

EPEEC for Veterans

Education in Palliative and End-of-life Care for Veterans

Trainer's Guide

Module 12

Loss, Grief and Bereavement

Emanuel LL, Hauser JM, Bailey FA, Ferris FD, von Gunten CF, Von Roenn J, eds. EPEC for Veterans: Education in Palliative and End-of-life Care for Veterans. Chicago, IL, and Washington, DC, 2012.

EPEC® was created with the support of the American Medical Association and the Robert Wood Johnson Foundation. Subsequent funding has been provided by the National Cancer Institute and the Lance Armstrong Foundation. The EPEC for Veterans Curriculum is produced by EPEC and the EPEC for Veterans Work Group through funding provided by the US Department of Veteran Affairs. Acknowledgment and appreciation are also extended to Northwestern University's Feinberg School of Medicine, which houses EPEC.

Special thanks to the EPEC for Veterans team and all other contributors and reviewers.

Contact EPEC by E-mail at info@epec.net, or

EPEC®

750 N. Lake Shore Drive, Suite 601

Chicago, IL 60611

USA

Phone: +1 (312) 503-EPEC (3732)

Fax: +1 (312) 503-4355

Module 12 trainer's notes

Principal message

Adaptation to loss is an active process for both the Veteran and family members, starting with the onset of illness. Bereavement is the best acknowledged form of loss. The family bereavement assessment begins with the onset of the Veterans illness, identifying potential complicated grief, preparing the clinicians to provide bereavement support to the family after the Veteran's death.

Module overview

Veterans in palliative care face losses from the onset of their physical decline, beginning with the loss of their expectations for their future. Loss results in grief responses; mourning a loss and creatively adapting to life without what is lost are parts of creative adaptation. Veterans can respond creatively to multiple, major losses. Adverse responses include anxiety, depression, and their associated pathological manifestations. Family, caregivers and the members of the palliative care team are also affected by losses. Approaches to providing support for Veterans and families facing losses, as well methods for screening, assessment and management of uncomplicated and complicated grief are described. Lastly, approaches to follow up with bereaved family members are described.

Preparing for a presentation

1. Assess the needs of your audience

Choose from the material provided in the syllabus according to the needs of your expected participants. It is better for participants to come away with a few new pieces of information, well learned, than to come away with a deluge of information but remembering nothing.

2. Presentation timing

Allow sufficient time for participants to introduce themselves.

The suggested timing for each part of this module is:

Introduction	2-3 minutes
Trigger tape & discussion	5-7 minutes
Presentation	40 minutes
<u>Summary</u>	<u>2-3 minutes</u>
Total	49-53 minutes

3. Number of slides: 23

4. Preparing your presentation

The text in the syllabus was not designed to be used as a prepared speech. Instead, the slides have been designed to trigger your presentation. Although the slides closely follow the text of the syllabus, they do not contain all of the content. Their use presumes that you have mastered the content. You may want to make notes on the slide summary pages to help you prepare your talk in more detail and provide you with notes to follow during your presentation.

Practice your presentation using the slides you have chosen, and speaking to yourself in the kind of language you expect to use, until it is smooth and interesting and takes the right amount of time.

5. Preparing a handout for participants

The syllabus text and slides in the **Trainer's Guide** were designed to be reproduced and provided to participants as a handout, either in its entirety, or module by module. If the entire curriculum is not being offered, please include the following in each handout:

- **EPEC for Veterans Front Cover Page**
- **EPEC for Veterans Acknowledgment Pages** (to acknowledge the source of the material)
- Syllabus and slides for **Module 12**

6. Equipment needs

- computer with DVD capability or separate DVD player
- flipchart and markers for recording discussion points

Making the presentation

1. Introduce yourself

If you have not already done so, introduce yourself. Include your name, title, and the organization(s) you work for. Briefly describe your clinical experience related to the information you will be presenting.

2. Introduce the topic

Show the title slide for the module. To establish the context for the session, make a few broad statements about the importance of attending to grief and bereavement as a clinical skill. For instance, note that many patients and families experience the entire illness in

these terms. Tell participants the format and time you will take to present the session. Identify any teaching styles other than lecture that you intend to use.

3. Review the session objectives

Show the slide with the session objectives listed. Read each objective and indicate those that you are planning to emphasize.

4. Show the trigger tape or present the clinical case

After reviewing the objectives for the session, show the trigger tape or present the clinical case below. It has been designed to engage the audience and provide an appropriate clinical context for the session. It was not designed to demonstrate an ideal interaction, but to ‘trigger’ discussion.

Clinical case

T.S. is a 68-year-old recently bereaved Veteran who comes into VA 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 losing weight. He has a history of colon cancer 8 years ago, and his daughter is worried that he may have a recurrence.

