Complicated Grief in the COVID-19 Era

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Speaker Bios

Kenneth J. Doka, PhD, MDiv, is Board Certified. Conducted the 2011 Lifetime Achievement Award from the Association for Death Education and Counseling to Dr. Kenneth J. Doka, a past president of ADEC. He is the author of more than 300 articles, books, and book chapters on grief and loss. In 2011, he was named the Distinguished Lecturer by the American Counseling Association (ACA) and the American Psychological Association (APA) of the International Work Group on Death, Dying, and Bereavement (IWGD). In 2013, the IWGD presented him with the IWGD Honorary/Methodological Award for contributions to the field of complicated grief.

Robert A. Neimeyer, PhD, is Professor Emeritus of the Department of Psychology at the University of South Carolina. He is the author of over 170 books, articles, and book chapters on grief and loss. His research focuses on the experience of grief and the impact of loss on mental health. He is also the Director of the Center for Loss and Grief Studies at the University of South Carolina.

Leah McDonald, MD, is a Senior Fellow in Hospice and Palliative Medicine at Hope Health. She is an Associate Professor of Medicine at Brown University. She is the author of several books and has written extensively on the topic of complicated grief.

Questions to Consider

- What is complicated grief?
- How does the COVID-19 pandemic complicate grief?
- How can we help individuals cope with the anxiety and losses associated with the disease?
- Is posttraumatic growth possible?
Complicated Grief

Estimates show between 20% to 33% of people are at risk for such a reaction.

Perhaps 10% to 20% exhibit it.

What is Complicated Grief?

A generic term indicating that, given the amount of time since the death, there is some compromise, distortion, or failure of one or more of the processes of mourning.

(Rando, 1993)

Complicated Grief

A clinically significant deviation from the cultural norm in either (a) the time or intensity of specific or general symptoms of grief and/or (b) the level of impairment in social, occupational, or other important areas of functioning.

(Stroebe, Hansson, Schut, & Stroebe, 2008)
Complicated Grief
Shear and Associates

Acute Grief

Integrated Grief

Complicated Grief

How Can we Classify Complicated Mourning?

Worden's Complicated Grief Syndromes

- Chronic
- Exaggerated
- Masked
- Delayed
Complications of Grief Acknowledged in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)

Complications of grief can include:
- Adjustment Disorder Related to Bereavement
- Separation Anxiety Disorder
- Major Depressive Disorder (MDD) (Note: the DSM-5 attempts to carefully differentiate grief from MDD)
- Prolonged Grief Disorder (Presently the American Psychiatric Association is considering comments prior to proposal to add the diagnosis)
- Posttraumatic Stress Disorder (PTSD)
- Increase in physical mortality, including suicide
- Increase in physical and mental morbidity

(Parkes & Prigerson, 2010)

What Complicates Deaths During the COVID-19 Pandemic?

Grief in the COVID-19 Pandemic

Grief and COVID-19 Deaths

- Complicated grief likely
- Deaths often relatively sudden and unexpected
- Minimal visits to patients
- Contagious nature of disease and the issue of survivor and/or death causation guilt
- Possible stigma
Grief in the COVID-19 Pandemic

Non COVID-19 Deaths

- The disenfranchisement of non COVID-19 deaths
- Lack of physical presence and limits to funeral rituals
- Anger, including cosmic anger, as a likely component of grief
- Subsequent treatment of complicated grief

Grief in the COVID-19 Pandemic

Non-Death Losses

Non-death losses are often disenfranchised and can be a complicating factor to complicated grief.

In the COVID-19 pandemic, such losses are extensive:

- Loss of employment and income
- Loss of educational opportunities
- Loss of freedom and social movement
- Loss of collective gatherings (sporting events, entertainment, graduations, proms)
- Loss of routine and connection

Complicated Grief in Medical, Mental Health, and Spiritual Care Staff

- The Stockholm Syndrome in end-of-life care
- Caregiver losses can be extensive; loss of relationship with patient, family, unmet goals
- Moral distress in staff and feelings of helplessness (especially in supportive staff, clergy, and volunteers who are inhibited from normal practice)
- Papadatou’s Dual Process of Caregiver Grief: Oscillating between experiencing and containing grief (burnout v. detachment)
Complicated Grief & COVID-19

Robert A. Neimeyer, PhD
Professor Emeritus, University of Memphis
Director, Portland Institute for Loss and Transition

Coronavirus Anxiety

• Measurement
• Correlates
• Mediators
• Interventions

Coronavirus Anxiety Scale (CAS)

• 775 diverse US adults assessed from March 11-13, 2020
• 20 candidate items from anxiety literature in cognitive, behavioral, emotional and physiological domains
• Rated on Likert scale from 0 (not at all) to 4 (nearly every day)
• Results subjected to PCA and CFA, validity tests and ROC analysis
• Final scale correlated with range of symptoms and attitudinal self-reports

Sherman A. Lee, Ph.D.
Christopher Newport University
Death Studies, 2020
How often have you experienced the following activities over the last 2 weeks?

