Grief, Demoralization, and Depression: Diagnostic Challenges and Treatment Modalities

E. Alessandra Strada, PhD

ABSTRACT
Patients with advanced illness and their caregivers are intimately familiar with the experience of grief and loss. Being diagnosed with a serious illness is often the beginning of emotional and physical losses that may end with the patient's death. Along the difficult journey through illness, patients and caregivers may develop varying degrees and types of emotional distress. Depression, severe grief reactions, and demoralization are common types of disorders experienced by patients and caregivers in the palliative care setting. While commonly recognized as separate diagnostic entities, these disorders share many symptoms, making their differentiation challenging. Accurate diagnosis is crucial because of its treatment implications. This article reviews the characteristic features of these disorders in the context of palliative and end-of-life care. Assessment and non-pharmacologic treatment modalities are presented.

INTRODUCTION
Depression, demoralization, and complicated or prolonged grief reactions can cause severe distress in patients and families in palliative care settings. As these disorders share many clinical features, the initial presentation can result in misdiagnoses and, not uncommonly, undertreatment.

Demoralization and normative grief may respond more positively to psychosocial support and psychotherapeutic interventions, without the need for psychotropic medications. Major depressive disorder (MDD) and complicated or prolonged grief reactions may have a more significant physiologic component and more disruptive psychopathology, which often warrants the addition of medication. Developing the ability to differentiate among these conditions will allow providers to recommend the most suitable treatment option to the patients or the family.

GRIEF AND BEREAVEMENT
While the experience of grief is a normal reaction to loss, it is a multidimensional process and its course is varied and complex, involving a multitude of distressing symptoms that can significantly impact on individuals' level of functioning.1-5 
Research has shown that bereaved survivors have higher mortality rates than control participants from cardiovas-
cicular disease and infectious diseases. Loss of a spouse is associated with increased mortality in surviving spouses and in widowers it has been associated with a 40% increase in mortality rates compared to controls. Suicide is also a consequence of bereavement for many individuals. In particular, elderly bereaved individuals tend to be at greater risk for suicide given higher rates of social isolation and depression, especially if they have cared for a loved one during a long illness. Mental illness, especially MDD and posttraumatic stress disorder, is one of the most common consequences of bereavement.

The first empirical study of survivors mourning was conducted by Lindemann in 1944, after the fire at the Cocoanut Grove Nightclub in Boston. The features of mourning he described were guilt, anger, loss of regular pattern of conduct, identification with physical symptoms of the deceased, and preoccupation with sad memories about the deceased. Bowlby conceptualized grief as a series of attachment behaviors that could also be observed in infants separated from their caregivers. Parkes described the bereaved individual’s experience of loss as having the power to change the “assumptive world,” meaning the set of beliefs, expectations, and thoughts about how the world functions or is supposed to function. The loss of a loved one shatters the set of familiar expectations and leaves the individual in an unfamiliar territory, where familiar assumptions are no longer valid.

Even though the process of recovering from a loss is highly individual and does not follow a predictable course, most bereaved individuals are able to integrate the loss into their lives, as a result of a complex process that can be accurately described by the dual process model of grief developed by Stroebe and colleagues. The dual process model of grief includes a loss-oriented response and a restoration-oriented response. While the former represents the active form of grieving and can be highly distressing, the latter runs parallel to it and involves the expression of active coping skills that allow the individual to process the loss and integrate it into their lives.

