



Grief, Loss and Bereavement. Understanding Concepts, Clinical Manifestations and Cultural Considerations at End of Life

Kimberly Shapiro

There is no correct way or time to grieve.
—Elisabeth Kübler-Ross and David Kessler
On Grief and Grieving

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K. Shapiro (✉)
Outpatient Mental Health and Wellness Programs, Mission Hospital, Laguna Beach, CA, USA
e-mail: kimberly.shapiro@gmail.com

Understanding Grief and Bereavement in the Context of Terminal Illness

The weight of grief is heavy on both patients with terminal illness, and their loved ones. We are now aware that grief is not limited to the time of death—grief reactions begin to occur at the time of diagnosis of terminal illness and evolve over time, impacting the patient and family unit in a variety of ways. Loss of what life “could have been” with better health, decline in physical functioning due to illness, and loss of identity and role within the family or community all play a part in the grieving process. It is important that caregivers and clinicians working with end-of-life patients understand the clinical, diagnostic, and cultural implications of grief and loss to care for the patient and their family in a more holistic, complete way.

8.1 How Grief Presents in Practice

8.1.1 Clarifying General Terms

Grief is considered to be the emotional response to a loss. This could be the death of a loved one, the loss of a relationship, a home, family, or even loss of a dream. In mainstream culture, it is often seen as interfering with life. However, as it is not realistic to go through life without any loss, grief is in fact intrinsic to the experience of living. Grief can be a long, emotional process, encompassing a variety of thoughts, feelings, and behaviors that are personal to each individual [1]. Factors affecting grief reactions include the relationship to the person who died, their age, the circumstances surrounding their death, and an individual’s own personal experience, cultural beliefs, and coping mechanisms. It is important to recognize that Uncomplicated Grief is a normal process and is *not* a mental disorder [2].

Mourning is an outward expression of grief and loss. It is what is often visible to the public, and may include rituals, cultural customs, and religious beliefs. The rituals associated with mourning often provide meaning and structure to those who have experienced loss. These may include gathering with friends and family, planning a funeral, and burials.

Bereavement refers to a period-of-time, or state, in which grief is experienced and mourning occurs. It identifies the period of sadness after a loss. Eventually, there will be a shift in the bereaved person’s state of emotional well-being, and the period will end. A person is in bereavement for as long as it takes them to process their grief.

8.2 Grief During End of Life

8.2.1 Anticipatory Grief

Anticipatory grief is experienced by all who know of an upcoming loss of a terminally ill patient. Patients and families experience an emotional response to the future loss, which can begin months to years before the actual death [3]. As in normal, uncomplicated grief, anticipatory grief has associated thoughts, feelings, and behaviors, yet is often experienced in a more silent manner than grief after a loss. Described as “grieving forwards,” these emotions are distinct to the time period before the actual loss. Experiencing anticipatory grief is not protective for post-loss grief, and is not a reliable predictor of future outcomes. Even if grieving is already in process, it may continue or even worsen post-loss.

Symptoms associated with anticipatory grief include anger, anxiety, sadness, irritability, and dread. Furthermore, individuals may experience lack of motivation, desires to withdraw from social situations, and guilt. There is hope, however, during this period, as families have time to come together to say goodbye, spend quality time with the dying person, make peace, and make future plans. Clinicians would do acknowledge the challenges that patients and families are experiencing during this unique time, to provide support and referrals as indicated.

8.2.2 Grief Reactions Around Active Dying Phase

While a patient is actively dying or has immediately passed away, emotions run high, and grief reactions may be expressed passionately in the moment. They may be hard to manage or determine their “normalcy” in the early days after the loss. However normal uncomplicated grief gradually lessens into an acceptance of the reality of the loss. Distressing symptoms felt at the onset may decline over time, as the loss becomes more normalized and integrated into the life of the survivor. Symptoms may flare up at specific times that serve as a reminder of the deceased, such as birthdays and holidays. A hallmark of normal grieving is the ability not necessarily to move on, but to adapt to a new way of life without that person.

8.2.3 Prolonged Grief Disorder

While most bereaved people feel better with time and are able to adapt to new life circumstances without the deceased, approximately 10% of those experiencing grief have symptoms that do not improve.

