Psychosocial-Spiritual Alberta Series

Complex Grief and Self-Care for the Practitioner

Host and Moderator: Ellen Mi

Facilitator: Sheila Killoran

Presenter: Dr. Noelle Liwski Hanson

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Introductions

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Presenter

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The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness.

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Reminders

- This session is being recorded. A copy of this recording will be made available on the compassionate Alberta ECHO hub page.
- Please do not disclose any personal health information during the session.
- Your microphones are muted. When we invite participation, please unmute yourself if you'd like to speak at that time.
- If you experience technical difficulties, please let us know in the chat.

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Covenant Health Palliative Institute

Complex Grief and Self-Care for the Practitioner

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Adapted from previous presentations by Dr. Kevin St. Arnaud, PhD, RPsych, and Dr. Sarah Burton-MacLeod, MD, CCFP (PC) and Dr. Noëlle Liwski, PhD, RPsych

Land Acknowledgment

- I would like to acknowledge with tremendous respect that we are situated on Treaty 6 territory and a traditional gathering place for diverse Indigenous peoples. In our discussions today about Grief, Self-care and Wellness, I want to honour what we continue to learn from our Indigenous Colleagues about life, death, and wellness. We also learn from each of our patients and, in particular, deeply value the wisdom shared with us by our Indigenous patients and their families. I recognize their willingness to share knowledge with us as being particularly gracious in light of the systemic racism they have faced, including within our healthcare institutions.
- This acknowledgement isn’t an ending; it’s a beginning. I hope we can honour and internalize teachings, connect with others, and contemplate possibilities.

Faculty Disclosures

- I have nothing to disclose, no payment was received for this presentation.

Objectives

1. Describe risk factors associated with compassion fatigue/professional burnout/complicated grief when working in palliative care.
2. Describe some strategies to prevent and reduce professional exhaustion and burnout and to build resilience and psychological flexibility.

“Grief can be the garden of compassion. If you keep your heart open through everything, your pain can become your greatest ally in your life's search for love and wisdom.” *-Rumi*

Normative Grief

- Approximately 80%–90% of bereaved individuals experience normal or uncomplicated grief.

- Acute grief can be highly distressing and disruptive yet ***should not be considered an illness or disorder.***

- Physiological and behavioural manifestations of grief may include:
  - Fatigue
  - Loss of appetite
  - Sleep disturbance
  - Agitation

- Psychological manifestations of grief may include:
  - Anxiety
  - Depressed mood
  - Guilt
  - Anger

(Shear et al., 2011; Waller et al., 2016; Zhang, El-Jawahri, & Prigerson, 2006).

Conceptualizing Grief & Grief-Work

- Concept of ”grief work” was originally coined by Freud.

- With significant loss, part of one’s context for understanding, organizing, and defining the self is lost.

- The symptomatic features of grief reflect this loss of stability and predictability.

- ***Adjusting*** to loss requires grieving individuals to accommodate to the major change in life circumstances.

- Grief-work thus entails slowly changing one’s self-concept to find a new sense of coherence in one’s life.

- High levels of social and emotional support may help to moderate grief by providing the structure and support necessary for ***constructing a new sense of meaning.***

(Fulton, Madden, & Minichiello, 1996).

Psychopathological Responses to Bereavement

- Most bereaved individuals will experience uncomplicated grief and will recover from their loss with time.

- However, as a major stressor, bereavement can prompt the onset or worsening of physical or mental disorders.

- Metaphor: Bereavement as an “injury;” grief as the “inflammation” associated with healing.
  - Just as healing a wound can be hindered by complications, healing from grief may be hampered by complications.

- Major psychopathology associated with bereavement can include:
  - Complicated Grief/Persistent Complex Bereavement Disorder (Prolonged Grief Disorder)
  - Major Depression
  - Post-Traumatic Stress Disorder

Complicated Grief

- A significant minority (~10%) of bereaved individuals will experience disabling and pathological grief.

- Individuals with complicated grief may be viewed as “frozen” in a chronic state of acute grief.

