



Helping to manage anxiety and depression is a common task in primary care. <sup>1</sup> In contrast, the impact of loss and grief has received far less attention in this setting. <sup>2</sup> While most people cope well with this universal experience, the health consequences of grief can be far-reaching. <sup>3</sup> Studies have linked bereavement or grief to depression, anxiety-related symptoms and disorders, impaired immune function, poorer physical health, increased physician visits, increased use of alcohol and cigarettes, suicide, and increased incidence of and mortality from conditions such as cardiovascular disease. <sup>4-7</sup> Several clinicians <sup>2,8-10</sup> have stressed the importance of addressing grief and loss in primary care, and there is a need for specific education/training for health professionals in caring for bereaved individuals. <sup>11</sup> With its emphasis on the health of the whole person (bio-psycho-social-spiritual components), Integrative Medicine is optimally positioned to help focus attention on the importance of addressing grief in the primary care setting and can suggest non-pharmaceutical therapeutic approaches following major loss.

## Grief is a different entity from depression.

#### Grief is a reaction to loss

- While typically thought of as a reaction to death, grief reactions can occur following any type of major loss. 12,13 Much of the focus of this paper is on grief following a death loss. The content can be adapted if the loss is not related to a death. (See the third bullet in this section for examples of other losses.)
- Grief is more than emotion, also encompassing behavioral, cognitive, physical, and spiritual elements. (See our patient handout on grief for a list of grief reactions).
- Many grief symptoms are consistent with those of depression.<sup>14</sup> In fact, it is likely that many patients are labeled as depressed when in reality they are grieving a major loss.<sup>8,15</sup> One study based on survey data from more than 8,000 Americans suggests that the prevalence of major depressive disorder (MDD) may be reduced by almost one fourth if individuals who are grieving major losses such as marital dissolution, job loss, natural disasters, severe physical illness, and failure to achieve important goals are excluded from depression statistics as are those who have experienced a loss through death.<sup>16</sup>
- Grief versus depression is an important distinction to make because 1) a patient's burden can be increased if misunderstood and misdiagnosed, and 2) an appropriate course of action may be different for the two conditions.<sup>16</sup>

#### Querying patients about losses

When considering a diagnosis of depression, it is important to learn what, if any, major losses the patient has experienced. Some individuals will self-diagnose grief (especially following a death) and come in seeking specific assistance, e.g. treatment for insomnia. Many others may present with physical, cognitive, emotional, or behavioral symptoms without connecting them to loss. Differential diagnosis requires talking with patients about known or possible losses, their reactions to those losses, and the time period involved. For someone who has had a significant loss and whose symptoms are ongoing, differentiating "typical" grief from the more debilitating "complicated grief" or from clinical depression can be tricky. It may best be accomplished via referral to a mental health professional experienced in the area of grief for further assessment and facilitation/support of mourning. Patients can experience grief reactions coincidentally with anxiety, depression, and posttraumatic stress disorder.



#### Differential Diagnosis

## Typical grief

While universal, "typical" grief can be profoundly painful and disruptive and may feel anything but normal to the person who is grieving. In addition some typical grief symptoms, such as feeling short of breath and muscle weakness, may not be recognized as grief reactions and others, e.g., auditory or visual hallucinations, may appear pathological to those unfamiliar with grief symptomatology. Discussion has occurred about prescribing medication for acute, normal grief; the consensus is that it should be used sparingly to give relief from anxiety or insomnia, rather than to treat depressive symptoms.<sup>17</sup>

#### Complicated grief

Deviations from "typical" grief that require more aggressive intervention were described as early as 1944.<sup>18</sup> More attention has been focused on complicated grief recently. An estimate published in 2011 indicates that 7% of those bereaved experience complicated grieving.<sup>19</sup> In complicated grieving, symptoms are long-lasting and may intensify over time, and the person has trouble accepting the death and resuming life. It is as if the person is in a chronic, heightened state of mourning.<sup>20</sup>

