2.0 CONTACT HOURS CE

Grief & depression at the end of life

Abstract: People may experience grief and depression with serious illness at the end of life or as a loved one who survives. While grief is a normal reaction to loss, complicated grief and depression are not. Accurate diagnosis, treatment, and referral are essential clinical tools for practitioners managing this population.

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Whether working with the very young, the middle aged, or older adults, nurse practitioners (NPs) often find themselves on the front lines of managing patients nearing or at the end of their lives and their caregivers. As a consequence, grieving and loss are a part of many providers' practices. Unfortunately, managing people's suffering at the end of life is not incorporated into standard nursing training. In *The Nature of Suffering and the Goals of Nursing*, Ferrell and Coyle eloquently note, "Helping patients regain control in the face of illness and to cope with the vulnerability and uncertainty of life is part of nursing care".[1] So while it is not a part of nursing training, it is a very real part of nursing practice. Supporting individuals through what may be one of the greatest challenges in their lives can also be one of the most rewarding and enriching experiences in a nurse's career.

Grief, bereavement, and mourning are often used interchangeably; however there are some differences. Grief can be a reaction to loss whether it is the loss of a loved one, the loss of function, or the loss of a potential future due to a progressive terminal illness. Those who have lost a loved one may experience acute grief (which is the initial reaction) and integrated grief (the permanent expression of bereavement). Bereavement is the experience an individual may have who has lost someone close to him or her, and mourning is the process of coming to terms with loss.[2]

Reports of the incidence of end-of-life depression vary widely.[3] Because of the devastating and often treatable impact of depression on the quality of life of a patient nearing the end of life, it is important to remain alert to the signs and symptoms. Understanding how to differentiate between grief and depression is an important skill for managing patients effectively, as the treatment is different.

A brief history of grief

There have been many theories and models of grief written over the past 80 years.[4] Though not the first to write about

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grief, Sigmund Freud, MD is credited with introducing grief to the psychological lexicon.[5] Dr. Freud's work generated a focus in Western thought that grief is an active process in which the bereaved must struggle to give up an emotional attachment to the one who is lost. Dr. Freud felt this struggle would take time and rarely resulted in a pathologic state.

Erich Lindemann, MD, a psychiatrist and bereavement specialist, pulled grief even further into the domain of psychiatry and also differentiated between normal and abnormal grief experiences.[4,5] Dr. Lindemann's theory conceptualized grief in phases in which the bereaved was required to emotionally detach from the deceased while learning to live in an environment in which the deceased did not exist.[6]

Through her work with dying patients, psychiatrist Elisabeth Kübler-Ross, MD, further developed the idea that grief moved in five distinct phases: denial, anger, bargaining, depression, and acceptance. This model has been described as linear and somewhat rigid nature. Furthermore, Charles Corr, PhD, a social psychologist, felt the Kübler-Ross model was only applicable to the dying, not the bereaved, and that it was based on observation rather than empiric data.[6]

Moving away from the linear type of model, Dr. Colin Murray Parkes, a British psychiatrist specializing in grief, thought of grief as a series of phases that shifted over time fading in and out in waves.[4] Each individual experienced these waves differently based on the type of loss and the uniqueness of the bereaved. J. William Worden, PhD, ABPP, a psychologist, solidified the role of counselors and therapists in offering care to those who had suffered loss.[4] Dr. Worden conceptualized the work of the bereaved in a series of tasks: accepting the loss, processing the pain of grief, learning to adjust to a life in which the deceased no longer exists, and learning to find a place in their life for the deceased while moving forward with their own.[7]

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Dutch psychologists Margaret Stroebe, PhD and Henk Schut, PhD thought of grieving as a dynamic process. They were concerned the bereaved who did not follow these more linear models of grieving would be judged as grieving "wrong". Dr. Stroebe and Dr. Schut's Dual Process Model of Coping with Bereavement integrated the previous work of clinicians and researches, such as Dr. Worden, in which the bereaved oscillates between coping with loss and learning to make the lifestyle changes that accompany that loss.[6]

