquitous nature of patients facing losses due to illness and despite the frequency with which physicians encounter bereaved patients and families, medical education has provided minimal training in the provision of care for this aspect of patients' experience or for the bereaved.

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

Loss and grief during illness

Perceived loss requires adaptation. This is true whether the perceived loss 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, and adaptation can be difficult. Assistance in achieving the adaptations that allow the patient and their family to maintain a quality existence is an integral part of comprehensive cancer care.

Understanding the nature of, and the implications of a loss, discarding exaggerated fears and accepting unwanted realities, are necessary before any adaptation is likely to be an optimal fit for the challenge.

However, the emotional responses to loss can be so great that comprehension is difficult. Some people need discussion and repeated 'fact checking.' Others need a tangible event. Others need time to let the realities 'sink in.'

Many people need to disconnect from their previous engagements, loosing interest in them, as they internally adapt and reintegrate as a whole person ready for relationships with others – without what has been lost.

Patient losses and adaptations

Sense of future

Often the first loss that a cancer patient faces is 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 puts 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 are required to accommodate a wide range of transient and permanent losses of function. Whether they are transiently too fatigued to perform instrumental activities of daily living, or lose normal taste, hearing acuity or fine cognitive skills, each is a loss. Adaptations often involve family members who may now need to shop for the first time or who may need to help the patient in the bathroom in ways not previously experienced. Many of these new approaches to living entail skills that may be new.

Self-image

Physical losses and engagement in new approaches to life precipitate a changed self-image. Whether hair loss, weight loss, breast loss, or limb loss has occurred, self-image has to adjust. Ideally, the patient and family can learn to feel good about the new physical form, but this is often difficult.

Roles

Less tangible and often very difficult is the loss of social role that cancer can bring. Children temporarily or more permanently lose their role as a school-goer. Adults may loose their job; be less functional in their family role, whether as a parent, child or a sibling; and/or be less functional in their community role, whether as an active church-goer or activist or welcoming host or proud gardener or other group participant. In place of these roles patients take on the 'sick role' and family members the 'caregiver role,' with varying degrees of personality fit for those roles.

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 sick. Her or she expects and is expected to be cared for by others who tend to needs that he or she cannot fulfill alone.[6,7] In the caregiving role, 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 instrumental and core activities of daily living, the caregiver must learn how to help with personal function. This type of intimacy may not be welcome, involving as they do different self-images and relational boundaries. A sense of loss for ones' former self may exist for the patient and for the caregiver. It may be necessary for each party to experiment with various ways of performing the roles.

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

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

The dying role and successor roles

Society assigns a slightly different role for people who are expected to die soon. They are no longer expected to struggle for cure and recovery. They are expected to reach a peaceful state with others and offer parting gestures. They are expected to reach some type of conclusion on their life story or personal legacy. They are expected 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 life time, 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 roles of successors. They accept the role of guarding the person's personal and material legacies, sometimes finishing an unfinished project and sometimes creating a sense of the dying person's story so that it can be passed down through the generations.

Negotiating timely role transitions

While important, new roles can also be detrimental if they are entered prematurely. The patient can feel discarded before his or her time, and the future caregiver or future successor 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 where 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.[11,12]

Relationships

Along with the changing social roles, personal relationships are often also 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 used to. 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 as 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.[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 functions, 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, let go of their expectations of a mother or spouse or child, make time to perform domestic functions, and so on. Adaptations by family members are an integral part of the process of adapting to living with cancer, adjusting to losses, and to eventual bereavement. Comprehensive cancer care requires awareness of these needs and intervention to help meet the needs. 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 utilizing self care approaches that incorporate the mental, physical, emotional, and spiritual dimensions.[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 cancers with an excellent prognosis, quality of life appears to be high, suggesting that patients adapt well to their cancer experience.[15] Survivors who live with cancers of less prognosis experience continuing stress; eg, breast cancer survivors with persistent fatigue have altered cortisol responses to psychologic stress.[16] The quality of studies, however, is still limited.[17] This topic is further discussed in EPEC-O Module 5: Survivorship.

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 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 and require considerable ongoing support to help them deal with all the changes to their lives.[18,19,20,21,22] 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 and to seek ongoing assistance from their physicians to help them 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.'[23]

Theoretical perspectives have offered frameworks for understanding why we grieve. Bowlby[24] suggested that grief occurs when an attachment necessary to one's safety and security is disrupted. Others conceived 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, eg, sadness, anxiety, anger
- Physical, eg, loss of appetite, fatigue
- Cognitive, eg, preoccupation, confusion
- Behavioral, eg, restlessness, searching
- Spiritual, eg, 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 suggested four tasks of grief:[18]

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 way, but in a variety of manners and with different timing for each person.

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

- When the bereaved is able to talk about the deceased without intense, fresh feelings of loss
- When 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.[25,26]

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 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.

For some losses, grief continues for several months to several years. Grief may continue longer in some situations. Mediating factors include:

- Mode of death, eg, natural, traumatic
- Historical antecedents, eg, depression, stress
- Personality variables, eg, coping, resilience
- Social and cultural context, eg, traditions, rituals, social network
- Relationship(s) to the deceased, eg, close, conflicted or ambivalent

The duration as well as the intensity of the symptoms, coupled with diminished ability to function, help distinguish uncomplicated from complicated grief. Worden provides clues to diagnosing complicated grief:[18]

- Inability to speak about the loss without experiencing intense and fresh grief
- Relatively minor event triggers intense grief reactions
- Themes of loss permeate clinicians 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
- Phobia about illness or about death

Bonanno and others have found that psychological resilience is more common during bereavement than previously thought.[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 included recognized diagnoses in the American Psychiatric Association's Diagnostic and Statistical Manual (DSM). Clinical depression is one example.