- The major features of abnormal grief, traumatic grief, prolonged grief disorder, and persistent complex bereavement disorder include:

    - Intense yearning and preoccupation with the deceased
    - Disbelief and protest against the reality of death
    - Recurrent pangs of painful emotions, anger, and bitterness
    - Social alienation and isolation.
    - Intrusive thoughts related to the death coupled with avoidance
    - Lack of meaning and interest in life
    - Sense that a part of oneself has died with the deceased

- Complicated grief is associated with prolonged distress and disability, negative health outcomes, and suicidality.

(Prigerson et al., 2009; Shear et al., 2011; Thomas et al., 2013; Waller et al., 2016; Zhang, et al., 2006; Zisook & Shear, 2009).

DSM-5 Prolonged Grief Disorder

March, 2022 Text Revision, Newest Disorder to be added to DSM-5

- An individual with prolonged grief disorder may experience intense longing for the person who has died or preoccupation with thoughts of that person. In children and adolescents, the preoccupation may focus on the circumstances around the death. Additionally, the individual may experience significant distress or problems performing daily activities at home, work, or other important areas. The persistent grief is disabling and affects everyday functioning in a way that typical grieving does not.
- For a diagnosis of prolonged grief disorder, the loss of a loved one had to have occurred at least a year ago for adults, and at least 6 months ago for children and adolescents. In addition, the grieving individual must have experienced at least three of the symptoms below nearly every day for at least the last month prior to the diagnosis.
- Symptoms of prolonged grief disorder (APA, 2022) include:
  - Identity disruption (such as feeling as though part of oneself has died).
  - Marked sense of disbelief about the death.
  - Avoidance of reminders that the person is dead.
  - Intense emotional pain (such as anger, bitterness, sorrow) related to the death.
  - Difficulty with reintegration (such as problems engaging with friends, pursuing interests, planning for the future).
  - Emotional numbness (absence or marked reduction of emotional experience).
  - Feeling that life is meaningless.
  - Intense loneliness (feeling alone or detached from others).
- ***In addition, the person's bereavement lasts longer than might be expected based on social, cultural, or religious norms.***

Prolonged Grief Disorder

- Estimated 7%-10% of bereaved adults will experience the persistent symptoms of prolonged grief disorder (Szuhany et al., 2021).

- Among children and adolescents who have lost a loved one, approximately 5%-10% will experience depression, posttraumatic stress disorder (PTSD), and/or prolonged grief disorder following bereavement (Melhem et al., 2013).

Normal Grief vs. Major Depression

Shared Features:
- Intense sadness
- Insomnia
- Poor appetite or weight loss

Normal Grief:
- Painful feelings in waves interspersed with positive emotions; in time these waves spread apart and decrease in intensity
- Self-esteem is usually preserved
- Emptiness and loss
- Rumination about the deceased

Depression:
- Mood and thoughts are almost entirely negative
- Feelings of worthlessness and self-loathing
- Persistent, pervasive sadness
- Generalized self-critical and pessimistic rumination

- "Bereavement Exclusion" removed in DSM-5
  - One may experience normal grief *and* be diagnosable with MDD

Bereavement-Related PTSD

- When confronted with stressors that disrupt our assumptions, worldview, or identity, this can result in trauma.
- Diagnosis with a terminal condition, hearing of a loved one's terminal condition, or the death of a loved one can be traumatic.
- Estimated PTSD is present in 12%–27% of bereaved individuals.

- **Complicated Grief/PGD:**
  - Intense yearning for the deceased
  - Intrusive images/preoccupation with the deceased
  - Avoidance behaviour
  - Estrangement and mistrust of others
  - Concerns about interpersonal abandonment

- **PTSD:**
  - Fear
  - Intrusive thoughts/images of the trauma
  - Avoidance of fear-inducing stimuli
  - Fears of violence or harm to self or significant others
  - Hyper-vigilance triggered by a sense of impending threat

*Traumatic or violent losses may incur symptoms of both PGD and PTSD.