NORMATIVE GRIEF

Normative, non-pathologic grief is characterized by a constellation of physical, cognitive, psychological, and spiritual symptoms that can create significant suffering but with varying frequency and severity. The various models of grief share the principle that bereavement involves an initial period of shock, disbelief, or denial, often followed by a phase characterized by distressing physical and emotional symptoms. In the majority of cases, bereaved individuals are able to integrate the loss and continue to function. However, the length of time necessary for the loss to be processed and integrated, which is usually referred to in the literature as a period of “restitution,” is variable, unique to the individual, and often unpredictable. The course of normal grief is affected by numerous factors, such as the survivor’s relationship to the deceased, the survivor’s level of functioning and mental health prior to the loss, and the nature and circumstances of the death (Table 1). Normative grief reactions include physical, psychological, and spiritual symptoms. Physical symptoms to loss may include shortness of breath, tightness in the throat, feeling of emptiness and heaviness, physical numbness, feeling outside one’s body, muscle tension, body aches, headaches, dizziness, nausea, gastrointestinal problems, and heart palpitations. Commonly experienced are also somatic symptoms of depression, such as crying spells, fatigue, disturbances in sleeping and eating patterns, anorexia, weight loss, lack of strength, loss of sexual desire, or hypersexuality. Normative grief can also include perceptual disturbances such as visual and auditory hallucinations, impaired memory, and constant worry; slowed and disorganized thinking; suicidal ideation; and constant preoccupation with the deceased. The content of the perceptual disturbances is often related to traumatic circumstances surrounding the death of the loved one or unresolved issues that may elicit guilt. Spiritual symptoms may include conflicts in faith beliefs and loss of meaning and purpose.

COMPLICATED GRIEF

The last decade has seen a significant amount of research aimed at understanding the nature of grief and its manifestations, distinguishing what is commonly referred to as normative grief from pathologic forms of grief. This investigation has been motivated by the clinical observation that even though the majority of bereaved individuals are able to inte-

**TABLE 1**

<table>
<thead>
<tr>
<th>FACTORS INFLUENCING GRIEF AND BEREAVEMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Factors related to the nature and circumstances of the loss</strong></td>
</tr>
<tr>
<td>• Degree of suddenness</td>
</tr>
<tr>
<td>• Length of illness prior to the death</td>
</tr>
<tr>
<td>• Perception of preventability</td>
</tr>
<tr>
<td>• Psychosocial context of the death</td>
</tr>
<tr>
<td><strong>Factors related to the relationship with the deceased</strong></td>
</tr>
<tr>
<td>• Psychological character</td>
</tr>
<tr>
<td>• Strength</td>
</tr>
<tr>
<td>• Security of the attachment</td>
</tr>
<tr>
<td>• Amount of unfinished business between the deceased and the bereaved</td>
</tr>
<tr>
<td>• Level of ambivalence in the relationship</td>
</tr>
<tr>
<td>• Roles of the deceased occupied in the bereaved life and social system</td>
</tr>
<tr>
<td><strong>Factors related to characteristics of the bereaved</strong></td>
</tr>
<tr>
<td>• Previous experience with grief and loss</td>
</tr>
<tr>
<td>• Presence of concurrent losses and/or other stressors</td>
</tr>
<tr>
<td>• Mental health prior to the loss</td>
</tr>
<tr>
<td>• Developmental stage of life</td>
</tr>
<tr>
<td>• Social, cultural, ethnic, religious, and spiritual</td>
</tr>
</tbody>
</table>

Grief, Demoralization, and Depression: Diagnostic Challenges and Treatment Modalities

The grief experience of patients who are dying should also be carefully understood, assessed, and treated because it presents unique features that warrant an individualized approach. The term preparatory grief has been used in the literature to indicate a normative grieving process that may be experienced by patients with advanced illness as they approach death. It has been described as a natural element of the life cycle, with the potential to create significant suffering for the patient and the family system. Kuebler-Ross’s description of anticipatory grief as the grief that “the terminally ill patient has to undergo to prepare himself for his final separation from this world” has been frequently utilized to indicate this process, unique to each patient. Patients’ grieving process has a multidimensional nature that involves the physical, emotional, and spiritual domain. While preparatory grief can elicit intense negative affect, it is arguably different from depression (Table 2).

Patients’ preparatory grief to some extent parallels the anticipatory grief experienced by family members. Spiritual orientation and religious affiliations modulate the extent to which the patient’s own death is perceived as an absolute loss of self or a transition to another existence of self that is primarily spiritual. In this sense, patients with advanced illness who are grieving their own death may be faced with the same tasks involved in grieving the loss of a loved one.