Today, the concept of phases or tasks of grieving are somewhat limited. Accepting that loss is not limited to the death of a loved one, counselor Dr. Keren M. Humphrey suggests critical guidelines for conceptualizing grief and loss, which include a recognition that everyone's grief experience is unique; grief is experienced within an individual's cultural, personal, historical, and social context; grief does not follow a proscribed linear progression; grief is a normal reaction to loss; grief may change, but it does not end; those who are grieving are active participants in the process; and treatment must be tailored to the individual.[8]

Grief

In direct contrast to depression, grief is an expected and universal adaptive reaction to loss.[2] For instance, a patient diagnosed with a serious illness may experience grief for the losses he or she is likely to suffer, such as the loss of independence as the disease progresses or even the loss of his or her future.

The symptoms of uncomplicated grief fall within four categories: feelings, physical sensations, thoughts, and behaviors.[7] Some commonly experienced symptoms include sadness, anger, tightness in the chest or throat, confusion, and insomnia (see *Symptoms of uncomplicated grief*). The physical symptoms of grief are also commonly experienced physical symptoms of serious illness and/or the medications used to treat illness. As a consequence, it is important that providers include a grief reaction in their working differential diagnosis for patients who complain of these symptoms once all treatable physical reasons have been excluded.

Grief is a process that is experienced differently for each person and with each loss. While timing may vary, uncomplicated grief is often experienced in waves that can range from overwhelming sadness to relief, joy, peace, and happiness. Most people will never stop grieving a loss but will move from the acute experience of grief in which the feelings are a constant presence to a more integrated grief in which feelings may only reappear at the anniversary of the death, birthdays, holidays, or other significant events.[9] It is helpful to understand that grief is not an illness. Rather, grief can be an opportunity to work out a way to accept the loss of a loved one, the diagnosis of a serious illness, and to find meaning, purpose, and joy in life despite loss.[10]

Treatment

Normal grief does not require treatment. Most benefit from education about the symptoms of normal grief as well as the support of a healthcare professional who actively listens and accepts the feelings of grief associated with loss.[2] Many may also benefit from the informal support of friends and family as well as more formal supportive services that may be offered by a local palliative care program, hospice, or religious community. As providers, it is helpful to support the grieving by actively listening and acknowledging emotions; setting and reinforcing realistic goals; encouraging engagement in pleasurable activities; and facilitating communication with loved ones.[2,3]

Complicated grief. Complicated grief occurs in about 7% of those experiencing bereavement, impairing their ability to live meaningful, purposeful lives.[11] Individuals experiencing complicated grief have difficulty accepting the loss of a loved one and find that their grief is taking over the focus of their life. The bereaved may find their grief frightening or shameful and feel their life is over.[9] Dr. Worden suggests the use of the term complicated mourning as opposed to complicated grief.[7] This is due to the feeling that the persistence of the grief experience is related to ineffectively adapting to loss. Regardless of terminology, it is helpful to understand the incidence of complicated grief rises with a prolonged, delayed, or exaggerated grief experience.[7]

The symptoms of complicated grief include an intense yearning or longing for the deceased, preoccupation with thoughts of the deceased, anger and bitterness about the loss, and intrusive thoughts related to the loss.[9] Some bereaved feel that they would betray their loved one if they were to receive some enjoyment from life. The symptoms of complicated grief usually occur after at least 6 months following the death of a loved one. They can be quite distressing and impair the ability to function and lead a rewarding life.[11] Complicated grief also increases the risk of suicidal ideation in certain populations.[9]

Risk factors for complicated grief include the loss of a loved one with whom the person may have had a complicated relationship or for someone who has suffered multiple significant losses.[9] Those who have a history of mood or anxiety disorders are at increased risk. Violent deaths, suicides, and loss of a child or significant other also increases risk.[11] Finally, individuals with poor health, poor social support, or those who are experiencing other life stressors are also at risk for complicated grief.[9]

The treatment of complicated grief does not require medication. Because of the risks associated with complicated grief as well as the devastating impact on quality of life, providers should refer patients with suspected complicated grief to a qualified mental healthcare professional or bereavement specialist. For more information about complicated grief, visit the website of the Center for Complicated Grief at www.complicatedgrief.com.

