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2022 Annual Conference and Trade Show · August 30 – September 1, 2022

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Dying, Death, and Bereavement in a Digital World

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1

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Define thanatechnology



Identify at least two ways people can express their grief digitally



Identify potential negative effects of relying on social media for grief support



Identify at least two changes that have occurred in the way we conduct end-of-life care business as a result of the pandemic

2

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Thanatechnology

- Encompasses rapidly changing societal practices and views about dying, death, and loss that are increasingly influenced by modern communication technology. - *Dr. Carla Sofka*
- Any technology used in dealing with death, dying, grief and other end-of-life issues.

3

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The Digital Impact

- Advancements in technology has changed the way bad news is delivered.
- Information can be sent and received across multiple platforms very quickly.
- Information sent this way may not be accurate.
- Information sent this way may not be with the consent of those involved.

4

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The Digital Impact

PRIVACY

- Each new technology impacts existing tensions:
 - privacy versus sharing,
 - freedom to die or grieve one's own way versus surveillance and censure by others,
 - power versus resistance to power.
- Research indicates that internet use often provides the illusion of anonymity, which may encourage a false sense of privacy.
- Some websites allow individuals to set privacy preferences for posts.
 - This is usually not automatic and requires action by the user.

5

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THE DIGITAL AFTERLIFE


- Technology allows for the storage and retrieval of images, voicemail messages, and texts from the deceased.
- The digital data of the dead is far more than code—it contains the digital “souls” of the deceased.
 - While, for some, the internet provides comfort by enabling a continuing relationship with the departed, for others it is causing a new anxiety—the fear of second loss.
- In more recent years, technology has provided additional ways to remember and mourn, such as creating online memorials, seeking distant or virtual grief counseling and connecting with family, friends and even strangers without geographical limitations.
 - It erases time and distance and allows for virtual experiences and expressions that promote a narrative that lives forever.
- Who owns a deceased person's digital self?

The Digital
Impact

6

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How News Travels –

Survey following local crash and how people found out about it

The crash occurred at approx. 10:17 PM

How quickly did you find out?	How did you find out?
Saturday night:	Facebook: 26.1%
Within 15 minutes: 7.6%	Local news: 17.4%
16-30 minutes after: 18.9%	Phone call: 12.3%
31-60 minutes after: 27.3%	Twitter: 11.9%
Within 1-2 hours: 46.2%	Face to face: 9.0%
Sunday: 47.6%	Text message: 9.0%
Monday: 3.8%	

7

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Social Media

Statistics show that the younger generations are more likely to visit a deceased person's social media pages more than they will visit their grave or niche.




“Before you take me away, I just want to update my profile picture.”

https://www.boredpanda.com/cartoon-smartphone-cellphone-addiction/?utm_source=google&utm_medium=organic&utm_campaign=organic

8

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Social Media Guidelines for Negative Posts



9

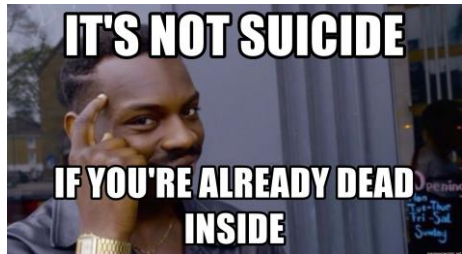
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When Posts Cross the Line


- When “hot words” associated with self-harm or wanting to die are detected on Facebook, Tumblr, or Instagram posts, users receive messages about mental health and links to the National Suicide Prevention Lifeline.
- While some experts see this as an opportunity to bond with those who are struggling, others insist that there is a fine line between destigmatizing suicidal thoughts and normalizing them.



<https://dontgetserious.com/suicide-memes/>

10

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Generations and Thanatechnology

- Without a doubt, the youth of today are often exposed to significant and traumatic losses.
 - Instant access to information both positive and negative
 - Often seek support online
 - Comfortable with the technology and applications
- The older generations do not feel as comfortable
 - May avoid online activities
 - May be resistant to learning new things
 - May need help navigating websites/apps

11

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Telehealth

- Telehealth is the distribution of health-related services and information via electronic transfer and telecommunication technologies.
- It allows long-distance patient and clinician contact, care, advice, reminders, education, intervention, monitoring, and remote admissions.



12


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Before Death

- In the days and weeks leading up to the death of Leonard Nimoy, the actor and director most known for playing the gravel-voiced Vulcan Mr. Spock in Star Trek, knew he was dying. He used **Twitter** as a means to make peace with this fact, and to say goodbye to his friends, family and fans around the world with sayings, poetry, and wise words.



13


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Before Death

- Auto-pathography: published autobiographies about the writer's own dying, almost always of cancer. (Includes blogging).
- Art photographers are documenting the withering bodies of people dying of cancer or AIDS, or portraits taken before and after death – often at the request of the dying person.



