Death and Dying during COVID-19

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Four Common Trajectories of Death

- Sudden death
- Terminal illness: Certain kinds of cancer, in which people maintain high functional status that rapidly declines
- Organ failure: Chronic obstructive pulmonary disease, congestive heart failure. Gradually decreasing functional ability.
- Frailty: Slow decline of functional ability (e.g., Alzheimer's disease). (Lunney, Lynn, & Hogan, 2002)
- COVID-19 is NOT a common trajectory for death

Lunney, J. R., Lynn, J., & Hogan, C. (2002). Profiles of older Medicare decedents. *Journal of the American Geriatrics Society, 50*(6), 1108–1112. doi:10.1046/j.1532-5415.2002.50268.x

Understanding Death

- Familial, societal, and cultural norms provide the context for understanding the how, when, and where of our deaths as well as our experiences of bereavement and grief.
- We know that each person and family prepares for death and experiences it differently.
- During COVID-19, how pastors, medical personnel, health care clinicians, and public health workers are able to care for those who are ill or dying is compromised. This affects families, loved ones, friends, community survivors and care providers.

Loss of the Assumptive World (LAW)

- LAW is a theory of traumatic loss. Our assumptive world are our core beliefs that "…ground, secure, stabilize, and orient". In the face of COVID-19 illness and deaths, these beliefs are shattered.
- Most people assume three inherent assumptions: 1. overall benevolence of the world, 2. meaningfulness of the world, and 3. self worth (Janoff-Bulman, 1992).
- We are collectively experiencing anticipatory grief and are each becoming survivors of loss. This grief is occurring on a micro and macro level and touches everyone.

Loss of the Assumptive World

- Collectively experiencing COVID-19 changes how we view ourselves and interact with the world.
- The situation is worse when the enemy is something invisible that is destroying our basic sense of safety and quality of life.
- We are mourning the loss of our future and uncertain about what the new normal will be in the months to come.
- COVID-19 has shattered our core assumptions, and coping involves rebuilding a viable assumptive world.

Attitudes Toward Death (cont'd)

- Kübler-Ross's *On Death and Dying* (1969) proposed five stages people have before death: denial, anger, bargaining, depression, and acceptance.
- Some researchers have recently proposed a sixth stage: anxiety.
- However, when large numbers of people are ill and dying from a highly infectious disease, these stages and their potential supports (i.e., religious, psychological, social, etc.) are disrupted.

Kübler-Ross, E. (1969). *On death and dying*. New York, NY: Macmillian.

Disruptions to Bereavement and Mourning

- **Grief** is the emotional reaction to bereavement (the situation of loss and dealing with a death of a significant person). Grief includes behavioral, physical, cognitive, and social expressions.
- **Mourning** is the "Social expressions or acts expressive of grief that are shaped by the practices of a given society or cultural group" (Stroebe et al., 2001, p. 6)
- COVID-19 prevents people from saying goodbye to their love ones.
- Large numbers of ill and dying people adversely affect the ability of medical providers, clergy, mental health clinicians, and public health workers to support distressed survivors.

Psychological Reactions to Bereavement

- **Affective:** Depression, despair, anxiety, guilt, anger, anhedonia, and loneliness.
- **Behavioral:** Agitation, crying, lethargy, social withdrawal
- **Cognitive:** Thoughts of the deceased, decreased self-esteem, self-reproach, helplessness, sense of unreality, decreased memory and concentration.
- **Physical:** Loss of appetite, disturbed sleep, loss of energy, physical complaints similar to those of the deceased, susceptibility to illness.
- **Spiritual:** Change in participation in religious activities, sense of anger or betrayal, deepening religious/spiritual beliefs.

Persistent Complex Bereavement Disorder

	Uncomplicated Bereavement	Major Depressive Episode	Posttraumatic Stress Disorder	Persistent Complex Bereavement Disorder
Affect	Sadness, emptiness and loss; can experience positive emotions	Depressed; inability to experience positive emotions; pervasive guilt	Fear; anger; horror; shame; inability to experience positive emotions; guilt focused on the cause or consequences of the traumatic event	Sadness; intense sorrow and emotional pain; guilt focused on interactions with the deceased or circumstances of the death
Intensity	Decreases over days-to-weeks; occurs in waves with increases often associated with reminders of the deceased	Persistent; not necessarily tied to specific triggers	Increases associated with reminders of the traumatic event; usually specific to the event; avoidance of stimuli related to the event	Increases are more pervasive and unexpected; severe symptoms > 12 months; avoidance of situations and people related to reminders of the loss
Thought Content	Preoccupation with thoughts and memories of the deceased	Self-critical; pessimistic rumination	Persistent and exaggerated negative beliefs about oneself, others, or the world	Preoccupation with yearning and longing for the deceased and/or circumstances of the death
Self-esteem	Typically preserved	Worthlessness; self-loathing	May worsen in response to negative beliefs and expectations about oneself	Self-blame; confusion about one's role in life; diminished sense of identity
Thoughts of death	If present, generally focused on the deceased and joining the deceased	Focused on ending one's life because of feeling worthless, undeserving of life, unable to cope	May be associated with reckless or self-destructive behavior	Desire to die to be with the deceased; sense that life is meaningless or empty without the deceased

Persistent Complex Bereavement Disorder

- The inability to mourn introduces the potential for new and extended grief.
- Family and close friends may be disturbed that they were not able to be in the ICU offering love and support at a time when their loved one needed it most.
- If the death of a loved one is also coupled with financial losses (i.e., loss of a job, diminished retirement account), diminished personal freedoms (i.e., travel restrictions), and social distancing, mourning may be complex and protracted.