Symptoms of uncomplicated grief[7]

Category	Symptom
Feelings	• Sadness • Anger • Guilt • Anxiety • Fatigue • Helplessness • Loneliness • Shock • Relief • Numbness
Physical sensations	• Tightness in the chest • Tightness in the throat • Hollow stomach • Increased sensitivity to noise • Low energy • Dry mouth • Breathlessness • Sense of unreality • Muscular weakness
Thoughts	• Preoccupation with loss • Disbelief • Confusion • Hallucinations (visual and/or auditory)
Behaviors	• Sleep disturbance • Absentmindedness • Withdrawal • Changes in appetite • Restlessness • Crying

Table developed by the author.

Depression

Despite what some may believe, depression is not a universally experienced symptom at the end of life.[2] Furthermore, being diagnosed with a terminal illness does not usually trigger major depression.[12] That being said, depression is often unrecognized and undiagnosed in patients nearing the end of life.[13] For those who have experienced a loss, both grief and depression can be present at the same time. For those with complicated grief, depression can exacerbate grief

Risk factors for depression[13]

- Cancers such as pancreatic cancer or brain tumors
- Endocrine disorders such as hypothyroidism and diabetes mellitus
- Neurodegenerative disorders such as Parkinson disease, Alzheimer disease, or multiple sclerosis
- Poor pain and symptom management
- Family or personal history of depression
- Substance abuse
- Poor social support
- Financial distress

Table developed by the author.

Differences between grief and depression[2,11]

Grief	Depression
Guilt or shame focused on specific events such as smoking for the patient with lung cancer Guilt or shame focused on the death of a loved one for the bereaved	Excessive feelings of guilt or shame, loss of self-esteem
Reduced engagement in activities due to serious illness Withdrawal from people and activities related to the death of a loved one for the bereaved	General withdrawal from people and activities
Maintaining an ability to experience interest and pleasure for those with serious illness Loss of pleasure and interest as it relates to the loss of a loved one for the bereaved	Loss of interest and pleasure that is pervasive
Occasional feelings of hopelessness but a general positive outlook about the future	Persistent feelings of hopelessness
Symptoms come in waves	Symptoms are persistent and protracted

Table developed by the author.

symptoms and vice versa, grief can exacerbate depression.[11] (See *Risk factors for depression*.)

As in grief, the symptoms of serious illness as well as those caused by medications used to treat illness, such as changes in appetite, sleep disturbance, and decreased energy, are often found in depression confounding timely diagnosis. This can be even more challenging in older adults, as older adults may be less likely to report having a depressed mood.[12] Distinguishing between grief and depression in the bereaved is challenging due to the similarities in symptoms, such as intense sadness, social isolation, and low mood. To aid the provider in distinguishing the two, there are a few characteristics of both that can aid in diagnosis. Those experiencing grief may also experience positive emotions simultaneously.[9] As previously stated, grief may also be experienced in waves as the bereaved come across both internal and external reminders of their loss. Depression, a pervasive experience, is generally not experienced at the same time as positive emotions. Furthermore, depressed individuals may report a loss in self-esteem, whereas persons who are grieving would likely not.[7] (See *Differences between grief and depression*.)