Assessment

Indications of uncomplicated grief are the painful yet forward movement toward incorporating the loss into one's life and beginning a meaningful life that includes entering into relationships and activities again.

Effectively anticipating and reducing the severity of the grief reactions of patients and families begins early in the process and involves repeated assessments of anticipated and actual losses, emotional responses, and coping strategies. Gentle inquiry may provide support to the bereaved, and help the physician understand how the survivor is coping. Cognitive, emotional, and physical reactions to grief, and the need for bereavement support, can be ongoing for months. Physicians and healthcare workers need to be skilled at assessing grief reactions, providing basic supportive care, and referring individuals to bereavement experts quickly when grief reactions become complicated.

Recognition of the underlying cause 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. Try to identify individuals who are at particular risk early. 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.

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 HCPs need to be attuned to behaviors that might indicate complicated grief, especially if these continue beyond 6 to 12 months.[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. Pre existing 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. Discernment 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 with the experience of pleasure, sleep disturbance, and appetite loss, making it difficult to distinguish among them. Table 1 adapted from Cook and Dworkin (1992) contrasts uncomplicated grief versus clinical depression. It is important to note that, while full depressive reaction may accompany normal grief response, typically grief does not include the loss of self-esteem, worthlessness, or overall sense of guilt that characterizes depression. The depressed person has 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, having a low threshold for inquiring about depression is appropriate when treating patients with cancer and their families.

Table 1 (adapted from Cook & Dworkin, 1992)

	Uncomplicated grief	Clinical depression
Loss	Recognizable and current	Loss may be symbolic, loss is not always recognizable, may be associated with a loss
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

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. 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.

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?

Management

The patient and family during the course of cancer

As the patient takes in the diagnosis, he or she will be experiencing stress.[29] Acknowledge the loss of sense of future. This will likely facilitate more candid discussions and facilitate insight into the reality for most cancer patients, as well as allowing a more candid and supportive passage through the transition. Some evidence indicates that early counseling intervention prevents development of distress in both the patient and the caregiver.[30] Counseling can be particularly needed if patients and family members have differing expectations. As the patient begins to experience loss of function, practical strategies and psychological support from all team members, from nursing or social work, or from support group members, a pastor or community members may all be beneficial. For the patient suffering from altered self image, cosmetic approaches may be appropriate as well as counseling. Adaptation by patients and families is particularly difficult if symptoms go unrelieved; careful attention to symptom relief may therefore also be considered an essential part of adaptation to loss.[31]

Reassess frequently

As cancer progresses, the responses to the challenges may trigger rapid change in the patient's emotions. Frequent reassessment is therefore 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.[32] Indeed, experience of traumatic grief predicts mental and physical morbidity more than bereavement alone.[33]

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 the 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 is a significant accomplishment. If the physician perceives that the patient or family has begun, or even achieved this, it is

important to acknowledge and affirm, both to reinforce the process and foster skills that will likely be necessary each time the patient and family face a new loss.

Facilitate discussion

Physicians can discern and allow for the patient and family needs, normalizing the process along the way. Meeting with the nurse, social worker, or counselor to achieve the prerequisites of an optimal adaptive process may be useful, and the physician can help orchestrate.

Encourage participatory activities

Encourage the bereaved survivor to talk about what it is like to live without the deceased. Encourage her/him to participate in rituals such as attending the funeral or memorial services, or identifying personal rituals and write letters to family and friends, recounting the story and their feelings. After a period of time in which internal reflection has allowed the bereaved person to acknowledge the loss and become capable of recreating life with the reality of their loss, encourage their participation in activities with family, friends, and community. Acknowledgment that initially these activities may seem meaningless may help the bereaved person to continue engagement until meaning can be recreated.

Treat anxiety, depression, insomnia

If the loss, 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; that the length of time needed for the grief process will vary with each person and situation; that 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

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.

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.[18,19,20,21,22] 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 and seek ongoing assistance from their physicians to help them address their feelings of loss and their emotions. 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.

A bereavement card and attendance at the patient's funeral may be appropriate. For many physicians and members of the professional team, encouraging follow-up visits from family members to assess the severity of their grief reactions to their recent loss and coping strategies and to provide support is a part of their professional duty of care.

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.[34] Such a note has 2 goals: offer tribute to the deceased as someone who was important and be a source of comfort to the survivors. Mourners 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 two weeks after the death, will be far more effective than a late one. Use any standard stationery and write it by hand. Here are some specific guidelines for writing a good condolence note:

- 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-the 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 really be giving the bereaved a 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. Whatever you offer, do it - don't make an offer you cannot fulfill.
- 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.
- 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 patient 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, to express emotions with others having similar feelings, and to 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. Acknowledgment and teaching the patient and family about the process of response 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 for taking in the reality, creative adaptation, and reintegration. 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.[8]

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 as well as for other difficult coping mechanisms for adapting to loss may be best administered by a social worker, pastor, or other counseling professional.

Key take-home points

1. Patients and families experience a variety of losses throughout the progression of the illness and after the death of the patient. The physician is instrumental is assisting with the adaptations and reactions that accompany a loss.
2. Thorough assessment of the physical, emotional, and mental health as well as personal history will allow physicians to intervene or refer with patients who have suffered a loss.
3. Grief is a continuum. Consider intensity and duration of symptoms and level of functioning as initial monitors that may result in 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 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.

Pitfalls

1. Forgetting the importance of 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 death of the patient.
6. Missing the diagnosis of depression in the bereaved family member.

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[34] Fast Facts And Concepts #22 Writing A Condolence Letter Ron Wolfson, PhD and Elizabeth Menkin, MD. End of Life Physician Education Resource Center http://www.eperc.mcw.edu

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