Discussion

If the discussion is slow to start, you may want to ask more direct questions:

- Have they had similar patients?
- How did the patient react to the clinician’s questions?
- How did the clinician start? What was well done? What was missing?
- What did the clinician do to foster a comfortable atmosphere?
- How did the physician address the patient’s concerns?

Use the discussion to set the stage for the material to follow. Don’t let the discussion focus on a critique of the technical quality of the trigger tape or how ‘real’ the players seemed. If the participants don’t like something that was said or done in the trigger tape, ask them how they would do it themselves.

Setting limits to discussion time

Limit discussion of each scene of the trigger tape to no more than 5 minutes, then move on to the presentation. To help move on if the discussion is very engaged, try saying something like:

- Let’s hear two last points before we move on.

- Now that you have raised many of the tough questions, let's see how many practical answers we can find.

5. Present the material

Recommended style: Interactive lecture

An interactive lecture will permit you to engage your audience, yet cover your chosen material within 45 to 60 minutes.

One possibility in this didactic yet interactive approach is to demonstrate the follow-up visit with a bereaved family member by interviewing a real or standardized patient in front of the group, after presenting the approach in the lecture-based format. After the staged interview, ask the group for their comments. Use the discussion to emphasize the points made during the lecture.

Alternative style: Role-play

Summarize the goals for following up with a bereaved family member either by using a few slides or by listing them on a flipchart or overhead projector. Then, introduce the role-play exercise. Develop your own scenario for the small groups to use, or use the one from the trigger tape.

Ask participants to divide into clinician, bereaved family member, and observer or family member groups. One way to do this is to ask them to 'count off' from 1 to 3. Then, tell the '1s' they are clinicians, '2s' they are patients, and '3s' they are observers or family members. Ask the clinicians to deliver the news for 10 minutes, and then stop for small group discussion for 10 minutes.

After the small group discussion, lead the larger group in a discussion of the results. Ask for feedback first from the clinicians, then from the patients, then from the observers. Use the flipchart or overhead projector to capture the important discussion points. Use the discussion to interweave the key take-home points from the syllabus.

6. Key take-home points

1. Thorough assessment of physical, emotional, and mental health as well as personal history will allow palliative care team members to intervene with or refer Veterans who have suffered a loss.
2. 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.
3. Introduce the idea of loss and creative adaptation early in palliative care to assist Veterans and families with coping resources during each transition.

4. Acknowledge each loss and adaptation, including the attainability of quality of life despite each loss. Do this without minimizing or discounting the loss.
5. Involve a chaplain early, from the time of admission to palliative care for the Veteran and relevant family members, to assist with grief processing during the hospitalization. Later involve the bereavement coordinator for continued follow up with family.

7. Summarize the discussion

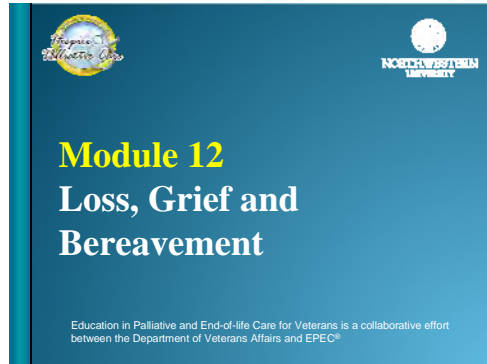
Briefly review each part of the presentation. Recap 2 or 3 of the most important points that were discussed.

8. Post-test/evaluation

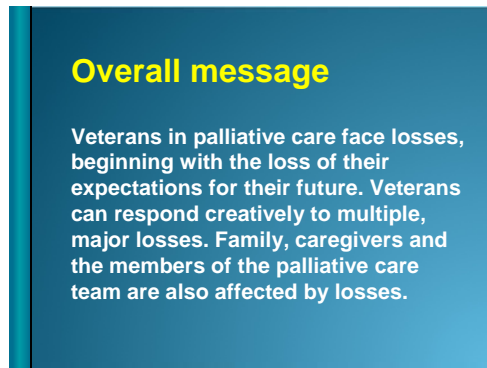
Ask the participants to evaluate the session.

Abstract

Slide 1



Slide 2



Veterans in palliative care face losses from the onset of their physical decline, beginning with the loss of their expectations for their future. Loss results in grief responses; mourning a loss and adapting to life without what is lost are parts of creative adaptation. Adverse responses include anxiety, depression, and their associated pathological manifestations. Additionally, there is a higher percentage of Posttraumatic Stress Disorder (PTSD) among this population – often untreated. Family, caregivers and the members of the palliative care team can also be affected by losses. Approaches to providing support for Veterans and families facing losses, as well as methods for screening, assessment and management of uncomplicated/complicated grief are described.