Recently added the DSM-5-TR, Prolonged Grief Disorder captures these pathological grief responses in people who have lost a loved one within the past year. This person not only has lingering symptoms of grief, but these symptoms are intense and include preoccupation with or longing for the deceased that occurs almost daily for at least a month. The symptoms are distressing enough that they

cause impairments in one's daily functioning, such as at work, in relationships with others, or taking care of themselves.

Other common symptoms include emotional numbness, feeling that life is meaningless, intense loneliness, an avoidance of reminders of the deceased, and continued emotional pain. Those with Prolonged Grief are at higher risk for medical co-morbidities and hospitalizations, additional mental health disorders and disability, and self-harm or suicide. If able to be evaluated, these patients can do very well with proper treatments.

8.2.4 COVID-19 Considerations

As COVID-19 has ravaged the planet, it has brought new challenges in end-of-life care. These include social distancing, isolation. People are unable to visit hospitalized patients, say goodbye to those dying, or perform usual rituals including funerals and burial. As a result, this has fundamentally changed how families cope and process grief during lockdowns and quarantining. COVID-19 has also disrupted traditional clinical practice, decreased access to social support for those dying, and decreased support for their surviving family [4].

8.3 Stages of Grief

Swiss-American Psychiatrist Elisabeth Kübler-Ross, in her groundbreaking 1969 book *On Death and Dying*, first postulated that those dying go through a series of stages of grief. She developed this Five Stage Model as a framework for how individuals learn to live with loss. Originally controversial due to its observational nature, over the years it has become widely acknowledged and adopted in medical practices, psychology, and end-of-life care. The stages of grief can affect both patient and family and are considered to be **Denial, Anger, Bargaining, Depression, and Acceptance** [5].

Denial is considered to be more disbelief than actual refusal to believe something is true. People tend to feel like "I can't believe this is happening" to me or my loved one. Avoidance, shock and, fear are commonly associated. Anger is often directed at the loved one for getting sick and leaving; at themselves for not taking better care or noticing that something was wrong with their loved one. Anger can also be placed on the diagnosing or treating physician [6], or on a Higher Power. Frustration, anxiety, and irritation are common symptoms of this stage. At the bargaining stage, people think of what they can "do" for their loved one to be spared. Thoughts such as "take me instead," and feelings of lack of control are common. This negotiation could be internal or spoken out loud and maybe medical, social or religious. Depression is the feeling of sadness that is an appropriate response to a significant loss. It is not to be confused with Major Depressive Disorder, a DSM-V-recognized disorder that includes depressed mood in addition to several other associated criteria that together create a syndrome/disorder [7]. And finally,

acceptance is an acknowledgment of the reality that a loved one is dying, or gone. It does not mean that this person is alright or likes this reality, however they can learn to adapt and live with it [8].

The Stages of Grief are generalized, however the way each person experiences them is unique and individualized. Not every person goes through all stages, they can be experienced in a non-linear fashion, as people go back and forth between them on their way to healing and growth. People dealing with anticipatory grief go through the same five stages, More recently these have been expanded upon to include a sixth stage of grief, Meaning [9].

8.4 Treatment Options

While psychiatric or psychological treatment is not necessary for a normal grief reaction where a person is still functioning fairly well despite their loss, people do well in supportive psychotherapy due to the ability to vent and obtain feedback from an objective listener, or participate in group therapy or support groups to feel a sense of support and community [10].

For a patient experiencing prolonged grief, or perhaps major depression, both therapy and psychiatric evaluation may be useful. Treatment modalities include Cognitive Behavioral Therapy [21], Narrative Therapy, and Grief Counseling, and specific treatment for Prolonged Grief Disorder [11]. Support for Caregivers has been shown to improve symptoms, and medication support if indicated on a case-by-case basis [2].

8.5 The Impact of Culture on Bereavement Practices

While all humans are united by a sense of loss and a period of grief after the death of a loved one, the manner in which they mourn and experience this grief can be remarkably different depending on their upbringing. Culture, religion, and core values affect these practices. There is no right or wrong way to grieve [8], and religious or cultural beliefs impact experiences people have throughout end-of-life care. Clinicians working with terminally ill patients have an opportunity to help patients and their families process loss by understanding the cultural elements contributing to the dynamic.

