





We Tell Ourselves Stories in Order to Heal Processing Grief Through the Written Word

A Compassion in Action Webinar May 12, 2020 the schwartz center FOR COMPASSIONATE HEALTHCARE



Your Moderator

Stephanie Adler Yuan, MS Director, Education & Training The Schwartz Center for Compassionate Healthcare







The Schwartz Center for Compassionate Healthcare

Putting compassion at the heart of healthcare through programs, education and advocacy

Through national and international partnerships, the Schwartz Center's coalition of caregivers, patients, families and other leaders work together to make **compassion a vital element** in every aspect of healthcare.





Please Note

- This series is made possible by the generous support of the Coverys Community Healthcare Foundation and by a donation made in memory of Julian and Eunice Cohen.
- You may submit your questions via the "Questions" pane to the right of your screen at any time.
- We appreciate your feedback! Please take a moment to complete our very brief survey following the webinar.





Today's Host

Beth Lown, MD Chief Medical Officer The Schwartz Center for Compassionate Healthcare







Today's Speaker

Sunita Puri, MD, MS

Medical Director, Palliative Medicine & Supportive Care University of Southern California - Keck Hospital & Norris Cancer Center

Author, That Good Night: Life and Medicine in the Eleventh Hour





Poll







A Story Of My

Own



Joan Didion, The White Album

"We tell ourselves stories in order to live...We look for the sermon in the suicide, for the social or moral lesson in the murder of five. We interpret what we see, select the most workable of the multiple choices. We live entirely, especially if we are writers, by the imposition of a narrative line upon disparate images, by the "ideas" with which we have learned to freeze the shifting phantasmagoria which is our actual experience."



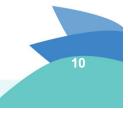


What is Grief?

Reaction to profound loss

- Has multiple stages
- Has not just emotional but physical, cognitive, spiritual effects
- Universal experience









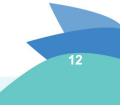




Grief Amid COVID-19

- Medical staff
 - Uncertainty
 - Rationing, suffering, deaths
 - Inadequacy, loss, inability to do one's job
 - Trauma, depression, anxiety
- Patients/Families
 - Separation
 - Inability to connect meaningfully; fears of contagion
 - Ongoing fear and uncertainty
- All of us
 - Loss of normalcy
 - Economic hardship
 - Loss of connection and safety
 - Lack of ritual
 - Anticipatory and complicated grief





Grief as Unspeakable

"In those first months, I quickly came to feel almost embarrassed by my sorrow. Most people are uncomfortable around loss. Friends talk to you about "getting through it" and "moving on" and "healing." I think this is part of why there are so many memoirs and movies about loss: they create a public space where we can talk safely about grief." Megan O'Rourke, author of *The Long Goodbye*







Study of Physician Grief (Granak, et al. JAMA-Internal Medicine, 2012

- 2010 -2011 in three Canadian hospitals
- 20 oncologists varying in age, sex, ethnicity
- Balancing grief and detachment didn't work
- More than half reported feelings of failure, self doubt, sadness and powerlessness
- A third talked about feelings of guilt, insomnia crying.





Study of Physician Grief (Granak, et al. JAMA-Internal Medicine, 2012

- Grief in the medical context is considered shameful, weak and unprofessional
- Hiding grief is common
- Compartmentalization (perceived as necessary) resulting from patient loss
- Disenfranchised grief: Grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported (Kenneth Doka)

Impact of Disenfranchised Grief

- Half distanced and withdrew from patients as patients got closer to dying.
- Effects of grieving impact oncologists' personal lives
- Need to normalize death and grief as part of both life and medical practice
- Few if any rituals for physicians to process and explore their grief (debriefs after Codes, Schwartz rounds)





Of Particular Concern

Disruption of Rituals

"This is what rituals are for. We do spiritual ceremonies as human beings in order to create a safe resting place for our most complicated feelings of joy or trauma, so that we don't have to haul those feelings around with us forever, weighing us down. We all need such places of ritual safekeeping." – Elizabeth Gilbert, *Eat, Pray, Love*





Can Literature and Writing Help?

- Last stage of grief: Meaning making (David Kessler)
- Writing/humanities to protect empathy in medical students
- Self-empathy?
- Writing: Exploration, catharsis
 - Journaling
 - Letters
 - Snapshots of days/scenes
- Literature: Connecting the personal and the universal
- Can writing become a form of ritual for care providers?













Writing Two Sentences

- Write two sentences (or one or three) describing a person or situation you are grieving or struggling with
- Those who would be willing to share can do so in the chat box and we will read a few of the responses.
- What we write reflects our perception of an event *at this time*





The Story We Tell Ourselves – 2 Sentences

- "He died. I'm exhausted and feel like I failed him." (ICU physician)
- "I'll never forget her husband's scream over Zoom. She was beautiful, vibrant, and my age, and I don't know why I couldn't save her. I haven't slept for days." (Hospitalist physician)
- "His name was Simon and he was only 35 and he died alone in my ER. He was one of the new COVIDs who came in all at once and he looked stable until he suddenly crashed. I don't know how I'm going to live with myself. I've done so much training but I was totally unable to help him.I" (ER physician)
- "My long-time patient is in the COVID ICU and I can't even go in the room to see him. This is totally out of control and there's nothing I can do to help him." (Oncologist)