14

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Before Death



- Dying individuals may find comfort blogging about their experiences.
- Online mutual help groups of those with fatal conditions also enables them to communicate, anywhere, any time.
 - Online, they can find emotional and practical support from one other.
- <https://www.caringbridge.org/>

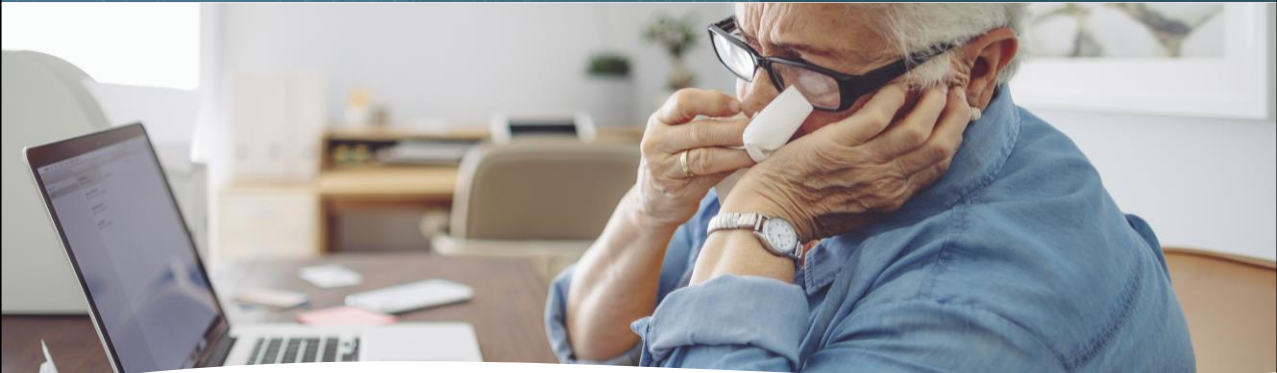
15

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Funeral and Memorial Services

- Video conferencing for arrangements
- Online portals
- Automated documents
- Crowd Funding (Go Fund Me)

16

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Crowd Funding

- Pros
- Cons



17

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Funeral and Memorial Services

- Webcasting services
 - Allows mourners to connect and experience the funeral remotely
- Recorded or zoom eulogies
- Video tributes
 - Print media
- Online guest books
- Online obituaries and memorials



18


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Cemeteries

- Solar powered video headstones
- QR codes on headstones that allow visitors to view photos, videos, and other information about the deceased
- Digital mapping
- Virtual reality 360-degree view of a cemetery
- Holograms



19

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After Death

- After death, social media enable grief to become more shared, more public, than it generally was in the 20th century.
 - Sufferers can express their suffering. And in so doing, they educate others about dying and mourning.
- Visibility also increases the chances of unhelpful comments and even censure.
 - This is apparent in grieving, where mourners may be criticized for grieving too much or too little, too long or not long enough, for being too stoical or too expressive.
- Disenfranchised Grief – when an individual feels that they cannot grieve normally or publicly and resort to expressing grief online.

20

Netiquette for Helping Patients and/or Families

- Have conversations about how those involved want information about illness or death disseminated.
- Encourage people to THINK BEFORE POSTING OR TEXTING. Always ask for permission before sharing information.
- Some treatment consent forms may now include options for digital communications including texts, emails, and video calls.



21

Problems with Online Support

- Cultural Lag = certain aspects of the culture, such as technology, can advance faster than the norms and laws that regulate the use of technology.
- Some websites share information without the user's consent.
 - This can lead to unscrupulous business solicitations.
- Cultural/racial inequality may limit access to online support for certain underprivileged cultures or communities.
 - Limited access to online support can make some interactions more difficult, such as telehealth.
 - May also prevent some individuals from seeking help.

22






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Issues with Online Support

- While social media can provide support and encouragement to griever, it may also invite negative comments and posts.
- People who post about the death of a loved one online should limit who can view the post. Scammers search social media posts for vulnerable people to take advantage of.
- Not all websites and applications are run by trusted experts in the field of grief support and grief counseling.
 - Amateur support sites can cause more harm than good.
 - Challenges deciphering which site are good and which are not.

23

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Benefits of Online Support

- Individuals may have better access to support online that might not be available in their communities in person.
- Online groups restricted to particular age groups with particular conditions or particular religious beliefs, can be valuable.
 - People seeking group support are more comfortable talking with other people with similar experiences.
- Individuals have access to information about terminal diseases, the benefits of hospice care, and even grief and bereavement online.
- People can nearly always find suggestions for literature that pertains to their needs.

24

Benefits of Online Support

- The internet and other technological ways of communicating offer new ways of familiarizing ourselves and others with death: printing, photography, sound recording, television, email, Facebook, Twitter, and so on.
- Information is persistent and endures.
 - There is a sense of immortality and legacy when a person's comments, photos and work is posted in cyberspace.
 - It is visible to infinite numbers of individuals.
 - It is spreadable, and with one repost or share, hundreds more are invited into our experience.
 - It is searchable.