Applying Worden’s task model of grief to dying patients’ preparatory grief may allow providers to understand the nature and manifestations of preparatory grief and identifying areas that may require specific interventions to minimize distress for the patient. According to the original model, the tasks of grief work involved in processing the loss of a loved one include accepting the reality of the loss, working through the pangs of grief, adjusting to a world without the loved one, and emotionally relocating the loved one and continuing on with life. When applied to patients, the first task involves dealing with awareness of a limited prognosis and impending death. While this task involves a pragmatic and cognitive process for family members, it allows room for various shades of gray in the palliative care setting.

### Grief in the Palliative Care Setting

Grief assessment and bereavement care should begin at the first contact between the patients and family and the palliative care or hospice team. Research has shown that complicated grief (ie, PGD) is associated with physical and psychiatric morbidity, including increased suicidal ideation and overall reduced quality of life. Therefore, identifying individuals at risk for developing complicated grief should be a particular focus of the palliative care team. Factors described in the literature as exposing bereaved individuals to a higher risk for bereavement include a childhood history of separation anxiety, over-controlling parent, parental abuse, early parental death, and insecure attachment styles. Additionally, a history of mental illness prior to the loss and an ambivalent relationship with the deceased increase the risk for developing prolonged grief disorder and may seriously undermine patients and families’ ability to cope with the progression of illness and impending death.

### The Experience of Grief in Patients with Advanced Illness

<table>
<thead>
<tr>
<th>Preparatory Grief</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mood fluctuates</td>
<td>The patient feels sad or low most of the time, tearfulness</td>
</tr>
<tr>
<td>Self-esteem is generally intact</td>
<td>Feelings of worthlessness and guilt</td>
</tr>
<tr>
<td>The patient is able to enjoy seeing and interacting with friends and family</td>
<td>The patient withdraws from friends and family, less talkative</td>
</tr>
<tr>
<td>The patient is able to experience pleasure in various activities</td>
<td>Anhedonia. The patient experiences a loss of interest in activities</td>
</tr>
<tr>
<td>The patient is able to look forward to special occasions</td>
<td>Thoughts of early death, or suicide. May frequently ask physicians to hasten death</td>
</tr>
<tr>
<td>Decreased ability to focus and concentrate</td>
<td>Inability to make decisions</td>
</tr>
</tbody>
</table>

when it comes to dying patients. In other words, bereaved family members are faced with the task of accepting that the loved one is, in fact, dead, and no longer living. Patients may, however, experience various degrees of awareness and acceptance of the fact that their death is near. Their willingness to openly acknowledge that they are dying should not necessarily be interpreted as a sign of benign acceptance and “better” adjustment to the dying process, the same way that unwillingness to openly acknowledge that death is near is not necessarily a sign of unhealthy denial. Open awareness of dying does not automatically translate into acceptance or peace. Similarly, while patients may choose not to openly acknowledge they are dying, they may still be internally engaged in processing this reality. Death awareness is a complex construct, initially explored in Glaser and Straus’s landmark study which described possible scenarios reflective of awareness contexts between patients and caregivers. The types of awareness described in their study are open, suspected, mutual pretense, and closed. In open awareness both patient and caregiver are aware that the patient is dying and are open to talk about it. In closed awareness the caregiver is aware that the patient is dying, but this awareness is hidden from the patient. In suspected awareness the patient suspects, but the topic is not openly discussed. In mutual pretense one or both parties in the patient-caregiver dyad pretend that they do not know the patient is dying. Many factors impact how awareness of dying is conceptualized by patients and caregivers. Culture, spiritual and religious beliefs, and family history, including perceived ability of patient or caregiver’s ability to cope with the impending death, are some of the factors that add to the complexity of the issue.

The second task of Worden’s model involves working through the pangs of grief. For dying patients, this task may become a major source of distress as their care transitions from a curative to a palliative mode. For many patients with advanced illness, the moment they first hear about hospice care may mean getting in touch with the fact that their illness will not improve and they will probably die soon. This moment of awareness is not experienced by all patients, nor do patients who have awareness of their impending death experience the same level of emotional distress as a result of it. However, whatever resources can be mobilized by the palliative care team should be used to relieve suffering for the patient and the family.