Writing as Reflection

- Don't think, just feel
- Write in one sitting
- Keep moving forward
- Don't edit; let the writing be
- Letters, stream of consciousness, responding to prompts
- Undoing our impulses as care providers





Joan Didion, The Year of Magical Thinking

- Life changes fast.
- Life changes in the instant.
- You sit down to dinner and life as you know it ends.
- The question of self-pity.
- Those were the first words I wrote after it happened. The computer dating on the Microsoft word file ("Notes on change.doc") reads "May 20, 2004, 11:11 pm," but that would have been a case of my opening the file and reflexively pressing save when I closed it. I had made no changes to that file in May. I had made no changes to that file since I wrote the words, in January 2004, a day or two or three after that fact.
- For a long time, I wrote nothing else.





My Initial Sentences

 Why did I code him for that long? Why did I even offer a code? I know being angry won't bring him back. But I can't stop, I want a do over and I won't have one. He's dead. Dead in the worst possible way because of me.





Articulation

Try to live *the questions themselves* as if they were locked rooms or books written in a very foreign language. Don't search for the answers, which could not be given to you now, because you would not be able to live them. And the point is, to live everything. *Live* the questions now." – Raina Maria Rilke, from *Letters to a Young Poet*





Isolation: C.S. Lewis, A Grief Observed

"An odd by-product of my loss is that I'm aware of being an embarrassment to everyone I meet ... Some funk it altogether. R. has been avoiding me for a week ... Perhaps the bereaved ought to be isolated in special settlements like lepers."





Isolation: Henry Marsh, Do No Harm

"Few people outside medicine realize that what tortures doctors most is uncertainty, rather than the fact they often deal with people who are suffering or who are about to die. It is easy enough to let somebody die if one knows beyond doubt that they cannot be saved - if one is a decent doctor one will be sympathetic, but the situation is clear. This is life, and we all have to die sooner or later. It is when I do not know for certain whether I can help or not, or should help or not, that things become so difficult."





Anger, Bargaining, Depression: Elisabeth Tova Bailey, The Sound of a Wild Snail Eating

• "When the body is rendered useless, the mind still runs like a bloodhound along well-worn trails of neurons, tracking the echoing questions: the confused family of *whys, whats* and *whens*, and their impossibly distant kin, *how*. The search is exhaustive, the answers, elusive. Sometimes my mind went blank and listless; at other times it was flooded with storms of thought, unspeakable sadness, and intolerable loss."

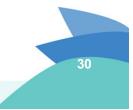




Connections: Elizabeth Tova Bailey, The Sound of a Wild Snail Eating

 My bed was an island within the desolate sea of my room. Yet I knew there were other people homebound from illness or injury, scattered here or there throughout rural towns and cities around the world. As I lay there, I felt a connection to all of them. We, too, were a colony of hermits.

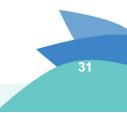




Meaning Making: Cheryl Strayed, Torch

Torch is the result of my first sustained effort at digging.
 When I scratched beneath the surface as I wrote it, I came to understand that I didn't know what I was going to find as each layer revealed itself. It was only after I'd finished that I could see what I'd done: written a novel not only about grief and loss, but also about love in its many forms, about how we find light in the midst of the most profound darkness, about how we survive what we think we will not."





Full circle

Two hours later, my hands compressed his chest, blood spurted out of the tube connecting him to a ventilator, and I was doing everything to him, but nothing for him. The code was bloody, long, and suddenly over. I've blamed myself for so many years for how he died, in his own blood and shit, utterly alone. I've carried the guilt and the grief for so long – but how has it helped me? Has it made me a better doctor? Has it made me a better person? What should I do with all the anger, depression, and self hatred? All of it was my way of grieving, and I had nowhere to put those feelings. So today I'm going to bury a flower in the ground for him, and forgive myself, finally.





Full Circle – Rilke

Perhaps then, someday far in the future, you will gradually, without even noticing it, live your way into the answer. – Rainer Maria Rilker, *Letters to a Young Poet*

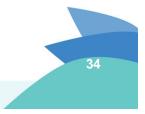




Works Consulted and Recommended

Bailey Tova, Elisabeth. The Sound of a Wild Snail Eating
Didion, Joan. The White Album
Didion, Joan. The Year of Magical Thinking
Gilbert, Elizabeth. Eat, Pray, Love
Lewis, CS. A Grief Observed
MacDonald, Helen. H is for Hawk
Rilke, Rainer Maria. Letters to a Young Poet
Strayed, Cheryl. Torch



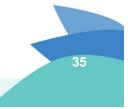


Thank You!

• Feel free to reach out to me with questions or feedback!

• <u>Sunita.Puri@med.usc.edu</u>







Questions & Answers





Sunita Puri, MD, MS

Beth Lown, MD

Please type your questions in the "Questions" pane on your screen.







New Date! May 20

"Managing Our Fears and Stress: Strategies to Cultivate Emotional Agility"

Dr. Susan David McLean Hospital/ Harvard Medical School Author, Emotional Agility

Register at theschwartzcenter.org







Learn more at compassioninactionconference.org







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