Objectives

Slide 3

Objectives

- Define loss, grief, and bereavement
- Understand 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 Veteran's death

After studying this module, clinicians will be able to:

- define loss, grief and bereavement;
- understand creative adaptation to losses;
- screen for and assess uncomplicated and complicated grief;
- manage reactions to loss, including anxiety and depression; and
- follow up with bereaved family members after a Veteran's death.

Clinical case

Slide 4

Clinical case

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

Introduction

Slide 5

Definitions

- Loss: the condition of being deprived of something / someone
- Grief: personal experience of loss
- Mourning: the act of grieving
- Bereavement: the state of living with a loss

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

Grief is the *personal experience of a loss*. It can be emotional, intellectual, spiritual, physical, behavioral, and/or social.

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*.

Slide 6

Introduction

- Losses can occur at any time
 - sense of future
 - function
 - body image
 - relationships
 - control
 - independence
 - dignity

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

Slide 7

Grief response...

- All losses produce a grief response
intensity varies by importance of loss
- Uncomplicated grief reaction
time-limited
seeks out existing resources for support
no long-term impairment in daily functioning

Slide 8

... Grief response

- Complicated grief reaction
emotional response does not resolve
little to no adaptation
harmful behaviors can develop
daily functioning impaired

Each loss can produce 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 an *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.¹

The impact of illness and loss on Veterans varies widely. Also, each family member will have reactions to the Veteran's losses and her/his own secondary losses, such as the loss of the Veteran's ability to work or the change in his or her familial role. The family system will have to cope with and adapt to changes. Sometimes this will be constructive, sometimes not.

Experiencing a loved one's death

- Bereavement associated with declines in health
inappropriate health services use
increased risk of death, depression, insomnia, suicide attempts
increased consumption of tobacco, alcohol, tranquilizers

In general, experiencing a loved one's death is extremely stressful. Complicated grief 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.²

With such a high prevalence of loss and grief amongst Veterans and their families, palliative care team members may be susceptible to countertransference (in which elements of the clinicians own history, experiences and feelings are triggered by a patient or family) and potential burnout if the cumulative losses expressed by Veterans and families are internalized without recognition or strategies for coping (see EPEC for Veterans Module 15: Professional Self-Care). In general, clinicians have been noted to be less comfortable with grief and bereavement than with other active interventions.³

The time course of adaptation to loss often 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 usually reduces 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 deceased loved one. The time course of adaptation among terminally ill Veterans 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 Veteran's life and the changes that 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

The Veteran and family during the end-of-life course

As patients take in a diagnosis, or learn they are entering an end-of-life stage, they will often experience increased stress.⁶ Clinicians can acknowledge the loss of a sense of future. This will likely facilitate more candid discussions and insight into the reality for most Veterans. Some evidence indicates that early counseling interventions prevent development of distress in both the patient and the caregiver.⁷ As the Veteran begins to experience loss of function, practical strategies and psychological support from all team members, or from support group members, a pastor or community members may all be beneficial.

For the Veteran suffering from altered self-image, such as those who have lost limbs in combat, this will be important to recognize in the course of counseling and may worsen with the other physical losses of illness. Adaptation by Veterans 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.⁸ It is important that team members do not give false hope or reject grief processing with statements such as, “well don’t give up hope” or “there’s always hope,” etc. Each of these kinds of statements can come across as superficial in the face of suffering, even if not meant as such.

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.⁹ But creative adaptation is not easy. For those facing the end of life, the demands are often repeated and severe, and adaptation can be difficult. Assistance in achieving the adaptations that allow the Veteran and their family to maintain a quality existence is an integral part of comprehensive palliative care.

Understanding the nature and 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, losing interest in them, as they internally adapt and reintegrate as a whole person ready for relationships with others – without what has been lost.

Losses and adaptations

Slide 10

Loss and grief during illness...

- **Adaptation**
sense of future
self-image
- **Roles**
sick role vs. caregiver role
dying role vs. successor role
negotiating timely role transitions

Slide 11

...Loss and grief during illness

- **Relationships change**
Veterans can feel abandoned
- **Family losses**
be aware of family adaptations
- **Effect of loss on the health care team**
cumulative effect can be overwhelming

Sense of future

Often the first loss that a Veteran in palliative care faces is confidence about the future. Even Veterans who do not ‘lose hope’ probably confront this adjustment in some fashion. The diagnosis of serious and chronic illness and the entry into a palliative care or hospice program almost inevitably raises a Veteran’s awareness of mortality and puts it in a new light. This existential challenge is likely to have ramifications in the psychological, relational, and spiritual domains.