The third task involves adjusting to a world without the loved one. For dying patients, this task may involve progressively withdrawing from a world that will soon be without them. It is possible that the progressive emotional withdrawal that many patients experience as they are entering the terminal stage may not only be caused by the physical decline but also by a progressive grieving process that facilitates patients’ symbolic disinvestment of emotional energy from the outside world.

The fourth task applied to bereaved individuals involves “emotionally relocating” the loved one and continuing on with life. For patients who are dying, this task may involve emotionally relocating loved ones, family members, and other sources of emotional attachment, in order to find some form of peace with their own death and dying process. For the palliative care team, the task is to understand and facilitate dying patients’ grieving process as well as guide and support the family.

TREATMENT APPROACHES FOR NORMATIVE AND PROLONGED GRIEF

Educating patients and families about the nature of grief and its manifestations in the context of palliative and end-of-life care should be approached early. Normalizing the distressing symptoms in the early phases of grief should not take the place of ongoing assessment to identify the presence of risk factors for developing prolonged grief or severe depressive symptoms that should be addressed pharmacologically.

Shear and colleagues conducted a randomized controlled trial of an intervention for the treatment of complicated grief comparing 16 sessions of interpersonal therapy, in lieu of a control, with 16 sessions of complicated grief treatment. Results showed that even though participants in both groups improved, participants who received the complicated grief treatment experienced faster improvement of greater magnitude. Complicated grief treatment involved a combination of modified in vivo and imaginal exposure focusing on processing traumatic symptoms related to the death, promoting a sense of connection with the deceased loved one, and restoration from the grief. Recently, treatment of complicated grief has been tested in randomized controlled studies combining Shear’s therapy for complicated grief with pharmacotherapy. Results showed that adding an antidepressant improved compliance with treatment in the experimental group, but not in the control (interpersonal therapy) group. Interpretive, supportive group therapy and cognitive-behavioral group therapy have been studied with promising results. Escitalopram, bupropion, and paroxetine have also been studied in the context of complicated grief and have shown to reduce symptoms of depression without worsening grief symptoms.

Family interventions should be the preferred choice when the family as a system is at risk, if there are children or adolescents at risk, or if one or more family members develop a substance use disorder as a way of managing emotional difficulties. Family-focused grief therapy, developed by Kissane and Bloche, is a six- to eight- session family therapy intervention aimed at reducing emotional distress and dysfunctional communication patterns among family members, while facilitating appropriate expression of emotions.
DEPRESSION IN PATIENTS WITH ADVANCED ILLNESS

As patients’ medical care shifts from a curative to a palliative modality, they may experience emotional distress as a result. After intensely focusing physical and emotional energy on pursuing curative treatments, as in the case of many patients with cancer, transitions of care often mean not only that cure cannot be achieved but that the prognosis may be poor and death may become an increasingly certain and near outcome. Patients and caregivers may experience profound disappointment, sadness, and grief.

It has been estimated that rates of MDD in patients who are dying can be between 22% to 75%. Identifying risk factors for depression should be a priority of the palliative care team and a major focus of the initial assessment. Untreated depression creates significant suffering for patients and caregivers and is associated with suicidal ideation and increased requests for hastened death in terminal patients. Diagnosing depression in patients with advanced illness is challenging. While the term depression is sometimes used to indicate a variety of situations where the patient feels low, sad, or demoralized, a diagnosis of MDD implies that DSM-IV-TR criteria are met. However, many of the somatic symptoms of depression, such as fatigue, disturbances in the sleep cycle, loss of energy, and weight loss are common in patients with advanced illness. Clinicians should focus on patients’ psychological symptoms and utilize structured assessment tools that do not include somatic symptoms of depression. It has been argued that the majority of depression assessment tools are not appropriate for use palliative care patients. The Geriatric Depression Scale and the Hospital Anxiety and Depression Scale exclude most of the somatic complaints associated with depression, focusing on emotional complaints, and have been widely used in patients with advanced illness.

TREATMENT OF DEPRESSION

The palliative care team should carefully consider available treatment options when caring for patients with advanced illness who are suffering from depression. Depression is not developed by the majority of palliative care patients and should be actively treated. Antidepressants and psycho stimulants may have an important role in treating depression in patients with advanced illness. Goals of treatment, side-effect profile, drug interaction, and patient’s prognosis are important considerations that guide clinicians in their choice of pharmacologic agents. These issues have been reviewed elsewhere.

