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ELDER CARE

A Resource for Interprofessional Providers

Preparatory Grief

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Nearly 2 million older adults die each year in the United States. Many of the most common causes of death for older adults are life-limiting chronic illnesses, such as heart disease, cancer, chronic lung disease, dementia, diabetes, and chronic kidney disease.

What is Preparatory Grief?

Patients with these diseases may not initially recognize them as life-limiting, but disease progression will eventually bring this realization. Preparatory grief is defined as the cognitive, emotional, and spiritual responses to the understanding that one has a life-limiting disease - that death is approaching.

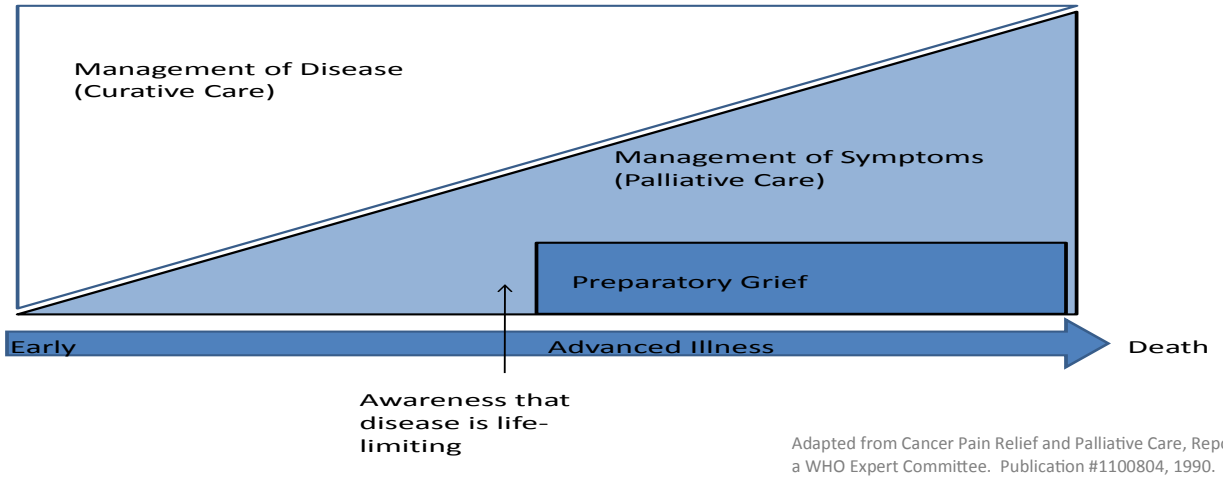
Patients may grieve for the loss of life itself, for the loss of small pleasures like their morning cup of coffee or their familiar routine. They may also grieve for what the loss means to those around them, for a grandchild they will never see grow up or a spouse they must leave behind.

The degree of preparatory grief that a patient will experience partially depends on factors such as their age; experience with loss; their diagnosis and treatment plan; and their religious and cultural beliefs. To provide patients with quality end-of-life care, an understanding of preparatory grief is necessary. The interweaving of curative care, palliative care, and preparatory grief in chronic illness is shown in Figure 1.

Underestimating Preparatory Grief

Health care providers routinely underestimate the amount of distress and preparatory grief that patients undergo. Many health care providers are either unaware of preparatory grief, or avoid assessing or discussing it with patients. However, research shows that patients are frequently willing and desire to talk about the grief process they are going through. Advanced preparatory grief is frequently confused with depression, and patients may be inappropriately treated for depression.

Figure 1. Preparatory Grief in the Context of Life-Limiting Illness



Adapted from Cancer Pain Relief and Palliative Care, Report of a WHO Expert Committee. Publication #1100804, 1990.

TIPS FOR DEALING WITH PREPARATORY GRIEF

- Don't underestimate or discount the possibility of preparatory grief. It is a common experience for patients who have terminal illnesses.
- Allow patients to self-reflect, acknowledge their losses, and discuss their relationships, accomplishments, and missed opportunities.
- Be sure to distinguish preparatory grief from depression. Differences are listed in Table 1.
- Use the RELIEVER mnemonic to guide your conversation with patients who are experiencing preparatory grief.

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Assessing Preparatory Grief

Patients at all stages of a chronic disease should be asked questions like "How do you think this disease will affect your future?" or "How does this disease affect the way you think about your future?" The goal is not to force patients to understand that their disease is life-limiting or to break down their "denial." Rather, it is a good place to start to assess where they are in terms of thinking about their disease progression or the possibility of death. Also ask patients about the way they are feeling about their disease and about their health in general. Ask them about how it affects their lives. Allow patients to vent their frustration with the losses that any disease brings – loss of function, independence, and privacy.

Remain alert for emotional responses such as sadness, anger, anxiety, or regret that may indicate preparatory grief. Research has shown that in patients with preparatory grief, anxiety is the most common emotional response, and if extreme or prolonged, may require treatment with counseling and/or medication.

Distinguishing Preparatory Grief from Depression

Severe depression is not a normal part of preparatory grief. If patients indicate that they have lost all joy in life, are apathetic, or indicate a desire for death, further probing for depression is required. Inquire about their average mood, whether they are able to enjoy daily life, whether they continue to enjoy previously cherished activities and whether they are having any thoughts of suicide. Anhedonia, apathy and suicidal ideation are all indicators of depression and should prompt intervention with counseling and medication. Table 1 contrasts preparatory grief with depression.

Table 1. Differentiating Grief and Depression

Preparatory Grief	Depression
Waxes and wanes	Consistent sadness
Sadness about death	Suicidal ideation or active desire for death
Specific anxieties about dying process and loved ones left behind	Vague pervasive anxieties
Continued ability to take pleasure in favorite activities	Consistent anhedonia Hopelessness
Continued involvement with loved ones	Social withdrawal

Helping Patients with Preparatory Grief

Once you have ruled out depression, you can use the RELIEVER mnemonic as a way to help patients deal with their preparatory grief.

- **R**eflect by acknowledging the patient's emotions. Say something like "I can see that you are sad."
- **E**mpathize, by saying something like "I know this is hard for you."
- **L**ead by exploring the patient's concerns with questions like "What concerns do you have about how your loved ones will cope after you are gone?"
- **I**mprovise by keeping in mind that every patient will experience preparatory grief in an individual manner. Some patients may be more open than others in discussing their grief.
- **E**ducate patients by explaining the grief process and the emotions that accompany it.
- **V**alidate the experience, by reminding patients that their grief is completely normal.
- **R**ecall by helping patients celebrate the life they have lived, and recognize any tasks they still want to complete.

It may also help the patient to discuss practical concerns that arise at the end of life. These include managing symptoms, reconciling differences with family members, financial concerns, and advanced directives.

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Interprofessional care improves the outcomes of older adults with complex health problems

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