Disenfranchised Grief and COVID-19
April 29, 2020

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Speaker Bios

Kenneth Doka, PhD, MDiv, is a Senior Consultant to HFA and the recipient of the 2010 Distinguished Achievement Award from the Association for Death Education and Counseling (ADEC). A prolific author and editor, Dr. Doka serves as editor of HFA’s journal with religious themes, Its Daughters, and other books and periodicals. He is past president of ADEC, a former board member of the International Work Group on Death, Dying, and Bereavement (IWGD), and is the recipient of the IWG’s prestigious Herman Holdt Award and ADEC’s Award for Outstanding Contribution to the Field of Death Education.

Maria Georgopoulos, LMHC, FT, is Director of the Bereavement Services Department at Calvary Hospital. She is responsible for 33 bereavement support groups at the Bronx, Brooklyn, and Manhattan sites that serve hundreds of adults, children, and teenagers with needs arising from grief, loss, and serious medical conditions. Calvary’s efforts to expand the hospital’s professional learning programs in the New York area. Prior to Calvary, Ms. Georgopoulos worked in the mental health profession in other settings including The American Red Cross of Greater New York as a Community Health Worker. In addition to her work in bereavement, Ms. Georgopoulos is a licensed mental health counselor with a private practice in NYC and provides counseling for diverse populations of people with varying interests.

What is Disenfranchised Grief?

A loss that is not socially sanctioned, openly acknowledged, or publicly mourned

We have a loss but “no right” to acknowledge that loss

Disenfranchised grief is recognized as a risk factor in complicated grief

(Doka, 1996, 2002)
Why is Disenfranchised Grief Important in the COVID-19 Pandemic?

Many losses associated with the pandemic are disenfranchised:
- Loss of an assumptive world
- COVID-19 deaths
- Non COVID-19 deaths
- Grief in healthcare staff

Many factors that disenfranchise grief:
- Physical distancing
- Limits on travel and gatherings
- The role of ritual

Loss of an Assumptive World

The "assumptive world" means that we tend to see the world as safe, predictable, and benevolent.

The loss of an assumptive world is a defining factor in trauma.

Grief in the COVID-19 Pandemic

Non-Death Losses

Non-death losses are often disenfranchised:
- 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
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

Grievers With A COVID-Related Death

- Survivor guilt: Mental and emotional stress experienced by someone who has survived an incident that others have died from (Demi & Mies, 1984)
- Causation guilt: Our actions caused the death in some way (Demi & Mies, 1984)
- Feeling cheated of the ability to mourn with others
  - The calming nature of attachment figures
  - Lack of physical contact
  - Loved ones not getting the rites they deserve

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
Disenfranchised 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, colleagues...
- Moral distress in staff and feelings of helplessness (especially in supportive staff, clergy, and volunteers who are inhibited from normal practice)
- Papadou’s Dual Process of Caregiver Grief – oscillating between experiencing and containing grief (burnout vs. detachment)

Disenfranchised Grief

- Parkes and the importance of social support
- Limits to informal social support
- Role of grief support groups
- Validation
- Support
- Coping advice and grief education
- Respite
- Helping others—helps self (Lund)
- Limits to formal social support
- Complicating grief

Services Calvary Hospital Usually Provides

- Inpatient hospice services
- Calvary @ Home
- Palliative Care Institute
- Bereavement services
Scope of Bereavement Services
- 32 bereavement groups offered across three sites
- Calvary’s Camp Compass®
- Memorial services
- Community outreach to schools and other community agencies
- Clinical education on end-of-life care

Our Mission of Non-Abandonment Continues… Despite the Many Challenges Presented by COVID-19

Virtual Visits for Patients and Family Members: Benefits
- Opportunity for family members to interact with the patient
- Assists with feeling less distant
- Families very grateful
Virtual Visits For Patients and Family Members: Challenges

- Not everyone can access virtual platforms
- Many patients very disoriented and don’t understand why their families aren’t visiting
- Families are having even more difficulty understanding the dying trajectory with virtual visits

What About the Healthcare Staff?

- Helping in this time of great need reaffirms their commitment
- Delivery of service is not what they are used to
- Needs have increased
- Compartmentalization
- Bereavement overload (Kastenbaum, 1969)
  - Multiple losses occur in a short time
  - Not enough time to process one before another occurs
- Navigating their own fears and anxieties
- Presence of support staff can be reassuring
Virtual Bereavement Support Groups: Benefits

- Members are grateful to still have a space to process their grief
- Bereavement overload applies here too
- Presents a unique opportunity to bring in objects/spaces that are important to families
- Provides a space to discuss grief related to lifestyle changes as a result of COVID-19

Virtual Bereavement Support Groups: Challenges

- Not everyone has access
- For some, this may be their 6th video conference for the day and they may not be fully present
- In-person groups is different, privacy and other household demands may interfere
- Harder to engage children in this process
A Word About Virtual Children’s Groups
- Care packets
- Short, engaging activities
- Caregivers may be overburdened and have a hard time assisting with access
- Important to maintain contact with the children

What Helps?
- Movement
- Music
- Meditation
- Visualization
- Being seen and heard

Enfranchising Grief
- Sensitivity to loss
- Validation
- The power of naming
- The role of grief education
- Virtual support
- Analyze and counter empathic failure
- Disenfranchised grief IS grief
Creating Ritual

- Streaming funerals
- Recording funerals
- Two-part rituals (burial and a promise of a memorial service after the crisis)
- Website memorials
- Other opportunities
  - Largest Night Service
  - Mitzvah Joint Memorials

Therapeutic Ritual

Types
- Continuity
- Transition
- Reconciliation
- Affirmation

Developing Therapeutic Ritual
- Emerge from the narrative
- Objects are both visible and symbolic
- Planned and processed
- Use primal elements

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?
Questions?

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Upcoming HFA Webinars

May 21  Increased Relevance of Advanced Care Planning in the COVID-19 Era

June 16  The Evolving Role of the Trained Death Doula in End-of-Life Care

For more information on these upcoming programs and to access other free on-demand COVID-19 programs, Go to hospicefoundation.org

Online Bereavement Support Resource

Journeys Newsletter is now available electronically

The April and May issues of Journeys is available as a PDF for unlimited use for a per issue fee. This online version makes it easy for you to forward these issues to your email distribution lists.
HFA’s 2020 Living with Grief® Program
*Intimacy and Sexuality During Illness and Loss*
Live broadcast: September 24, 2020, 1:00 pm – 3:00 pm 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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Questions? Email HFA at onlineceu@hospicefoundation.org

This program and CE instructions will be available through April 28, 2021

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