Complicated grief, identified as Persistent Complex Bereavement Disorder, has been added to the Fifth Edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-V)* published in 2013.<sup>21</sup> It is in Section III, which contains conditions that are in need of further research. For diagnosis, grief symptoms must persist to a "clinically significant degree" for at least 12 months (6 months for children) following the death of someone close and be "out of proportion or inconsistent with cultural, religious, or age-appropriate norms." A similar classification, Prolonged Grief Disorder, has been proposed for the eleventh version of the *International Classification of Diseases and Related Health Problems (ICD-11)* to be approved in 2015.<sup>22</sup>

A recent study of bereaved spouses found that those with poor health at the time of loss had significantly higher risks of complicated grief and major depressive disorder.<sup>23</sup>

#### SCREENING TOOL--BRIEF GRIEF QUESTIONNAIRE

The Brief Grief Questionnaire developed by M. Katherine Shear MD and Susan Essock Ph.D.<sup>24</sup> is an efficient tool to screen for complicated grief in primary care settings.<sup>25</sup> A copy is appended on page 12.

#### • Major depressive disorder (MDD)

Differentiation between grief and depression is complicated by a lack of established criteria. Overlapping symptoms include sleep disturbance, appetite disturbance, and intense sadness, while loss of self-esteem and general overall sense of guilt usually are associated with depression rather than grief. Rando, however, cautions that lowered self-esteem is not an uncommon consequence of major loss. In complicated grief, **longing** and sadness are salient emotions. For patients with MDD, treatment such as anti-depressants may help lift the depression, so that an individual is better able to focus on tasks of mourning.

#### Posttraumatic stress disorder (PTSD)

An individual may have PTSD if the circumstances of the death were violent or traumatic. Reactions might include: recurrent disturbing recollections of the death, avoidance of situations associated with the death, difficulty sleeping, difficulty concentrating, and angry outbursts.<sup>26</sup>



# RECOMMENDATIONS FROM THE LITERATURE ON SCREENING, REFERRAL, AND TREATMENT

- "Persistent interrupted sleep and persistent inability to concentrate lasting more than 3 months after the death of a spouse should be considered warning signs and trigger referral to a physician for screening for depression." (J. Richard Williams, page 202)
- "We recommend treatment for MDD or complicated grief lasting 6 months post-loss or beyond. The delay in treatment minimizes the identification and treatment of falsepositive cases of MDD or complicated grief—cases that would resolve without intervention. Obviously, immediate attention from a mental health professional should be sought if suicidality is suspected at any time post-loss."<sup>27</sup> (Holly G. Prigerson & Selby C. Jacobs, p. 1374)
- "Individuals with complicated grief have greater risk of adverse health outcomes, should be diagnosed and assessed for suicide risk and comorbid conditions such as depression and posttraumatic stress disorder, and should be considered for treatment."<sup>25</sup> (Naomi M. Simon, p. 416.)

## Cultural, gender, and individual differences in grieving

Commonalities exist in grief reactions of many people, but no reactions are absolute. The grief experience varies widely and is influenced by many things such as a person's age, gender, relationship with the deceased, culture, personality, previous experiences, coping skills, and social support.

#### Cultural

Cultural differences in grief are enormous and very important.<sup>28</sup> What is considered typical in one culture may be seen as pathological in another. A particular grief reaction may have totally different meaning within different cultures. If addressing grief with patients and families from a culture other than one's own, it is important to learn more about grief expression typical for that culture through asking directly, reading, or seeking consultants.

#### Gender

Many men (and some women) have muted emotional reactions. Their grief experience may be more behavioral or cognitive than emotional. In the past, this way of reacting to loss was considered less adaptive; more recent evidence challenges this assumption.<sup>29</sup> People whose grief experience is more behavioral or cognitive may benefit from grief strategies incorporating these approaches.<sup>13</sup> Behavioral approaches involve doing something based upon the bereaved person's interests and abilities: for example, a bereaved individual might build or make something to memorialize the deceased, sing a special song in memory of the deceased, or plant a tree or memory garden. Cognitive approaches focus on what the bereaved individual is thinking.

#### Individual

Worden has identified other influences on grieving. See box on page 4.



## Worden's Mediators of Mourning<sup>17</sup>

Who died? Relationship to the bereaved

**Nature of the attachment?** How close? Was relationship required for security and esteem? Was it dependent? Was it ambivalent? Was it conflicted? (These may cause grieving to be more difficult).