<table>
<thead>
<tr>
<th>Activity</th>
<th>Not at all</th>
<th>Rare, less than a day or two</th>
<th>Several days</th>
<th>More than 7 days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I felt dizzy, lightheaded, or faint, when I read or listened to news about the coronavirus.</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>2. I had trouble falling or staying asleep because I was thinking about the coronavirus.</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>3. I felt paralyzed or frozen when I thought about or was exposed to information about the coronavirus.</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>4. I lost interest in eating when I thought about or was exposed to information about the coronavirus.</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>5. I felt nauseous or had stomach problems when I thought about or was exposed to information about the coronavirus.</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

*Coronavirus Anxiety Scale (CAS)*

Sharon A. Lee, Ph.D.
Christopher Newport University

Death Studies, 2020

A CAS score ≥ 9 optimally classified adults as having (90% sensitivity) or not having (85% specificity) dysfunctional levels of anxiety (Youden's index of 75) with a false positive rate of 15%.

Coronavirus Anxiety Scale (CAS)

Sherman A. Lee, Ph.D.
Christopher Newport University

Symptoms Associated with Coronavirus Anxiety

CAS correlated .86 with Impairment in Work and Social Adjustment

Social Isolation and Coronavirus Anxiety

Jane Milman, PhD
Medical University of South Carolina
St. Edwards University, Austin, Texas

- Assessed use of social mitigation procedures and its relation to Coronavirus Anxiety (CA) in 408 American adults
- Sociodemographic variables (gender, age) and pandemic stressors (loss of employment, decreased income, loss of child care) unrelated to CA
- Examined meaning-making as a mechanism accounting for relation of social practices to CA
CAS Scores as a Function of Social Mitigation Behavior

- Social isolation measures decrease Coronavirus anxiety by minimizing effect of the pandemic on the people’s assumptive world—their core beliefs regarding controllability and predictability of life.

- Those who sheltered in place and ceased long-distance travel reported less belief violation, which in turn seemed to buffer their physiological anxiety about the pandemic.

Social Mitigation Behavior by Category

From Assessment to Intervention

Target physiological arousal, emotion regulation, social isolation through:

- Psycho-education about buffering effect of social mitigation practices
- Progressive muscle relaxation
- Controlled breathing, yoga
- Mindfulness-Based Stress Reduction
- “Time out” from exposure
- Physical exercise, Tai Qi
- Sleep hygiene
- Building virtual “communities of care”
- Somatic and art therapy approaches as possible bridge to symbolizing and verbalizing the unspeakable

For Whom the Bell Tolls: COVID-19 Infections
The Demography of Death

- Use demographic microsimulation to estimate parental and grandparental mortality in Americans under conditions of 10, 20, and 40% infection rates.
- Account for clustering of deaths within families given transmissible nature of Coronavirus.
- Report that “these models imply the potential for hundreds of thousands to millions of deaths... which would in turn lead to an even higher burden of bereavement.”

The Coming Tsunami

- “The COVID-19 pandemic may lead to enormous loss of life in the United States. The collateral damage that this level of mortality would exact on American families cannot be overlooked. It is important that the burden of bereavement, and its potential mental and physical health consequences, is factored into discussions of the public health challenges facing all nations.”
- NB: excludes all other COVID deaths, as of partners, siblings, children, and friends.
Guidelines for Working with End of Life

- **Speak truth:** Encourage candor about the illness
- **Connect visually:** Show up in image as well as voice
- **Build legacy:** Invite stories of a lifetime
- **Share memories:** Convey appreciation, humor, love
- **Review photos:** Celebrate high points and acknowledge low points
- **Solicit counsel:** Request “words of wisdom” or “life lessons” for family
- **Write letters:** Take dictation to share with specific others
- **Make meaning:** Explore what has significance now

**Unfinished Business**
Klingspon, Holland, Neimeyer & Lichtenthal
Death Studies

- Incomplete, unexpressed, unresolved relationship issues with deceased
- Studied in narratives of 224 adults bereaved of a variety of relationships
- Unfinished business reported by 43% of sample
Taxonomy of Unfinished Business

Unfinished Business

Statements of Admiration & Value
  - Recognition
  - Declaration of Love
  - Declaration of Love of Work

Missed Opportunities & Intentions
  - Patient's Death
  - Unfulfilled Plans
  - Unexplained Deaths

Unresolved Confessions & Disclosures
  - Decedent's Obedience
  - Decedent's Length of Death