(Rogalla, 2018; Shear et al., 2011; Waller et al., 2016; Zhang, El-Jawahri, & Prigerson, 2006).

How does grief work affect the practitioner?

- **Burnout:** "When work demands outstrip personal resources"
  - WHO: 'chronic workplace stress that has not been successfully managed. (Burn-out an "occupational phenomenon": International Classification of Diseases (who.int))
    - Associated with feelings of hopelessness and feeling ineffective doing your job and coping with work, emotional exhaustion, cynicism; loss of meaning in the work.
    - Often an insidious process (Horn and Johnston, 2020)

- **Compassion Fatigue:** "The negative aspect of helping those who experience traumatic stress and suffering" (Stamm, 2010).
  - Unique to helping professions, can include work-related trauma (primary or secondary)" (can still work, but compromised).
  - "Exhaustion that results from prolonged exposure to compassion stress among those who work in a caring profession" (Bageas, Davis, & Copnell, 2021).

Compassion Fatigue in Palliative Care

- “Working on the edge between life and death cultivates an acute awareness of the fragility of life”
- Exposure to death, trauma (primary and secondary)
- Feeling grief, sadness, guilt
- Hard conversations with intense emotions with dying patients and families
- Working with younger adults can be hard
  - Identifying more closely
  - More tragic

Signs of burnout in health professionals

- Worsening mental and physical health
- More errors, lower quality of patient care
- Less empathy
- Reduced patient satisfaction
- More absenteeism
- Retention affected negatively.

(Panagioti et. al 2018, Wang, et. al. 2020)

Risk factors for Burnout in Palliative Care

- Poor sleep, nutrition, lack of exercise
- Trying to do too much, excessive workload
- Lack of rewards, encouragement
- Not setting and keeping boundaries
- “Powering through” rather than taking breaks
- Internalizing problems “what is wrong with me?”
- Overthinking
- Perfectionism
- Lack of meaning in work
- Lack of support

(Back et al., 2016)

Working in Palliative Care: The Reward

Compassion Satisfaction: “The positive aspect of helping” (Stamm, 2010).

- Feeling pleasure in helping others through your work (Bageas, Davis, & Copnell, 2021).
- Compassion ‘occurs when caregivers are empathetic, while also demonstrating a sincere desire to reduce the patient’s suffering.’ (Horn and Johnston, 2020)

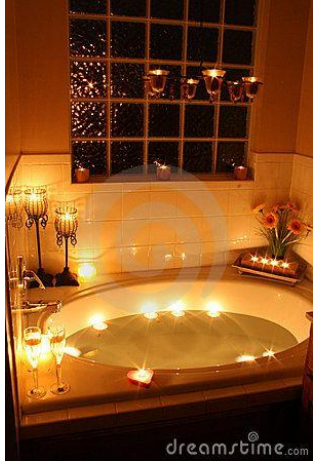
Protective factors working in palliative care

- Working exclusively in palliative care
- Being spiritual
- Working with more colleagues
- Having time to spend with patients and families
- Coping strategies and a sense of understanding when facing a patient’s death
- Effective communication
- Personal enrichment
- Personal gratification
- Professional satisfaction

(Peirera et. al., 2011; Wang et. al., 2020; Gomez-Urquiza et. al, 2022)

“…but by concentrating on the welfare of others, you also make yourself happier. Compassion diminishes fears about your own pain and increases your inner strength. It gives you a sense of empowerment, of being able to accomplish your tasks. It lends encouragement.” ~ Dalai Lama (in *How to be Compassionate*, 2011)

“Self-care” and Professional Wellness



- **Definition of self-care: Building a life you don’t always want to escape from**
  - More than just bubble baths, chocolate and massages (but those are nice ☺)
  - New research (Flemming, 2024) that individual-focused corporate wellness programs (e.g., mindfulness, relaxation, resilience training, yoga programs) don’t help improve worker wellbeing
  - Corporate well-being initiatives often aren't engaging with the root causes of work stress – workplace factors
  - Palliative Medicine Resident Wellness Program