**How the person died?** Geographically close? Anticipated or unexpected? Violent? Seen as preventable? Presumed dead or definitive? Stigmatized by some?

**History?** Experienced other major losses in the past? If so, how were these grieved? Family history regarding grief? Mental health issues?

**Personality?** Age? Gender? Coping style? Healthy attachments with others? Usually optimistic or negative over-generalizing (e.g., "I will never get over this.")? Level of self-esteem and self-efficacy? Beliefs and values (e.g., spiritual)?

**Social?** Satisfaction with available support? (A relationship with a companion animal has also been found to reduce symptoms).<sup>30</sup> What social roles (relative, friend, employee, involvement in groups) does griever hold? (Multiple are helpful). Identifies with subcultures (e.g., religious, cultural)?

**Concurrent stresses?** Other losses (deaths, finances, change in living arrangements)?

"It pays to treat everyone as though he or she were from a different culture. The crosscultural emphasis, in fact, is a kind of metaphor. To help effectively, we must overcome our presuppositions and struggle to understand people on their own terms."<sup>31</sup>

(Paul C. Rosenblatt, p. 18)

## Anticipatory and disenfranchised grief: times for heightened sensitivity

#### Anticipatory grief

Anticipatory grief occurs when a death or other loss is perceived as imminent and an individual begins grieving before the actual loss occurs. Mostly, it is a healthy experience; anticipation allows preparation, development of coping strategies, and mobilization of assistance. Rando has clarified that often anticipatory grief includes mourning over a series of shifting current losses as well as the eventual death, as an individual's health, abilities, and plans for the future fade. Anticipatory grief does not lessen the grief reactions that occur following the loss. One is a reaction to the expectation of loss and steps along that pathway; the other is a reaction to the finality of the loss. Awareness of the phenomenon of anticipatory grief allows the clinician to provide on-going support according to the needs of the patient and family.

"The more we can learn about anticipatory grief and mourning, the better we will be as helpers and as fellow human beings. In the long term, better understanding and appreciation are a constant goal; in the short term heightened sensitivity and genuine caring are most highly prized." (Charles A. Corr, p.17)



#### Disenfranchised grief

Disenfranchised grief—hidden sorrow--is grief experienced when a loss is not or cannot be openly acknowledged, publicly mourned, or socially supported.<sup>32</sup> The importance of the loss rests in the viewpoint of the person experiencing the loss, not the opinion of others. Disenfranchised grief is a growing issue affecting millions of people,<sup>35</sup> **putting them at risk for complicated grieving**. Some examples include:

- Unrecognized relationships: ex-spouse, partner from an extra-marital affair, gay partner, former friend, co-worker
- Losses often not socially validated: infertility, abortion, perinatal death, death of a companion animal, death of a very elderly person, loss of the personality in Alzheimer's disease, loss of ability, loss of a role or status
- Occasions when the griever and/or her/his social group have difficulty dealing with the
  circumstances of the loss: death involving stigma (e.g., following a suicide, AIDS or a criminal act),
  circumstances of the death too horrible to face.
- Occasions when the bereaved are assumed by some to be incapable of grieving or perceived as not being strong enough to handle the loss, needing to be "protected": children, people with intellectual disabilities, the elderly.
- Multiple losses in a short span of time, so that some have not been acknowledged.

**Disenfranchised grievers** may not recognize that their own symptoms are related to grief. An important step is helping the person verbalize the importance and meaning of the relationship (or non-death loss). **Primary care practitioners are in a unique position of trust to recognize disenfranchised grief** and start the process of validation and support for the grieving person.<sup>2</sup>

#### Grief theory in a nutshell: A shifting paradigm

Theory and research guide clinical action. No grief theory is applicable to all cultures; the following synopsis is relevant to many in our western culture. Most clinicians and many patients are familiar at least nominally with Elizabeth Kubler- Ross' stage theory of the process of dying: denial, anger, bargaining, depression, and acceptance, the lack of which was often applied to grieving individuals as well as the dying. While acknowledging her important pioneering work, some contemporary theorists note the lack of empirical evidence for her model, the lack of recognition of individual and cultural differences, and the inaccurate assumptions that individuals pass neatly through stages. These theorists view grief as a process or series of tasks towards integrating the loss into one's life and the griever as an active rather than passive participant. Worden describes four tasks of mourning and stresses that the process is fluid. An individual can work on multiple tasks simultaneously, and tasks can be revisited and reworked over time. He uses psychiatrist George Engel's analogy of healing to describe that a person can accomplish some of these tasks and not others, thus not fully adapting to a loss, as a person might not completely heal or recover function following a wound.