Recognition of Deceased's Worth

Declaration of Love

Missed Connections

Future Absence

Unresolved Disconnections

Unfulfilled Plans

Untimely Goodbyes

Need to Apologize

Secrets & Speculations

Extending Forgiveness & Lack of Closure

More common in immediate family relationships and sudden, tragic death

Controlling for age, gender, race, education, relationship to deceased, cause of death and time, distress about UB uniquely associated with:

- More complicated grief on the ICG-R
- Less meaning made of the death on the ISLES
- More intense continuing bonds on the CBS
- Type of unfinished business unrelated to bereavement outcome

Guidelines for Working with Bereavement

- Share
- Honor
- Change
- Meaning
- Ritual
- Strength
- Journal
Guidelines for Working with Bereavement

- Speak their names: Encourage conversations about loved ones
- Keep a journal: Shift between expression and reflection
- Share grief: Connect with others in family or online group
- Review photos: Celebrate high points, acknowledge low points
- Reconstruct legacy: Keep the loved one’s stories alive
- Review resilience: Explore strengths and success over adversity
- Live in the now: Slow down into the present moment
- Conduct rituals: Symbolically honor loved one as well as personal change
- Make meaning: Explore what has significance now

Unfinished Business in Bereavement Scale

- Unfulfilled wishes: Unspoken affirmations and missed opportunities
- Unresolved Contact: Unresolved disputes or indiscretions
- With meaning made of loss predicted 50-60% of PDQ

Grief Therapy as Meaning Reconstruction

- Recalling the Death Narrative
- Directed Journaing
- Analogical Listening
- Chapters of Our Lives
- Virtual Dream Stories
- Introducing the Loved One
- Correspondence with the Deceased
- Imaginal Dialogues, Chair Work
- Legacy Project
- Life Imprint

28 items rated on 5-point scales of distress over past month, e.g.:
- I wish I had told ___ how much she meant to me.
- I wish I had been there when ___ died.
- I should have been there when ___ died.
- I held onto a secret that I wish I had told ___.
- I wish I had told the choice to tell ___ that I forgive him/her.
- I never got to resolve a breach in our relationship.
Can the Pandemic Lead to Posttraumatic Growth?

 Significant or Traumatic Loss

- Significant or traumatic losses are seismic events that not only cause emotional distress but challenge beliefs, goals, and one’s sense of personal narrative.
- Life is now divided into before and after the event.
  (Calhoun & Tedeschi)
Past Pandemics

Past pandemics have created a wide variety of both positive and negative impacts on societies:

- The Black Death led to the first quarantines as sailors in Venice were kept on ships 40 days after landing.
- As the plague was perceived as divine punishment, theology became far more judgmental in tone.
- Marginal groups were often blamed for and persecuted because of the plague.
- It sounded a death knell for feudalism in Western Europe.
- The plague and pandemics of other diseases gave impetus to the development of medical care, sanitation services, social improvements, and other advances.

Possible Changes

- Changes in lifestyle
- Greater appreciation of life, relationships, and priorities
- Growth in character; Perceptions of strength
- Existential awareness
- Growth in skills
- Renewed spirituality

(Cahoun & Tedeschi)

Post-Pandemic Implications

- How will it change caring for the dying and bereaved?
- Will it lead to new ways to support medical, mental health, and spiritual professionals?
- Will we rethink rituals for bedside and funerals?
A Final Word

The world breaks everyone and afterward, many are stronger at these broken places

• Hemingway, A Farewell to Arms

Complicated Grief in the COVID-19 Era

One Clinician’s View

Leah McDonald, MD
Clinical Fellow in Hospice and Palliative Medicine at Brown University and HopeHealth

Case 1

Pre-COVID-19
Patient MS

- 72F with a history of HTN and DM admitted to the surgical ICU after presenting as a restrained passenger in an MVC resulting in multiple rib fractures, a pneumothorax, and a pelvic fracture
- Hospital course c/b acute hypoxic respiratory failure requiring intubation
- Palliative care consulted on hospital day 7 to discuss goals of care

Circumstances of the MVC
- Adult daughter with whom MS lived was driving the car
- She also endured non-life-threatening injuries including a fractured radius

Prior to the collision
- MS had been highly functional
- Her daughter took her to get her hair done the week prior to the crash

Family meeting
- Family discussed loss of other family members due to tragic events
- Daughter admits to feelings of guilt and struggle with seeing life without her mother
- Conclusion was a time-limited trial of critical care for 3 more days

Family meeting (Part 2)
- MS remained on high ventilator support and unresponsive
- Family opted for palliative extubation with family at bedside
Key Features

- Risk factors for complicated grief:
  - Sudden event
  - Anxious attachment
  - Unfinished business (need to apologize)

- Our ability to help mitigate:
  - Discussions of guilt and lack of control
  - Ability for family at bedside over a limited trial
  - Role of support from extended family