Self-image

Physical losses and engagement in new approaches to life precipitate a changed self-image. Whether weight loss, inability to walk, appetite loss, etc., has occurred, self-image has to adjust. Ideally, the Veteran and family can learn to accept the new physical form, but this is often difficult. For some Veterans, self-image has often already been challenged in their return from war with loss of limb or other physical deformities.

Roles

The sick role and the caregiver role

In place of established roles, Veterans may take on the ‘sick role’ and family members the ‘caregiver role’ with varying degrees of personality fit for these 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 Veteran may take on an identity of being sick. He or she expects and is expected to be cared for by others who tend to needs that he or she cannot fulfill alone.^{10,11} This can be complicated in the Veteran population as most are male and society as a whole continues to hold this gender up as the strongest, but also by the fact that all Veterans are taught on active duty to be strong in order to survive. On the other hand, there are a percentage of those in VA who have remained dependent on the system for years and therefore may more easily adjust.

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 Veteran 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 relationship boundaries. A sense of loss for their former selves may exist for the Veteran and for the caregiver. It may be necessary for each party to experiment with various ways of performing their roles.

Palliative care team members 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.¹² It can also be accompanied by significant burdens.¹³ One concrete manifestation of this is the finding that caregivers experience worse health outcomes than their matched counterparts.^{14,15}

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 may be expected to reach a peaceful state with others and offer parting gestures. They may be expected to reach some type of conclusion to their life story or personal legacy. They may be expected to make practical arrangements for material gifts and sometimes for their own death-related events, such as a funeral. However, this may not be true for everyone, especially those who would perceive the above as ‘sins’, of ‘giving up’, or ‘lacking faith.’

Negotiating timely role transitions

While important, new roles can also be detrimental if they are entered prematurely. The Veteran 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.

Veterans and families can be encouraged to settle their differences where possible. 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.^{16,17}

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 Veteran 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 Veteran can no longer perform in the ways he or she used to. Sexual drive and capacity very often change near the end of life, 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 palliative care team may be able to normalize the feelings associated with these changes and they will want to remain alert to the possible need for counseling. In addition to relationships with people, relationships with spirituality and with specific religious communities may also change. They may become strengthened or they may become challenged.

Family losses and adaptation

As the Veteran 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, let go of their expectations, 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 the end of life, adjusting to losses, and to eventual bereavement. Comprehensive care requires awareness of these needs and intervention to help meet them. The Veteran is not likely to do as well if his or her family is failing to cope.

Loss and grief after death

Slide 12

Loss and grief after death

- Aspects of grief
 - emotional
 - physical
 - cognitive
 - behavioral
 - spiritual

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 a new normal state. For survivors, life cannot return to exactly what it had been and some have thought of this as the establishment of a “new normal.”¹⁸

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.^{19,20,21,22,23} Some 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 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.

Theoretical perspectives have offered frameworks for understanding why we grieve. Bowlby²⁴ suggested that grief occurs when an attachment necessary to one’s safety and security is disrupted. Others conceive of grief as a part of the healing process, reestablishing equilibrium in a person’s life after the loss of a loved one. Love and grief are inseparable.

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; and
- spiritual, e.g., questioning beliefs, anger at God.

Uncomplicated grief

Slide 13



Uncomplicated grief process

- Worden's suggested four tasks
 - accepting reality of the loss
 - experiencing pain of grief
 - adjusting to environment in which deceased is missing
 - investing emotional energy from deceased in other relationships

Uncomplicated grief reactions include a wide range of physical, emotional, spiritual, and cognitive behaviors. The bereaved may experience 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:¹⁹

- accepting the reality of the loss,
- experiencing the pain of grief,
- adjusting to an environment in which the deceased is missing, and
- 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. Recent longitudinal studies have questioned the stepwise progression through stages of grief.²⁵ These tasks may be repeated during grieving. Although the length of grieving is individualized, most professionals believe that one year is a general timeframe to use as a guide with which to judge healthy grief processing, thereby allowing opportunity to experience the first annual events (holiday, anniversary, etc.) without the deceased.

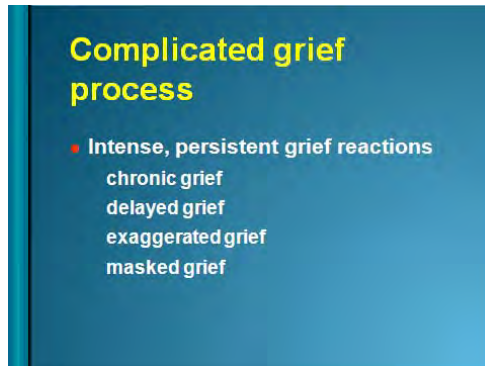
Worden and others also defined benchmarks from which to judge the resolution of grief process:

- when the bereaved is able to talk about the deceased without intense, fresh feelings of loss; and

- 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

Slide 14



Some people who are bereaved continue to experience intense cognitive, emotional and physical grief reactions over long periods of time that interfere with their wellbeing. When this occurs, it suggests that the person is experiencing complicated grieving that needs more attention.^{26,27}

Examples of four categories of complicated grief reactions include:

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

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

Exaggerated grief, 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; and

Masked grief, 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 which may be supportive or may worsen grief include:

- mode of death, e.g., natural, traumatic;
- historical antecedents, e.g., depression, stress, chemical dependency, PTSD;
- 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; and

- religious: relationship with God / higher power, church community, atheism.