25



Research: How People View Online Support

Survey results

Original Factor Section	Item
Distraction	I use the Internet or a mobile app to help me find something pleasant to think about.
	I look at old digital photos or text messages to revisit pleasant experiences from the past.
	I listen to or create digital music.
	I view or create digital artwork.
	I play or create video games, computer games, or apps.
	I take and/or edit digital photographs.
Catastrophizing	I blog about things I enjoy.
	I subscribe to events on social media that I might enjoy.
	Social media is overwhelming to me.
Ignoring Pain Sensations	I avoid looking up solutions to my pain online.
Distancing from Pain	I seek out artwork, music, or writing online that helps me characterize pain as something separate from myself.
	I post things to my social media accounts to remind myself to be brave.
Coping Self-Statements	I post things to my social media accounts to remind me that I can overcome the pain.
	I post things to my social media accounts that remind me to not let pain stand in the way of what I have to do.
	Although it hurts to see others sharing happy things on social media when I am sad, I just keep going.
Praying	I use websites or mobile applications that help me try to understand my grief in light of my faith.
	I use websites or mobile applications to find prayers or spiritual texts that give me comfort.
	I use group messaging on my phone or social media to keep in touch with people in my spiritual circle.
Increasing Activity	I leave the house and do something, such as going to the movies, shopping, or going to a social media event I have subscribed to.
Hoping	I know that someday someone from my social media connections will be there to help me and the pain will go away for awhile.
Reinterpreting Pain Sensations	I put in headphones and listen to music when I perceive pain.

Table 1. New and Adapted Technology-Focused CSQ Items

26






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Internet Resources

- Undoing isolation for young adults grieving the illness or death of someone close from COVID-19. [COVID Grief Network: https://www.covidgriefnetwork.org](https://www.covidgriefnetwork.org)
- Grief support for suicide loss survivors: <https://save.org/what-we-do/grief-support/>
- To put it simply, this website is about grief. <https://whatsyourgrief.com/>
- <http://griefnet.org/> has served as an internet community of support for persons dealing with death, grief, and major loss for about two decades.

27






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Internet Resources

- Modern Loss is a place to share the unspeakably taboo, unbelievably hilarious, and unexpectedly beautiful terrain of navigating your life after a death. <http://modernloss.com/>
- This site aims to offer hope, comfort and support for survivors of *suicide* loss. <http://www.oursideofsuicide.com/>
- Located in Portland, Oregon, The Dougy Center provides a safe place for children, teens, young adults and their families who are grieving a death to share their experiences. We do this through peer support groups, education, and training. <https://www.dougy.org/>

28






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Internet Resources

- Helping you cope with life after loss using meditation for grief, yoga and journaling. <http://mindfulnessandgrief.com/>
- It's OK to not be OK. <http://www.refugeingrief.com/>
- Led by grief counselor and educator Dr. Alan Wolfelt, we are an organization dedicated to helping people who are grieving and those who care for them. <https://www.centerforloss.com/grief/im-grieving-loss/>
- <https://www.opentohope.com/> is a non-profit with the mission of helping people find hope after loss. We invite you to read, listen and share your stories of hope and compassion.

29


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Internet Resources

- The Tragedy Assistance Program for Survivors offers compassionate care to all those grieving the loss a military loved on. <https://www.taps.org/>
- Will Carry On is about sharing miscarriage, stillbirth and loss resources, and about sharing hope. <https://willcarryon.wordpress.com/>
- The National Organization of Parents Of Murdered Children makes the difference through on-going emotional support, education, prevention, advocacy, and awareness. <http://www.pomc.com/index.html>

30

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Resources

- <https://theconversation.com/how-the-digital-age-has-changed-our-approach-to-death-and-grief-38207>
- <https://ct.counseling.org/2018/06/counseling-connoisseur-thanatechnology-grief-and-loss-in-a-digital-world/>
- <https://www.fastcompany.com/90320422/we-need-better-tools-for-the-digital-afterlife>
- <https://www.npr.org/2012/02/08/146585372/redefining-the-grieving-process-in-the-digital-age>
- <https://socialworkpodcast.blogspot.com/2017/02/digital-death.html>
- <https://firstmonday.org/ojs/index.php/fm/article/view/4998/4088>
- <http://griefnet.org/>
- <https://whatsyourgrief.com/>
- <https://youtu.be/LP0ivXE0-mc> (Harnessing Thanatechnology to Cope with Illness, Death, and Grief)
- Servaty-Seib, H. L., & Chapple, H. S. (2021). *Handbook of Thanatology: The essential body of knowledge for the study of death, dying, and bereavement*. Association for Death Education and Counseling.

31

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In Conclusion

- According to K. Charmaz: *“Death lies in the future for everyone. But the future of death takes shape in whatever collective meanings and practices are constructed by people around concrete instances of death as they engage in their everyday lives.”*
- It is interesting to think about how thanatechnology will evolve to develop additional ways to describe the social representations of death, opportunities for digital immortality, and the death positive movement.

32

