

Kubler-Ross Stages of Dying and Subsequent Models of Grief

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Medical professionals will work with dying patients in all disciplines, and the process is difficult as care shifts from eliminating or mitigating illness to preparing for death. This is a difficult transition for patients, their loved ones, and healthcare providers to undergo. This activity provides paradigms for the process of moving toward death as well as a discussion of how they should and should not be applied, supporting the interprofessional team to address the unique needs of their patients and guide them and their loved ones through the process.

Medical professionals in all disciplines work with dying patients, and doing so effectively can be difficult. In the context of death and dying, patients, their loved ones, and the health care team must shift their goals. Where treating acute and chronic illness usually involves finding a tolerable path to eliminating or preventing the progression of a condition, treating terminal illness must involve preparing for death as well as efforts to mitigate symptoms. Understanding the experience of dying and grief allows providers to support the unique needs of patients, their loved ones, and other healthcare team members.

Dr. Elizabeth Kubler-Ross introduced the most commonly taught model for understanding the psychological reaction to imminent death in her 1969 book, **On Death and Dying**. The book explored the experience of dying through interviews with terminally ill patients and outlined the five stages of dying: denial, anger, bargaining, depression, and acceptance (DABDA). This work is historically significant as it marked a cultural shift in the approach to conversations regarding death and dying. Prior to her work, the subject of death was somewhat taboo, often talked around or avoided altogether. Dying patients were not always given a voice or choices in their care plan. Some were not even explicitly told about their terminal diagnosis. Her work was popular in both the medical and lay cultures and shifted the nature of conversations around death and dying by emphasizing the experience of the dying patient. This led to new approaches to working with patients through the final phase of life. She highlighted the importance of listening to and supporting their unique experiences and needs and spurred new perspectives on ways practitioners can support terminally ill patients and their family members in adjusting to the reality of impending death.

Kubler-Ross and others subsequently applied her model to the experience of loss in many contexts, including grief and other significant life changes. Though the stages are frequently interpreted strictly, with an expectation that patients pass through each in sequence, Kubler-Ross noted that this was not her contention and that individual patients could manifest each stage differently, if at all. The model, which resulted from a qualitative and experiential study, was purposely personal and subjective and should not be interpreted as natural law. Rather, the stages provide a heuristic for patterns of thought, emotions, and behavior, common in the setting of terminal illness, which may otherwise seem atypical. Facility with these patterns can help health care providers provide empathy and understanding to patients, families, and team members for whom these patterns may cause confusion and frustration.

Kubler-Ross's Five Stages of Dying

Denial is a common defense mechanism used to protect oneself from the hardship of considering an upsetting reality. Kubler-Ross noted that patients would often reject the reality of the new information after the initial shock of receiving a terminal diagnosis. Patients may directly deny the diagnosis, attribute it to faulty tests or an unqualified physician, or simply avoid the topic in conversation. While persistent denial may be deleterious, a period of denial is quite normal in the context of terminal illness and could be important for processing difficult information. In some contexts, it can be challenging to distinguish denial from a lack of understanding, and this is one of many reasons that upsetting news should always be delivered clearly and directly. However, unless there is adequate reason to believe the patient truly misunderstands, providers do not need to repeatedly reeducate patients about the truth of their diagnosis, though recognizing the potential confusion can help balance a patient's right to be informed with their freedom to reconcile that information without interference.

Anger is commonly experienced and expressed by patients as they concede the reality of a terminal illness. It may be directed at blaming medical providers for inadequately preventing the illness, family members for contributing to risks or not being sufficiently supportive, or spiritual providers or higher powers for the diagnosis' injustice. The anger may also be generalized and undirected, manifesting as a shorter temper or a loss of patience. Recognizing anger as a natural response can help health care providers and loved ones tolerate what might otherwise feel like hurtful accusations. However, they must take care not to disregard criticism that may be warranted by attributing them solely to an emotional stage.

Bargaining typically manifests as patients seeking some measure of control over their illness. The negotiation could be verbalized or internal and could be medical, social, or religious. The patients' proffered bargains could be rational, such as a commitment to adhere to treatment recommendations or accept help from their caregivers, or could represent more magical thinking, such as efforts to appease misattributed guilt they may feel is responsible for their diagnosis. While bargaining may mobilize more active participation from patients, health care providers and caregivers should take care not to mislead patients about their own power to fulfill the patients' negotiations. Again, caregivers and providers do not need to repeatedly correct bargaining behavior that seems irrational but should recognize that participating too heartily in a patient's bargains may distort their eventual understanding.