Slide 15

Diagnosing complicated grief...

- Inability to speak about loss without fresh grief
- Relatively minor event triggers intense grief
- Themes of loss in clinical interview
- Unwilling to move possessions
- Physical symptoms similar to deceased

Slide 16

...Diagnosing complicated grief

- Radical lifestyle changes, i.e., isolation
- History of subclinical depression
- Compulsive imitation of deceased
- Self-destructive impulses
- Unaccountable sadness at a certain time of year
- Phobia about illness/death

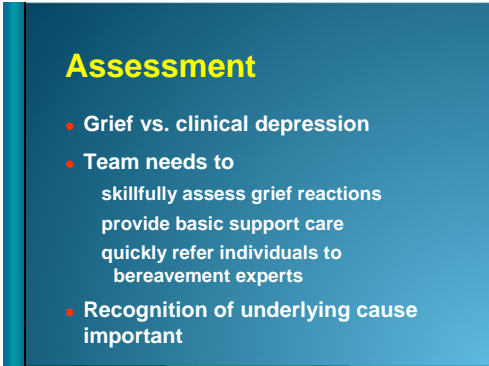
The duration as well as the intensity of the symptoms, coupled with diminished ability to function, help distinguish uncomplicated from complicated grief. Worden provides clues for diagnosing complicated grief, such as the following:¹⁹

- inability to speak about the loss without experiencing intense and fresh grief;
- relatively minor event triggers 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, e.g., isolating oneself;
- 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; and
- phobia about illness/death.

Bonanno and others have found that psychological resilience is more common during bereavement than previously thought.^{14,28} Their work suggests 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.

Assessment

Slide 17



Assessment

- Grief vs. clinical depression
- Team needs to
 - skillfully assess grief reactions
 - provide basic support care
 - quickly refer individuals to bereavement experts
- Recognition of underlying cause important

Effectively anticipating and reducing the severity of the grief reactions of Veterans and families begins early in the process of care 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 palliative care team understand how the survivor is coping. Cognitive, emotional, and physical reactions to grief, and the need for bereavement support, can be ongoing for months. Health care 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. To effectively anticipate and reduce the intensity of grief reactions, assess each family’s anticipated and actual losses, emotional responses, and coping strategies frequently during the first months of the identified illness and following the death. Gentle inquiry can help the clinician 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.

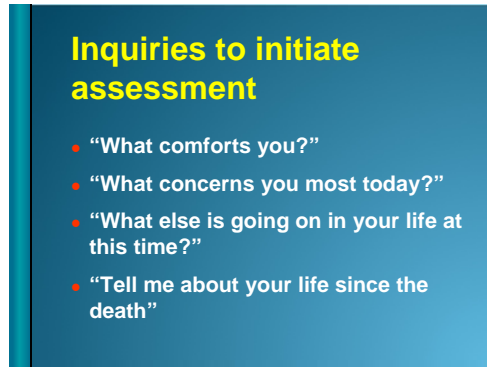
Some people will make a conscious effort to manage the loss. Others will deny what is happening and avoid dealing with the loss. Some coping strategies, e.g., increased smoking/alcohol/medication intake, overworking, and suicidal ideation, may accelerate and even become destructive, especially in the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

Clinicians need to be attuned to behaviors that might indicate complicated grief, especially if these continue beyond 6 to 12 months.²⁹ 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. The survivor may be

unwilling to move possessions belonging to the deceased. Minor events may unexpectedly trigger intense grief and sadness.

Ongoing assessment will help the clinician distinguish uncomplicated from complicated grief reactions. Understanding the bereaved person's pre-existing conditions is beneficial as these conditions may complicate the grief process. Pre-existing clinical depression, for instance, can predispose someone to a complicated grief process. 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.

Slide 18



Inquiries to initiate assessment

- “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”

Some inquiries to initiate assessment that any clinician in palliative care can do 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?” and
- “What physical sensations do you notice when your grief is most intense?”