#### TASKS OF MOURNING

Task I: To accept the reality of the loss.

Task II: To process the pain of grief

Task III: To adjust to a world without the deceased.

- External: How has the death affected everyday life?
- Internal: How has the death affected feelings about self and abilities?
- Spiritual: How has the death affected spiritual beliefs and views of the world?

Task IV: To find an enduring connection with the deceased in the midst of embarking on a new life.



## How to help

Recent grief specialists teach us that the goal for the bereaved is not to "recover" from the loss, but rather to focus on the change and learn how to integrate the loss into one's life.<sup>13</sup>

#### The PLISSIT model

The PLISSIT model can be a guide for primary health care practitioners in assisting their patients towards this goal. PLISSIT is an acronym for **P**ermission, **L**imited Information, **S**pecific **S**uggestions, and Intensive Therapy, a model developed by Annon to address sexuality issues.<sup>37</sup> Because of its utility, it can be applied in other healthcare situations as well.<sup>38</sup> The model includes four levels of intervention, ranging from basic to complex. It guides clinicians to support patients according to the clinicians' own comfort level and expertise as well as the needs of patients. Referrals can be made when patients' needs exceed clinicians' comfort, knowledge, and time.

#### Permission

Clinicians can initiate the topic of loss, giving patients the opportunity to talk about the experience. Some patients may choose not to do so. In our fast-paced, multi-tasking society, adults may feel pressured by themselves or others to resume their former lifestyle with minimal disruption. Clinicians can offer "permission" to grieve as needed. For many patients, this interest and support will be the only intervention needed.

#### • Limited Information

Limited information will be helpful to other patients. This second level requires more knowledge about grief to answer patients' questions and dispel misconceptions. Many people know little about grief reactions until they experience them. People frequently ask if their reactions are normal and if they are going crazy. They can be relieved to learn that their reactions and the duration of their grief are similar to the experiences of others with comparable losses. Or if different, they can be reassured that everyone grieves in her or his own unique ways. When appropriate, the clinician can educate patients about anticipatory grief or disenfranchised grief, so that grievers will understand that their reactions are valid and the relationships are important ones, as well as receive reassurance that they have strength to cope.<sup>39</sup> Factual information in patient handouts and a list of grief resources (e.g., support groups) may be helpful. (See our patient handout on grief).

#### Specific Suggestions

Fewer patients will require some specific suggestions. This level involves advanced knowledge and skill to understand a patient's unique situation and develop a plan. Clinician and patient can discuss the loss experience more thoroughly, collaboratively identify issues to be addressed, problem-solve, and choose strategies based upon one or more tasks of mourning. For example, for a patient distraught over the pain of grief (Worden's second task), a clinician could help develop a healthy plan to work through the pain. This might involve reassuring the individual that the pain will not always be so intense, identifying one or more people who are good listeners in the person's social circle to contact when emotions seem over-whelming, minimizing alcohol and other drugs, avoiding major decisions which one might regret later, and choosing a form of physical activity that would be do-able with current energy level.

#### Intensive Therapy

A minority of patients will require intensive therapy. This final stage usually requires referral to a specialist in grief.



## Helping strategies

"...people cope with loss in different ways and therefore may have different needs for intervention and different responses to a given type of intervention." (Dale G. Larson & William T. Hoyt, p. 169)

Many strategies exist to help individuals cope with major loss. Information is available from grief specialists, professional grief literature, and a plethora of books for the general public. Following are some non-pharmaceutical approaches that health care practitioners may feel comfortable doing or suggesting:

### • Salutogenesis-Oriented Sessions (SOS)

Probably the most important thing health care practitioners have to offer grieving patients is their compassion and understanding. Validation of the person's grief experience is important. Rakel proposes the use of salutogenesis-oriented sessions to facilitate health.<sup>41</sup> Such a healing session could be used to help assess whether grief is causing a patient's symptoms as well as to assist the patient with the tasks of grief. For bereaved families following a sudden death, being able to ask questions and receiving accurate information about the cause of death can be very helpful.<sup>42</sup> Families may need clinicians to repeat this information several times. Another helpful intervention is inviting and allowing time for family members to share their stories about the loss.<sup>42</sup>

## • Addressing spirituality issues

Certain losses challenge some grievers' spiritual beliefs, causing them to question their existential views. They may experience this as an internally chaotic time, feeling ungrounded or adrift. It can also become a time when grievers reaffirm or redefine their belief systems and grow in new directions. A referral to a chaplain, clergy, or other spiritual leader may be helpful.

#### Facilitating support from family and friends

People benefit from social support of their losses. Some grievers may be hesitant to seek the support they need. Others may need to tell the story of their loss over and over again as they come to terms with it. This need to retell may clash with the needs of people in their support system whose patience, time, and energy can become taxed. A clinician can encourage grievers to contact family and friends in the first situation and in the second situation can help them to identify those in their social circle who are particularly good listeners with time available or to locate a grief support group.

#### Grief support groups

Grief support groups are available in many communities and also on-line. Hospices are usually good sources for information on their availability. Some may wish to consider groups that incorporate Mindfulness Based Stress Reduction (MBSR), which is based on Eastern philosophies and uses meditation to calm the mind and body.

#### Non-pharmaceutical approaches to prevent or treat depression

For information on non-pharmaceutical approaches to prevent or treat depression, see our <u>clinician</u> and <u>patient</u> handouts on this topic.



#### Rituals

A ritual is an activity that is symbolic of feelings and thoughts related to the death and may be related to one's cultural traditions. Perhaps the most familiar rituals are those of a visitation/wake and a funeral/memorial service. Many kinds of informal rituals can be created based on the interests and needs of the bereaved. Some examples: lighting candles on special dates to remember the deceased, sewing a memory quilt (which may be created from clothes of the deceased), planting a memory garden, sharing a memory dinner to celebrate the life of the deceased.

#### Exercise

Encourage a form of physical activity that the patient enjoys or previously enjoyed. Doing the activity with others may be even more helpful.

#### Nature

Spending time in nature can be soothing and healing.

#### Writing or journaling

Writing or journaling about one's grief experience can help facilitate the expression of feelings and help focus on the meaning of the loss to the griever.<sup>17</sup> If grievers have unfinished business with the deceased they might consider expressing their thoughts and feelings through writing a "letter" to them. (See our handout Using Journaling to Aid Health).

#### Forgiving

An unexpected death can leave a bereaved individual with "unfinished business" with the deceased. If the bereaved have a sense of previously being "wronged" by the deceased, they may benefit from working on forgiveness. (See our handout Healing through Forgiveness).

#### Massage

Therapeutic massage may be helpful for someone who is experiencing tension or pain from "holding grief" in the muscles.

#### Healing touch

Healing touch is a form of energy medicine. Practitioners place their hands near or gently on the body to clear, energize, and balance the energy fields; the goal is to restore balance and harmony, so the receiver is placed in an optimal position to self-heal.<sup>43</sup> A directory for certified healing touch practitioners can be found at <a href="http://www.healingtouchprogram.com/energy/CHTPDirectory.shtml">http://www.healingtouchprogram.com/energy/CHTPDirectory.shtml</a>.

#### Referral to a grief specialist

Refer anyone who wants additional professional assistance and especially patients with possible complicated grief to professionals with more advanced training and experience in grief. These specialists have a wide variety of credentials (e.g., bereavement counselor, clergy, psychiatrist, psychologist, social worker). Not all professionals in these helping fields have focused on grief. Local hospices may be able to recommend specialists. See our patient handout on grief for other resources.