Culture is a broad term, incorporating the behaviors and social norms of various human societies. It blends in beliefs, customs, laws, artistic expressions, traditions, and rituals of a group. Each culture has developed its own rituals and expressions of grief and loss [12]. Additionally, culture influences what is perceived as a loss or trauma, and therefore the manner and degree to which patients and their loved ones suffer losses. Many cultures are comforted by beliefs in life after death, or that the spirit of the deceased is watching over the living. Each group has its own beliefs about the meaning of life and afterlife, which can mitigate some grief responses. Participating in cultural or religious rituals surrounding death and dying

helps people cope with loss, brings a sense of structure and control to a period of uncertainty, and provides comfort and community as patients and their loved ones prepare for loss [13].

We live in an increasingly diverse world where various cultures overlap, live in the same cities and communities, and families are often blends of different cultures and religions, creating their own unique rituals. This exposes clinicians to interactions with cultures and customs that they might not be familiar with. It would behoove those who work in end-of-life care to interact with patients in a culturally sensitive way, by acknowledging how these beliefs are affecting the patient experience at the end of life. Clinicians should be encouraged to research, ask questions and proceed with a culturally competent plan of care.

8.5.1 Cultural Rituals Surrounding Death and Dying

Rituals help people process loss, deal with the mystery surrounding death, and express grief in public and private. Communities unite over grieving rituals and come together to support those who have lost. These customs provide an organized, structured way to behave and help assign certain roles to a grieving family or community. They help inform a myriad of salient issues, including some of the following [7]:

- How grief is expressed—privately versus publicly, quietly versus vociferously.
- How patients are cared for/treated as they approach death—which ceremonies or prayers performed at the bedside, and which family, community members, or spiritual leaders are included.
- Where patients prefer to die.
- What happens to a person's body after death—how is it handled, where is it located, comfort level of people with the physically deceased body, and whether to bury or cremate.
- Length of time family members grieve, if and when a spouse can remarry, and customs/dress during period of mourning.
- New family dynamics and roles—who takes on role as head of family, or takes on tasks that the deceased was previously responsible for.

8.5.2 Bereavement Practices of Specific Cultures

As America is truly a melting pot of races, cultures and religions, it would be difficult to include the grieving practices of all cultures. For the purposes of this chapter, it is acknowledged that this list is limited, and rather serves to show the variety of practices across a select few cultures—all of which have significant biological, geographic, religious and cultural diversity within them. Listed are the common practices after one is deceased for several cultures.

8.5.3 African-American Culture

- Gathering of family and friends at the home of the deceased
- A wake with music, hymns, singing; post-wake meal with grieving loved ones
- High church involvement, belief that deceased are going “home” to be with other deceased relatives and loved ones
- Funeral service followed most commonly by burial rather than cremation
- Public displays of emotion well-accepted
- Perhaps dressing in white to symbolize resurrection [7, 12, 13].

8.5.4 Asian-American Culture

- Emphasis on exquisite care for the physical body of deceased—dressed in warm clothes and particular caskets chosen to protect body
- Elders in the family will take over planning and ceremonial responsibilities
- Open casket
- Quiet expression of grief—often with controlled affect
- Importance placed on burial location, monument at burial site
- Community meal after funeral to pay respects to spirit of deceased and give thanks to those who came to mourn
- Small shrine at home with pictures and memorabilia [7, 12, 13].

8.5.5 Hispanic-American Culture

- Family and friends encouraged to participate
- Priest and church involvement
- Rosary Prayers are performed by surviving family/loved ones at the home of deceased; some families say the rosary every month for a year, and then again on each anniversary
- Funeral services include a Mass
- Public expressions of grief encouraged
- May include community financial contributions to cover funeral and burial costs [7, 12, 13].

8.5.6 European-American Culture

- Public expressions of grief encouraged
- Funeral proceedings are often subdued; traditionally mourners wear dark or black clothing

- Reliance on funeral director or religious leader to prepare services and plan burial
- Gathering of mourners at the home of deceased or close family member to grieve together
- Visitation or viewing at the funeral home, followed by religious or gravesite service [7, 12, 13].

8.6 Conclusions

Grief is a normal, human response to losses big and small experienced over the human lifespan. It is of vital importance that those working with patients and with terminal illness or their families, are aware of and understand the unique intricacies of grief reactions in end-of-life care. Keeping cultural differences at top of mind can help provide better holistic care, help ameliorate emotional pain of loss of health and life, and aid in appropriate diagnosis and treatment of mental health pathology.

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