Grief vs. depression

Slide 19

	Uncomplicated Grief	Clinical Depression
Loss	Recognizable, current	Loss may be symbolic
Reactions	Intense, then variable	Persistently intense
Mood	Labile, acute, heightened when thinking about loss	Consistent low, pervasive, chronic, absence of emotion
Behavior	Variable	No enthusiasm, difficulty with enjoyment
Anger	Expressed often	Self-directed
Sadness	Periodic	Little variability

Slide 20

	Uncomplicated Grief	Clinical Depression
Cognition	Preoccupied with loss, confusion	Preoccupied with self, worthlessness, hopelessness
History	Little previous history of disorder	Previous history
Sleep	Periodic difficulties falling asleep, awakening	Regular early morning awakening
Imagery	Vivid dreams, capacity for imagery and fantasy	Self-punitive imagery
Responsiveness	Responds to warmth and assurance	Limited responsiveness

Table 1, adapted from Cook and Dworkin, contrasts uncomplicated grief and clinical depression.³⁰ It is important to note that while a full depressive reaction may accompany the 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 a consistently low mood or 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. Having a low threshold for inquiring about depression is appropriate.

Table 1: Distinguishing between grief and depression (adapted from Cook & Dworkin, 1992)

	Uncomplicated grief	Clinical depression
Loss	Recognizable and current	Loss may be symbolic, loss is not always recognizable
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	Refusals of most previously enjoyed activities, no enthusiasm, consistent difficulty enjoying activity

	enjoyable activities	
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.

With Veterans on palliative care units, the team has a psychiatrist present. For families dealing with post death clinical depression, the bereavement coordinator may need to develop a resource file wherein they know of persons in the community to whom they can refer family as needed.

Management

Slide 21

Management

- Acknowledge the loss
- Encourage participatory activities
- Treat anxiety, depression, insomnia
- 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.^{19,20,21,22,23} 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 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.

Acknowledge the loss

Team members' 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 Veteran, 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. During this time, potential conflicts surface. For example, the Veteran wants to go home but the family is not comfortable taking them home. The 'wants' and 'needs' of both Veteran and family must be balanced.

Encourage participatory activities

The bereavement coordinator should 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, identifying personal rituals and writing letters to family and friends, recounting their 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. When anxiety, depression or insomnia are interfering with daily activities and work life, they need to be actively treated. Post death counseling falls primarily to the bereavement coordinator. Most of these families will not be Veterans themselves and therefore the palliative care team physician / psychologist will not be able to treat them. A referral should be made for community resources. If family members have their own physician / psychologist it is helpful to learn this if a referral becomes necessary.

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 by the bereavement coordinator. Some people will need ongoing support, pastoral counseling and/or 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 chaplain, psychiatrist, psychologist or another specialist who is skilled in complicated loss, grief, and bereavement care so that appropriate interventions can be instigated rapidly to reduce the risk of harmful/destructive activities.

A bereavement card and attendance at the Veteran's funeral may be appropriate.³¹ For many 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. In a VA Palliative Care Program, there should be in place a follow-up package sent out by the bereavement coordinator. Ideally, this would continue for at least 1 year.

Follow up

Slide 22

Follow up

- Write a condolence note
 - acknowledge loss, name deceased
 - express sympathy
 - note deceased's special qualities
 - recall a memory of the deceased
 - offer specific help
- Bereavement visit

Write a condolence note

A note or letter from the palliative care team after the death has been reported to be helpful to the bereaved.^{32,33} Such a note has two goals: to offer tribute to the deceased as someone who was important and to 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. Use any standard stationery, though VA or unit letterhead with the palliative care logo can have a positive effect, and write it by hand. The following are some specific guidelines for writing a good condolence note:

- Acknowledge the loss and name the deceased, as 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.

- Express your sympathy using words of sympathy that remind the bereaved that they are not alone in their feelings of sadness and loss.
- Note special qualities of the deceased, and acknowledge those characteristics that you observed about the Veteran who has died; these might be qualities of personality, or attributes, or ways the person related to the world. Consider referring to the Veteran's military service.
- Recall a memory about the deceased, and 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.
- Remind the bereaved of their personal strengths, as 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.
- Offer help, but be specific; don't say, 'If there is anything I can do, please call,' as 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, but don't make an offer you cannot fulfill.

End with a word or phrase of sympathy, but be mindful not to use empty clichés, such as “God needed her more than you did,” “it was God’s will,” or “be strong; move on with life.”

Bereavement visit

Palliative care team members can assist the Veteran 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. 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.

VA palliative care programs 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 Veteran was enrolled in a community hospice care, family members are eligible for bereavement support services through that hospice without charge.

The health care team and loss

The cumulative effect of loss on the palliative 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.³⁴ Balancing work life with other activities will assist the health care team in responding to the emotional needs of Veterans and their families (see also EPEC for Veterans Module 15: Professional Self-Care). It is very important to emphasize that *all* team members are susceptible to the stress of loss and it does not equate weakness.