Depression is perhaps the most immediately understandable of Kubler-Ross's stages, and patients experience it with unsurprising symptoms such as sadness, fatigue, and anhedonia. Spending time in the first three stages is potentially an unconscious effort to protect oneself from this emotional pain. While the patient's actions may potentially be easier to understand, they may be more jarring in juxtaposition to behaviors arising from the first three stages. Consequently, caregivers may need to make a conscious effort to restore compassion that may have waned while caring for patients progressing through the first three stages.

Acceptance describes recognizing the reality of a difficult diagnosis while no longer protesting or struggling against it. Patients may focus on enjoying the time they have left and reflecting on their memories. They may begin to prepare for death practically by planning their funeral or helping to provide financially or emotionally for their loved ones. It is often portrayed as the last of Kubler-Ross's stages and a sort of goal of the dying or grieving process. While caregivers and providers may find this stage less emotionally taxing, it is important to remember that it is not inherently more healthy than the other stages. As with denial, anger, bargaining, and depression, understanding the stages has less to do with promoting a fixed progression and more to do with anticipating patients' experiences to allow more empathy and support for whatever they go through.

Criticisms of the Kubler-Ross Model

The DABDA model has been increasingly criticized in recent years. The model has both historical and cultural significance as one of the most well-known models for understanding grief and loss. Many alternative models have been developed based at least in part on the original DABDA model. The principal criticisms of Kubler-Ross's stages of death and dying are that the stages were developed without sufficient evidence and are often applied too strictly. Kubler-Ross and her collaborators developed their ideas qualitatively through in-depth interviews with over two hundred terminally ill patients.

Critics have focused on the fact that her research and use of "stages" have not been empirically validated. It is also said that the concept of "stages" is applied too rigidly and linearly. Instead, she aimed to describe a set of behaviors and emotions that may be experienced by a patient facing the end of life, and by describing them, improve understanding for both the patient and caregivers. Another important criticism of the model arises when it is viewed as prescriptive rather than descriptive, indicating that a patient must move through each stage to reach the final goal of "acceptance." This view holds many assumptions, including that progression through the stages is linear and that some stages are inherently less adaptive than others. Caregivers may view their job as helping a patient move through each stage, for example, moving through denial or anger onto more easily palatable stages such as bargaining or acceptance. Attempting to push the patient through the stages has the potential to cause harm, as they need to process their grief in their unique way. Dr. Kubler Ross and others have reminded readers that many patients will experience the stages fluidly, often exhibiting more than one at a time and moving between them in a non-linear fashion. It is also important to note that each stage can serve a protective role, and each patient will have a unique experience in their grief process.

Other Models of Grief

Bowlby and Parkes' Four Phases of Grief

Bowlby and Parkes proposed a reformulated theory of grief based in the 1980s. Their work is based on Kubler-Ross's model and describes four phases of grief. It emphasizes that the grieving process is not linear.

Shock and Disbelief - The initial phase replaced the term "denial" due to negative connotations. In this phase, the reality becomes altered as the mind responds to a stressful situation by becoming unresponsive or numb to the new situation. Over time, the mind processes the new reality, and the patient moves to a new phase.

Searching and Yearning - This phase is closely related to the Anger and Bargaining stage of the DABDA model. The patient will attempt to undo the new reality and question the reason for it.

Disorganization and Repair - This phase closely relates to the Depression stage of the DABDA model. The patient experiences full acceptance of the new reality. They show signs of depression and apathy.

Rebuilding and Healing - In this phase, the patient experiences a "renewed sense of identity," which represents overcoming the sense of loss and beginning to feel in control of their destiny. They no longer show signs of depression.

Worden's Four Basic Tasks In Adapting To Loss

Worden's model of grief does not rely on stages but instead notes that the patient must complete four tasks to complete bereavement. These tasks do not occur in any specific order. The grieving person may work on a task intermittently until it is complete. This model applies to the grief of a survivor but may also be applied to a patient facing death.

Accepting Reality of Loss - Initially, the patient may have difficulty accepting the reality of impending death. Typically, acceptance is viewed as being ready to move forward with the process of preparing for death.

Experiencing Pain of Grief - Patients may feel sadness, anger, or confusion. They are experiencing the pain of loss. The task is completed as the patient begins to feel "normal" again.

Adjusting to Environment - An all-consuming focus on impending death will cause the patient to ignore other roles in life that are important to them. The patient will typically resume daily activities such as restarting work or hobbies or becoming engaged as a spouse or parent to complete this task.