Simon's clinical review suggests the first approach to consider for complicated grief is therapy targeted especially for this condition (that helps resolve complicating issues and facilitates the natural healing process), with anti-depressants as an adjunct if needed. Significant depression and/or suicidal ideation suggest earlier treatment with anti-depressants.<sup>25</sup>



On a systems level, clinicians can advocate for the development of a comprehensive bereavement program within their medical center. New York-Presbyterian Hospital/Weill Cornell Medical Center moved from providing minimal bereavement support to implementing a full program, which included sending condolence cards, making telephone calls to screen for complicated grief, and providing individual counseling, bereavement support groups, community referrals, and an annual memorial service. 44

## Health care professional as griever: the importance of self-care

"...grief in health care professionals is often disenfranchised, yet the effective holistic treatment of individuals with disease begins with an acknowledgment that loss is a constant companion to illness, for patients, families, and health care professionals alike." (Kenneth J. Doka, p. 205)

Clinicians, too, can experience disenfranchised grief, not always recognizing or acknowledging the grief inherent when one works meaningfully with sick and dying individuals and their families.

See Mourning on Morning Rounds. 45

Vallurupalli M. N Engl J Med. 2013;369:404-5. doi: 10.1056/NEJMp1300969.

There can be many types of losses:

- The death of a patient may feel like a personal loss because of the bonding that occurred with patient and family.<sup>12</sup>
- Loss of professional expectations, self-image and identity can occur when patient outcomes are less than expected or desired.<sup>12</sup>
- Loss of one's own assumptions or beliefs about life can occur especially with unexpected patient deaths or the death of a young patient.<sup>12</sup>
- Losses may remind clinicians of their own mortality.
- Losses can intensify the stresses intrinsic in complex medical organizations.

If these losses are not acknowledged and incorporated into one's life, grief can be compounded. Vachon describes a strategy to address the losses clinicians experience:

"However, through initially learning how to recognize and deal with loss and grief through a process of mentoring in a team of committed caregivers, taking the time to grow and reflect on your own mortality, acknowledging and dealing with loss and grief as it occurs, having a full life outside the work situation, engaging in self-care, and exploring meditation and spirituality, you can continue to grow and thrive in your work." (Mary L.S. Vachon, p. 327)



#### **Recommended for Professionals**

#### Journal article

Simon NM. Treating Complicated Grief. JAMA. 2013;310(4):416-423. (Excellent clinical review.)

#### **Books**

- Ethnic Variations in Dying, Death, and Grief: Diversity in Universality edited by Donald P. Irish, Kathleen F. Lundquist and Vivian Jenkins Nelsen. Washington, DC: Taylor & Francis. (1993)
- Good Grief: Healing Through the Shadow of Loss by Deborah Morris Coryell. Inner Traditions/Bear & Company. (2007)
- Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner (4th Edition) by J. William Worden. New York: Springer Publishing Company. (2009)
- Living with Grief: Before and After the Death edited by Kenneth J. Doka. Washington, DC: Hospice Foundation of America. (2007)
- Treatment of Complicated Mourning by Therese A. Rando. Champaign, IL: Research Press. (1993)

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## To help screen for complicated grief

- Ask the five questions in the Brief Grief Questionnaire during a patient's appointment.
- Use with adults bereaved at least 12 months and children at least 6 months.
- Screen all bereaved individuals who seek treatment for suicide risk, mood, and anxiety disorders as well. These conditions may require treatment earlier than 6-12 months post bereavement.

	Brief Grief Questionnaire*			
1.	How much are you having trouble accepting the death of?			
	Not at all 0	Somewhat1	A lot2	
2.	How much does your grief still interfere with your life?			
	Not at all 0	Somewhat1	A lot2	
3.	How much are you having images or thoughts of when s/he died or other thoughts about the death that really bother you?			
	Not at all 0	Somewhat1	A lot2	
4.	Are there things you used to do when was alive that you don't feel comfortable doing anymore, that you avoid? Like going somewhere you went with him/her, or doing things you used to enjoy together? Or avoiding looking at pictures or talking about? How much are you avoiding these things?			
	Not at all 0	Somewhat1	A lot2	
5.	How much are you feeling cut off or distant from other people since died, even people you used to be close to like family or friends?			
	Not at all 0	Somewhat1	A lot2	
	A score of 5 or more suggests an individual <u>may</u> have complicated grief. <sup>24</sup> Refer the individual to a grief specialist for further evaluation.			

<sup>\*</sup> Developed by M. Katherine Shear MD and Susan Essock Ph.D. Included with permission.