Treatment

Patients at the end of life who are experiencing depression should be treated with both medication and psychotherapy. As in acute grief, patients experiencing depression should be referred to an appropriate mental healthcare professional. Reducing the symptoms of depression can not only improve the quality of life of the patient with serious illness but can also reduce caregiver stress. In addition, it is important to remember that aggressive treatment of symptoms such as pain, shortness of breath, and anxiety that may be related to serious illness is necessary in order to avoid suffering that may contribute to depression.[2]

Selecting the appropriate antidepressant medications should be based on a patient-centered approach. Physical and psychological symptoms as well as the prognosis can guide in the selection process of the appropriate medication. For instance, mirtazapine may be a good choice for a patient who may be experiencing insomnia and weight loss as a part of the disease process, as the adverse reactions of the medication include sedation, increased appetite, and weight gain.[2] As the standard medications used to treat depression such as selective serotonin reuptake inhibitors (SSRIs) and serotonin-norepinephrine reuptake inhibitors (SNRIs) may take up to 4 to 6 weeks to take effect, their use may be limited in those who are within days to week of the end of life. Caution must be taken in prescribing for children, adolescents, and young adults,

Medications used to treat depressive symptoms in advanced disease[2,3]

Listed below are examples of drugs that may be used to treat depressive symptoms in advanced disease. Consult the manufacturer's full prescribing information for recommended dosages, contraindications, and precautions.

Class and drug example	Indication	Onset of action	Issues to consider
SSRI **Sertraline**	FDA approved for major depressive disorder	4 to 8 weeks	Avoid alcohol use; do not stop abruptly
SSRI **Citalopram**	FDA approved for treatment of depression	4 to 8 weeks	Avoid alcohol use; do not stop abruptly
SNRI **Duloxetine**	FDA approved for major depressive disorder	4 to 8 weeks	May be helpful in the treatment of neuropathy; avoid alcohol use
Tetracyclic antidepressant **Mirtazapine**	FDA approved for major depressive disorder	4 to 8 weeks	May increase appetite and cause sedation
CNS stimulant **Methylphenidate**	Not FDA approved for depression. Studies have shown the drug is helpful in reducing depressive symptoms in patients with advanced illness	1 to 3 days	Do not dose after noon to avoid insomnia; good option for short prognosis

as they may have increased risk of suicidal thoughts and behaviors when treated with antidepressants, especially when first starting the antidepressant or with dose adjustments. While not FDA approved for depression, certain CNS stimulants, such as methylphenidate, may help reduce depressive symptoms when time limits may be present. A 2009 systematic review of the literature found 19 controlled trials on the use of methylphenidate in medically ill older patients indicating that it may be useful in the treatment of depression and fatigue.[14] Monitoring for adverse reactions such as restlessness, tachycardia, delirium, and insomnia is warranted. (See *Medications to treat depressive symptoms in advanced disease*.)

Selecting the appropriate antidepressant medications should be based on a patient-centered approach.

Implications for practice

Grief is a normal part of life experience. Complicated grief and depression, however, are not. Complicated grief and depression can have a devastating impact on the quality of life for both caregivers and patients with serious illness. As providers on the front line, NPs have an opportunity to make an enormous positive impact on patients who are suffering from loss while benefitting from this gratifying approach to the care of the individual holistically.

Grief and depression at the end of life may be uncomfortable for some providers to confront. This type of work may bring up personal feelings of loss as well as concerns for worsening the reactions for patients who have suffered loss. It may be helpful to know that contrary to what many providers feel, having conversations about end-of-life care does not increase psychological harm to patients or their caregivers.[4] Furthermore, Cheng and colleagues found that advanced cancer patients needed to share their grief with family, as it assisted with resolving conflicts and enhancing resiliency in the survivors.[15] Given their findings, the authors suggest that providers should support these types of conversations early in the course of the disease.[15]

NPs should not feel as if they should manage grief and depression at the end of life on their own. Palliative care programs are interdisciplinary programs for patients at all points of the disease trajectory, whether at diagnosis or the end of a serious illness. Hospices are interdisciplinary programs that address end-of-life issues specifically for patients in the last 6 months of life. Both of these programs specialize in the care of caregivers and patients at the end of

life who may be suffering from loss. Appropriate referral and collaboration with these specially trained professionals can be beneficial to caregivers and patients with serious illness as well as the providers managing their healthcare. Other mental healthcare professionals, bereavement counselors, and specialists in religious communities are also excellent collaborative resources. Managing patients with grief and depression provides an important opportunity for NPs to provide holistic care.

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