Redirecting Emotional Energy - This task is generally applicable to grieving survivors. Survivors redirect their emotional energy from suffering the loss of a loved one to engaging in new activities that bring pleasure and new experiences. Subsequent theories on grieving have transitioned from stages and tasks of grief to more experiential and narrative methods.

Wolfelt's Companionship Approach to Grieving

Wolfelt's companionship approach views grief as a natural extension of the ability to give and receive love. As such, grief is not something to avoid but should be fully experienced and even embraced in the path to healing. The grieving person must feel their grief and learn to incorporate it into their ongoing lives. A person supporting the bereaved serves as a witness and companion alongside the bereaved as they walk through their grief journey. Wolfelt states, "Companionship is about going to the wilderness of the soul with another human being; it is not about thinking you are responsible for finding the way out."

There are no tasks to complete, and no focus is placed on "fixing" the grief. However, he does describe six "needs of grief" or mourning that are more experiential. He acknowledges the need for grief to be both experienced and expressed, confronting the reality of the loss in tolerable doses. The bereaved must lean into or embrace the pain of the loss while focusing on self-compassion and self-care. He includes a narrative component as the bereaved transition their relationship with the departed from one of presence to one of memory and the need to explore their new identity in living without their lost beloved. They find a sense of meaning or peace with the loss and possibly confront their spiritual beliefs and framework while doing so. They also need to explore the positive aspects of their new identity after the loss. Finally, he also stresses the need to develop a support system that will encourage the bereaved toward self-compassion as grief resurges over the coming months and years.

Neimeyer's Narrative and Constructivist Model

Neimeyer views grieving as a process of meaning-making. He acknowledges that people co-construct their understanding of reality through a narrative of their own life stories, influenced by their beliefs and world views. He describes "six key realities influenced by death." In these six realities, he acknowledges that significant loss can validate or invalidate a person's framework and beliefs in life. It may require developing a new framework to heal and incorporate the loss into their worldview. Grief is simultaneously universal and unique, so the therapy for the bereaved must be tailored to each client's individual needs. The process of grieving is inherently an active rather than passive period, filled with decision-making and reconstruction both practically and existentially.

Emotions during the grieving period are useful and can serve as guides in the process of reconstructing a sense of balance and meaning in life after the disruption caused by significant loss. Reconstructing an identity after a significant loss is an inherently social process, as the new identity is in part defined in relation to their community and social norms. And finally, adapting to loss involves finding a way to incorporate the loss into a new identity and self-narrative, giving the loss a sense of meaning, and making sense of the changes. This can enable not only survival after a loss but eventual thriving.

Therapists using the narrative and constructivist model may have patients re-tell the story of their loss with visual aids exploring the thoughts and feelings that accompany the story. They may also suggest writing a goodbye letter to the deceased or exploring their feelings through metaphors.

Clinical Significance

The transition in care, from attempting to heal the patient to caring for them near death, can be difficult for everyone involved. Healthcare providers sometimes feel as if "their job is done" as they can no longer heal the patient and "drop out" of the patient's care. This can lead patients, and their loved ones, to feel they are being abandoned as they near death. They often wish for guidance on the complex changes that the patient is going through emotionally and physically. Actions that are a normal part of the dying process, such as anger and refusing visitors, can leave loved ones confused and upset. Understanding the stages of grief allows providers to give support and guidance during the dying process. The explanations provided by medical caregivers hold particular importance for patients and family members as they seek to understand and subsequently make sense of terminal illness. These key moments of communication and connection can be pivotal in the process of making sense of and healing from significant loss. Facility with the grieving process is also imperative for the healing and resiliency of medical caregivers as they navigate through grief alongside their patients.

Enhancing Healthcare Team Outcomes

For the healthcare team, caring for patients near death can be uniquely challenging for everyone involved. Healthcare providers sometimes feel as if "their job is done" as they can no longer heal the patient and "drop out" of the patient's care. This can lead to patients and their loved ones feeling abandoned by the healthcare team as they near death. They often wish for guidance emotionally and physically. This is where an end-of-life interdisciplinary team can be very helpful. Physicians can provide clarity on diagnostic and prognostic information. Pharmacists participate by dispensing appropriate comfort medication in a timely fashion by working directly with the nursing staff. Hospice care providers, including social workers and nursing staff, can provide counsel, administer comfort care, deliver emotional support, and empathize with both the patient and the family. The healthcare team should possess an understanding of the models for grief, which allows providers to give support and guidance during the dying process and provides a coordinated effort to provide the patient and family with much-needed emotional support.