Bereavement in during COVID-19

- There are new government and medical restrictions rapidly being introduced for public health and safety reasons that impact:
  - Interaction/access to the dying loved one
  - Timing and manner of funerals
- In addition to formal sanctions, not being able to touch, hug, or stand near people who are experiencing a loved one's death is strongly discouraged.
- Physical distancing is difficult for both families and providers of care (i.e., pastors, priests, mental health clinicians, public health workers, etc.)

Persistent Complex Bereavement Disorder

- People who are mourning their loved one may experience additional stress from the planning and coordinating of the funeral and burial services that are not expected.
- People who made final arrangements in advance for a public funeral and burial attended by friends and family may feel a sense of betrayal that is accompanied by additional stress, anger and grief.
- The ability of family, friends and the community to express condolences, providing comfort and honor the life of the person who died is limited to phone, video chats, etc.

Care Providers during COVID-19

- Care providers (i.e., spiritual, mental health, public health, and medical workers) may become overwhelmed and burned out by our inability to deal with a large number of people who are experiencing serious losses and deaths simultaneously.
- We are in uncharted territories when dealing with a collective trauma and mass deaths.
- As professionals, we may feel a loss of identity and purpose by our inability to function and meet these massive demands.

COVID-19

- A decrease in activities (i.e., walking, interacting with others) may result in more alone time and opportunities to think uninterrupted about loss, illness, and death.
- Whether a person's losses are directly related to COVID-19 or occurring during the outbreak, they may not know where to turn for help.
- Without adequate support, people may suffer more than they would under normal circumstances.

Grief work

Reviewing the past, including events at the time of death, focusing on memories, and working toward detachment from the deceased.

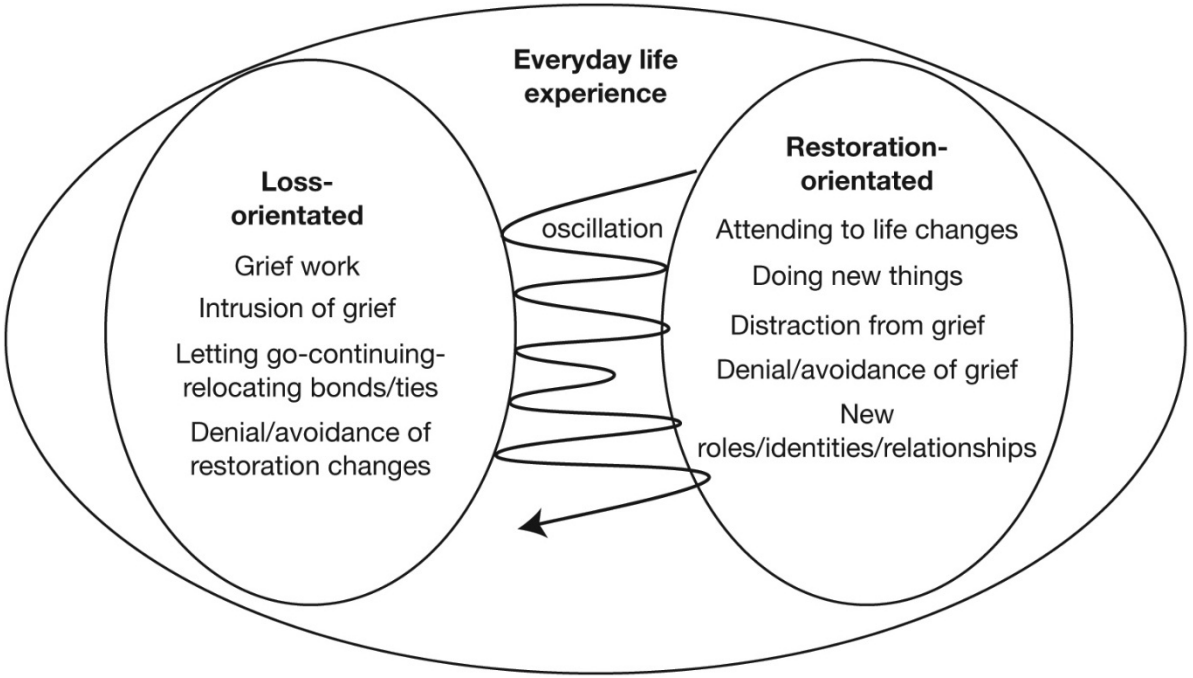

Figure 12.2 The dual process model of coping with bereavement.
Source: Stroebe and Strut (2001).

Stroebe, M. S. & Schut, H. (2001). Models of coping with bereavement: A review. In M. S. Stroebe, R. O. Hansson, W., Stroebe, & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 375–403). Washington, DC: American Psychological Association.

Making Meaning to Heal

- Meaning-making approach emphasizes the story of the death and story of the relationship with the deceased.
- Grief is integrated into a changed self-narrative.
- Continued connection with the deceased is normal and can be maintained through recalling happy memories or having a sense that the deceased person is still present in some way.
- Widowed individuals who made sense of the loss in early bereavement showed higher resilience and well-being 4 years later (Coleman & Neimeyer, 2010).

Coleman, R. A., & Neimeyer, R. A. (2010). Measuring meaning: Searching for and making sense of spousal loss in late-life. *Death Studies, 34*, 804–834. doi:10.1080/07481181003761625

Complicated Grief Therapy

- Complicated grief therapy (CGT) involves processing of traumatic symptoms related to the death, promoting a sense of connection with the deceased loved one, and restoring life in the context of a changed reality.
- CGT has shown improvement in symptoms in randomized controlled trials.