- **Attending to basic personal wellness**
  - Sleep, nutrition, exercise/movement/activity
  - Knowing and setting limits – 2 personal examples

- **Workplace support**
  - Looking out for each other, checking-in
  - Allowing time and space to grieve, taking time off, wellness days
  - Promoting psychological safety in the workplace; Helping reframe blame
  - Making time to process together, buddy programs, mentorship, support offerings

Resilience, Psychological Flexibility, and Grit

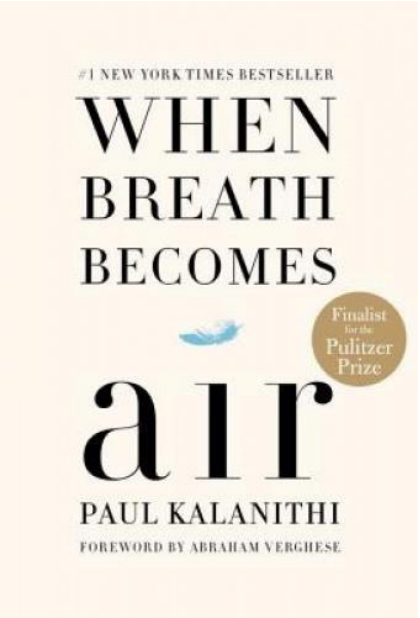
- **Brief Resilience Scale**
  - “I tend to bounce back quickly after hard times.”

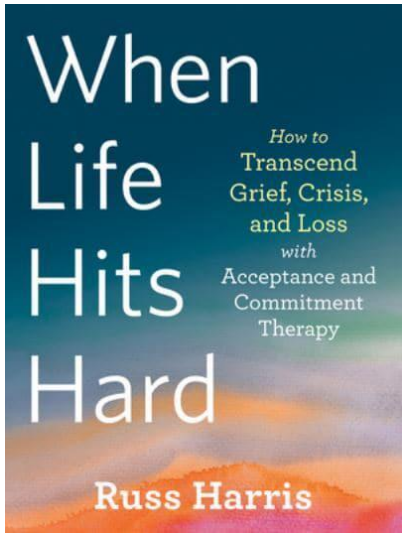
- **Psychological Flexibility**
  - Beyond resilience/bouncing back - continuing to move forward living your values

- **Grit Scale:** https://angeladuckworth.com/grit-scale/
  - “Setbacks don’t discourage me. I don’t give up

Some Good Reads

- *It's Okay That You're Not Okay* by Megan Devine, Psychologist
  - Grief Support Website: refugeingrief.com
- *Dying Well* by Ira Byock, MD
- *Being Mortal* by Atul Gawande, Surgeon
- *Being with Dying* by Joan Halifax
- *At the Will of the Body* by Arthur W. Frank
- *When Breath Becomes Air* by Paul Kalanithi, MD
- *Mourning Has Broken* by Erin Davis, Canadian radio broadcaster's personal story of tragic loss and healing
- *When Life Hits Hard: How to Transcend Grief, Crisis, and Loss with Acceptance and Commitment Therapy* by Russ Harris, MD
- ***Liwski Hanson**, N. T. (2022). Challenges and rewards of working in palliative care. The CAP Monitor, Winter/Issue 72, 30-33.*





Breakout Room Reflection Questions for Discussion

1. What are some potential barriers to self-care, taking breaks, asking for help?

2. Reflect on your own professional and personal needs, and discuss what helps you grieve and be able to keep going in this work?

3. Why do you do this challenging work?

Coming up: Psychosocial-Spiritual Alberta Series

Session 4: Exploring the Benefits of Music in Grief and Pediatric Palliative Care

Certified music therapists at the Alberta Children's Hospital share their experiences and provide insights on the use of music in environments of grief & pediatric palliative care.

- Presenters: Marc Houde, MTA MMT and Sarah Van Peteghen, MTA, BMT
- Join us on **March 21st, 2024**
- If you haven't already, register here: https://compassionatealberta.ca/echo-hub

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Evaluation

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Thank You

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