Summary

Slide 23



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

Understanding the processes of adaptive and maladaptive responses is essential. Acknowledgment and teaching the Veteran and family about the process of response to loss can help them in their adjustments 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.¹²

Care does not end until the palliative care team has helped the family with their grief reactions and helped those with complicated grief to get care. Interventions for adapting to loss may be best administered by the team's chaplain, psychologist, or bereavement coordinator.

Key take-home points

1. Thorough assessment of physical, emotional, and mental health as well as personal history will allow palliative care team members to intervene with or refer Veterans who have suffered a loss.
2. 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.
3. Introduce the idea of loss and creative adaptation early in palliative care to assist Veterans and families with coping resources during each transition.
4. Acknowledge each loss and adaptation, including the attainability of quality of life despite each loss. Do this without minimizing or discounting the loss.
5. Involve a chaplain early, from the time of admission to palliative care for the Veteran and relevant family members, to assist with grief processing during the hospitalization. Later involve the bereavement coordinator for continued follow up with family.

Resources

Bonanno GA, Wortman CA, Lehman DR, et al. Resilience to loss and chronic grief: A prospective study from preloss to 18 months postloss. *J Pers Soc Psychol.* 2002; 83(5): 1150-1164.

Corless, I.B. Bereavement. In B.R. Ferrell & N. Coyle (Eds) Oxford textbook of palliative nursing care, 3rd edition (Chapter 30, pp. 597-610) New York: NY: Oxford University Press. 2010.

Ferrell B. Understanding the moral distress of nurses witnessing medically futile care. *J Oncol Nursing Forum.* 2006;(33)5, 922-930.

Ferrell BR, Coyle N. *The nature of suffering and the goals of nursing.* New York, NY: Oxford University Press. 2008.

Eutsey DE, ed. Patient and family issues. In: *Palliative Care: Patient and Family Counseling Manual.* Gaithersburg, MD: Aspen Publishers, Inc; 1996.

Grassman D. *Peace At Last: Stories of hope and healing for veterans and their families.* St. Petersburg, FL: Vandamere Press. 2009.

National Consensus Project for Quality Palliative Care (2009). *Clinical practice guidelines for quality palliative care 2nd edition* Pittsburgh, PA. 2009.

Rando TA. *Grief, dying, and death: Clinical interventions for caregivers.* Champaign, IL: Research Press Company, 1984.

Sheldon F. ABC of palliative care. Bereavement. *BMJ.* 1998; 316(7129): 456-456.

Sudnow D. *Passing on: The social organization of dying*. Englewood Cliffs, NJ: Prentice-Hall, 1967.

Walsh F, McGoldrick M. *Living beyond loss: Death in the family*. New York, NY: W.W. Norton & Company, 1991.

Wilcox S, Evenson KR, Aragaki A, Wassertheil-Smoller S, Mouton CP, Loevinger BL. Effects of widowhood on physical and mental health, health behaviors, and health outcomes: The Woman's Health Initiative. *Health Psychology*. 2003; 22(5): 513-522.

Wortman CB, Silver RC. The myths of coping with loss. *J Consult Clin Psychol*. 1989; 57(3): 349-357.

References

- ¹ Niemayer RA, Prigerson HG, Daniel B. Mourning and Meaning. *American Behavioural Scientist*. 2002; 46(2): 235-251.
- ² Stroebe M, Schut H, Stroebe W. Health outcomes of bereavement. *Lancet*. 2007;370(9603):1960-73.
- ³ Prigerson HG, Jacobs SC. Perspectives on care at the close of life. Caring for bereaved patients: "All the doctors just suddenly go." *JAMA*. 2001; 286(11): 1369-1376.
- ⁴ Dobratz MC. The self-transacting dying: Patterns of social-psychological adaptation in home hospice patients. *Omega: Journal of Death & Dying*. 2002; 46(2): 151-167.
- ⁵ Grossman P, Niemann L, Schmidt S, Walach H. Mindfulness-based stress reduction and health benefits. A meta-analysis. *J Psychosomatic Research*. 2004; 57(1): 35-43.
- ⁶ Shaw C, Abrams K, Marteau TM. Psychological impact of predicting individuals' risks of illness: a systematic review. *Soc Sci Med*. 1999; 49(12): 1571-1598.
- ⁷ Hodges LJ, Humphris GM, Macfarlane G. A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their careers. *Soc Sci Med*. 2005; 60(1): 1-12.
- ⁸ Valdimarsdottir U, Helgason AR, Furst CJ, Adolfsson J, Steineck G. The unrecognized cost of cancer patients' unrelieved symptoms: A nationwide follow-up of their surviving partners. *Br J Cancer*. 2002; 86(10): 1540-1545.
- ⁹ Knight SJ and Emanuel L. Process of Adjustment to End-of-life losses: A reintegration model. *J Pall Med*. 2007; 10(5): 1190-8.
- ¹⁰ Stiggelbout AM, Kiebert GM. A role for the sick role: Patient preferences regarding information and participation in clinical decision-making. *Canadian Medical Association Journal*. 1997; 157(4): 383-389.
- ¹¹ Fahy K, Smith P. From the sick role to subject positions: A new approach to the