Case 2

COVID-19 Era: Those Infected

Patient EF

- 62M with COPD admitted to the hospital with acute respiratory distress requiring increased supplemental O2. Found to be COVID positive and admitted for further monitoring and treatment.
- Palliative care consulted on hospital day 6 after EF's oxygen requirement increased to 15L HFNC to discuss goals of care.
• EF discussed living with COPD
  • Challenges of an underlying progressive disease

• He reminisced about his wife
  • He had dated her in his 20s and ended up married to another woman
  • Both met years later and rekindled a relationship and ended up married
  • Both had children from previous marriages and his stepchildren had become like children to him
  • Now his wife had Alzheimer’s dementia and he visited her every day in her assisted living facility but they lived apart

• As he saw he was getting worse, we discussed poor prognosis. We included his stepdaughter and HCP over the phone in discussions.
  • Knowing time was short, his goal was to see his family for whatever time was left
  • Decided to transition to inpatient hospice

• Logistics:
  • How to allow his wife to see him
  • Would she be allowed back to her assisted living facility?
  • His children from across the country were not that close to him but wanted to see him at end of life
  • His stepchildren’s kids saw him as a grandfather and he wanted to leave them handwritten notes
• Patient awaiting inpatient hospice evaluation, became acutely ill and passed away prior to seeing family

Key Features

• Risk factors for complicated grief:
  • Family case: EF as relatively healthy and then acutely ill
  • Missed opportunities — daughter was unable to get him to see his wife
  • Future absence — his wife had relied on husband’s daily presence and her dementia made it difficult to understand why he stopped coming

• Our ability to help mitigate:
  • Social worker helped him to sign notes typewritten by his daughter (leaving a legacy)
  • Nurses assisted with Zoom calls

• Challenges to our usual abilities:
  • Visitor restrictions
  • Rapid progression of symptoms leading to unfinished business

Case 3

COVID-19 Era:
The “Bystanders”
Patient RB

- 62M with HTN and CAD s/p stents admitted to the hospital for altered mental status and found to have a large SAH due to a ruptured aneurysm
- RB became unresponsive requiring intubation for airway protection
- No family at bedside due to COVID-19

Circumstances of the collapse
- RB was living with his mother. His wife was a nurse on a COVID-19 unit, so they had decided to live separately for a few weeks to avoid possible infection.
- His mother found him unresponsive in her house and started CPR. His mother also lost her husband unexpectedly at the same home.

Neurosurgery unable to offer surgical intervention
- Remained unresponsive to stimuli and not overbreathing the ventilator
- Family opted for comfort-focused care and patient transferred to inpatient hospice for palliative extubation and symptom management
• Family interaction at hospice:
  - Wife’s regret around worry of COVID-19 infection "stealing" last days together
  - Daughter’s last memory was of a fight about "not being a good mother and daughter"
  - Distress about making difficult decisions from afar
• RS extubated with family around him and passed peacefully after a few hours

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Key Features

• Risk factors for complicated grief:
  - Sudden event
  - Unfinished business (daughter felt she was a bad daughter)
  - Trauma of multiple witnessed deaths by mother
• Our ability to help mitigate:
  - Ability to say goodbye
  - Recognition and exploration of unfinished business
• Challenges to our usual abilities:
  - Added layers of guilt
    - "Separation prior to the event"
    - "Did we make the right decision?"
  - Feeling of "time stolen" by pandemic worries

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Conclusion

• As palliative care and hospice providers, we are taught to recognize the risk factors for complicated grief
• Our role is to help mitigate development as well as involve the interdisciplinary team for their expertise in management
• COVID-19 is unique:
  - Every death seems like a "sudden event"
  - Unfinished business exacerbated by isolation and visitor restrictions
  - Lack of ability for bereavement support and memorial services present new challenges after the person’s death
Questions?

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July 14
Using the Dual Process Model of Coping with Bereavement
Henk Schut, PhD
Moderated by Kenneth J. Doka, PhD, MDiv
(part of HFA’s 2019-2020 Professional Education Series)

For more information, visit: hospicefoundation.org/Education/Upcoming-Programs

Upcoming HFA Webinars

Online Bereavement Support Resource
Journeys Newsletter is available electronically

The July issue of Journeys is available as a PDF for unlimited use for $250. This online version makes it easy for you to forward these issues to your email distribution lists.
HFA's COVID-19 Series
Free Programs Available On Demand

https://hospicefoundation.org/Education/Free-COVID-19-Programs

HFA's 2020 Living with Grief® Program
Intimacy and Sexuality During Illness and Loss
Live broadcast: September 24, 2020, 1:00pm to 3:00pm ET

Expert Panelists: Carrie Arnold, PhD, FT, M.Ed., RSW, CCC; Alua Arthur, JD; John G. Cagle, PhD, MSW; Kenneth J. Doka, PhD, MDiv

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