Psychological treatment of depression can be effectively provided alone or in conjunction with psychotrophic medications. Cognitive-behavioral therapy and interpersonal therapy have been demonstrated to improve depressive symptoms in patients with advanced cancer. Dignity-conserving and meaning-centered psychotherapies may allow patients to safely explore existential and psycho-spiritual questions and should be included in the treatment plan.

DEMORALIZATION

The term demoralization is not a new concept in the psychiatric literature. It was originally proposed by Frank to indicate a state of perceived incompetence, inability to cope, hopelessness, existential despair, and meaninglessness frequently prompting individuals to seek mental health treatment. Feeling demoralized involves a sense of “giving up,” described extensively in the psychosomatic literature. The predominant cognitive style in this syndrome is “giving up” because the individual feels hopeless and feels that the amount of energy utilized to accomplish a goal does not translate into a tangible result.

More recently, Kissane and colleagues have proposed the existence of the demoralization syndrome as a diagnostic category separate from depression and recognizable in palliative care and hospice settings. While researchers have highlighted the need to include demoralization in the psychiatric nomenclature, currently it is often referred to as adjustment disorder. However, it has been argued that adjustment disorder does not place sufficient emphasis on the personal narrative of incompetence that characterizes the lives of demoralized individuals. Bodily disfigurement, physical disability, chronic medical illness, and social isolation are some of the main clinical features associated with this syndrome.

Predisposing, precipitating, and perpetuating factors have also been identified. A personal history characterized by early medical illness and multiple losses can predispose to demoralization as well as life stressors that abruptly change the individual’s sense of hope and meaning in life. Factors that are important in maintaining the sense of demoralization include dysfunctional family dynamics, unmanaged countertransference on the part of clinicians, and lack of social support. While demoralization is prevalent in various patient populations, its recognition is especially important in the context of palliative care settings. It has been hypothesized that untreated demoralization can expose individuals to chronic distress, MDD, social withdrawal, impulsive suicidal behavior, and requests for physician-assisted suicide.

TREATMENT APPROACHES FOR DEMORALIZATION

Many authors agree that antidepressants do not address the sense of incompetence or meaninglessness. However, they should be used in conjunction with psychotherapy if...
patients have comorbid depression. Interventions that can foster hope and connection with a sense of meaning in life should be utilized to address demoralization.69 Narrative therapy can help patients reframe personal stories of failure and sadness into resilience and hope. Negative cognitive styles such as pessimism, magnification, selective focus on the negative, and self-labeling can be particularly maladaptive and increase patients’ suffering. Cognitive therapy can be utilized to address cognitive distortions and maladaptive cognitive styles typical of demoralized patients. Interpersonal therapy can foster a sense of interpersonal connection. Additionally, appropriate referrals to community resources and volunteer organizations can be particularly helpful for palliative care patients with no caregiver, or whose caregivers are unable to meet the patient’s need due to psychosocial stressors, physical illness, or mental illness.

DIFFERENTIATING DEPERSONALIZATION FROM DEPRESSION

Demoralization and depression share clinical symptoms and the differentiation may be challenging. While the core feature of depression is anhedonia and loss of pleasure or interest in present or future activities that used to elicit pleasure, the core feature of demoralization is meaninglessness and helplessness. Patients who are demoralized may not exhibit the psycho-motor changes typical of depression, such as retardation or agitation. Unlike patients suffering from MDD, patients who are demoralized can exhibit normal behavior or full range of affect and are capable of experiencing pleasure from engaging in pleasurable activities. Therefore, ability to experience pleasure in activities that are meaningful to the patient and ability to exhibit full range of affect can help providers distinguish between demoralization and depression.69-72

CONCLUSION

Depression, demoralization, and grief reactions are separable diagnostic entities commonly experienced by patients with advanced illness in the palliative care setting. Clinicians should become familiar with the core features of each condition in order to make appropriate treatment decisions and adequate referrals to members of the interdisciplinary palliative care team. PP

REFERENCES