- medical encounter. *Health* (London). 1999; 3(1): 71-94.
- ¹² Brown SL, Nesse RM, Vinokur AD, Smith DM. Providing social support may be more beneficial than receiving it: Results from a prospective study of mortality. *Psychol Sci*. 2003; 14(4): 320-327.
- ¹³ Grunfeld E, Coyle D, Whelan T, et al. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *CMAJ*. 2004; 170(12): 1795-1801.
- ¹⁴ Schulz R, Beach SR. Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *JAMA*. 1999; 282(23): 2215-2219.
- ¹⁵ Wilcox S, Evenson KR, Aragaki A, Wassertheil-Smoller S, Mouton CP, Loevinger BL. Effects of widowhood on physical and mental health, health behaviors, and health outcomes: The Woman's Health Initiative. *Health Psychology*, 2003;22(5):513-522.
- ¹⁶ Schulz R, Beach SR, Lind B, et al. Involvement in caregiving and adjustment to death of a spouse: Findings from the caregiver health effects study. *JAMA*. 2001; 285(24): 3123-3129.
- ¹⁷ Robinson-Whelen S, Tada Y, MacCullum RC et al. Long-term caregiving: what happens when it ends? *J Abnorm Psychol* 2001; 110(4): 573-584.
- ¹⁸ Carrington NA, Bogetz JF. Normal grief and bereavement: Letters from home. *J Pall Med*. 2004; 7(2): 309-323.
- ¹⁹ Worden JW. Bereavement. *Semin Oncol*. 1985; 12(4): 472-475.
- ²⁰ The Hospice Institute of the Florida Suncoast. *Grief and Bereavement*. Hospice Training Program. Largo, FL: The Hospice Institute of the Florida Suncoast; 1996.
- ²¹ Cassem NH. The first three steps beyond the grave. In: *Acute Grief and the Funeral*. Pine VR, Kutscher AH, Peretz D, Slater RC, DeBellis R, Volk RJ, Cherico DJ, eds. Springfield, IL: Thomas Publisher, 1976.
- ²² Yancey D, Greger HA, Coburn P. Determinants of grief resolution in cancer death. *J Palliat Care*. 1990; 6(4) :24-31.
- ²³ Janson LJ, Sloan JA. Determinants of the grief experience of survivors. *J Palliat Care*. 1991; 7(4): 51-56.
- ²⁴ Bowlby J. *Attachment and loss: Attachment (Vol. 1)*. New York, NY: Basic Books, 1969.
- ²⁵ Maciejewski PK, Zhang B, Block SD, Prigerson HG. An empirical examination of the stage theory of grief. *JAMA*. 2007; 297(7): 716-723.

- ²⁶ Vachon ML, Rogers J, Lyall WA, Lancee WJ, Sheldon AR, Freeman SJ. Predictors and correlates of adaptation to conjugal bereavement. *Am J Psychiatry*. 1982; 139(8): 998-1002.
- ²⁷ Chochinov HM, Holland JC, Katz LY. Bereavement. In: *Psycho-oncology*. JC Holland, ed. Oxford University Press, New York, 1998: 1016-1032.
- ²⁸ Bonanno GA, Kaltman S. Toward an integrative perspective on bereavement. *Psychol Bull*. 1999; 125(6): 760-776.
- ²⁹ Vachon ML. Unresolved grief in persons with cancer referred for psychotherapy. *Psychiatr Clin North Am*. 1987; 10(3): 467-86.
- ³⁰ Cook AS, Dworkin DS. *Helping the bereaved: Therapeutic interventions for children, adolescents, and adults*. New York, NY: Basic Books, 1992.
- ³¹ Irvine P. The attending at the funeral. *N Engl J Med*. 1985; 312(26): 1704-1705.
- ³² Wolfson R, Menkin E. Fast Facts and Concepts #22. Writing a Condolence Letter. End of Life Physician Education Resource Center. <http://www.eperc.mcw.edu>. Accessed February 8th, 2011.
- ³³ Bedell SE, Cadenhead K, Graboyes TB. The doctor's letter of condolence. *New Engl J Med*. 2001; 344(15): 1162-1164.
- ³⁴ Becvar DS. *In the Presence of Grief: Helping Family Members Resolve Death, Dying, and Bereavement Issues*. New York: Guilford Press, 2001.