



The Digital Legacy Association

Death, the internet and COVID-19 - Insights from the Digital Death Survey

James Norris, Digital Legacy Association, London, UK & Carla Sofka, Siena College, Loudonville, NY USA



(Poster R-46)

Background:

The Digital Death Survey explores society's attitudes and behaviours related to death, the internet and technology. This flagship survey was first carried out in 2014 by the Digital Legacy Association (UK). In recent years, the research has received further support from Dr. Carla Sofka of Siena College (USA). The 2020 survey was reviewed and approved by the Siena College Institutional Review Board before being conducted (IRB #08-02-20).

Aims & Goals (2020)

To understand how the internet, technology and COVID-19 is changing societies attitudes and needs around death, care planning and bereavement.

It is hoped that the data from the survey will help academics, healthcare professionals and policy makers better understand the importance of peoples digital assets and digital legacy. A secondary goal is to familiarise society with the importance of making plans for our increasingly complex, digital lives.

This topic has become increasingly important due to the increased reliance on technology as a resource to cope with death, remember and grieve during the pandemic.

Methodology

Following the development of a quantitative online survey with supplementary quantitative questions, a convenience sample (N=348) was obtained by disseminating the survey using the Digital Legacy Association's website, the Siena College Social Work Program Facebook page, the Siena College Daily Digest and more widely on various social media platforms.

Demographic data

Gender & Age range

Gender Identity	Age Range
	18-24 = 14.2%
Female = 83.7%	25-34 = 13%
Male = 14.6%	35-44 = 20.6%
Transgender: <1%	45-54 = 22.6%
Nonbinary: <1%	65+ = 9.6%
Prefer not to say: <1%	Prefer not to say = .6%

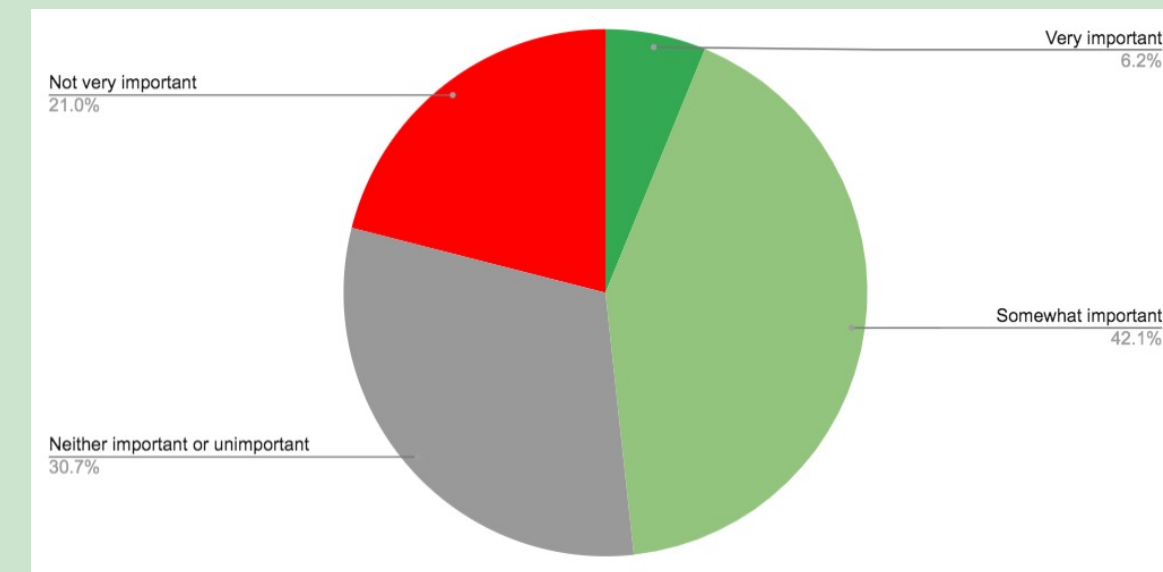
• 82.5% of the sample are comfortable talking about their own death with friends and family

• 67.1% of the respondents have communicated their wishes about their own funeral verbally and/or in writing.

End of life professionals compromised a large proportion (approximately 46.5%) of this

Findings

If someone you care about dies, how important would it be for you to be able to view their social media profile(s)?



Despite the importance placed on being able to view social media profiles from those cared about after their death, almost half (45.1%) of respondents are EXTREMELY UNFAMILIAR with policies that address what happens to online accounts when a user dies.

Does anyone other than yourself know the passcode for the following?

	Laptop/ Computer	Phone	E-mail	Bank Account
Yes	47%	62.8%	71.6%	35.6%
No	48.7%	30.8%	24.1%	62.9%

COVID-19 pandemic & Digital Death

• Since the Digital Death Survey 2017, there has been a 10% increase in respondents stating that they "would not mind" if their funeral were to be live-streamed (69.7% in 2020).

• As a result of the COVID-19 pandemic, 30.1% report being more likely to document their end of life wishes. 26.7% report that they are NOT more likely and 23.8% are not sure. 17.7% had documented their wishes prior to the pandemic, and 1.7% reported documenting them since the beginning of the pandemic.

• 52% respondents have watched the livestream of a funeral, graveside service, memorial service, or celebration of life

• 20% respondents watched a video recording of a funeral, graveside service, memorial service, or celebration of life

• 21% respondents participated in an online memorial service, candlelight service, or vigil to remember those who died from COVID-19

Discussion / Implications / Conclusions:

Many people (almost half) remain UNFAMILIAR with policies, laws and regulations that address what happens to online accounts when a user dies. Education should be included in public death education efforts and as a component of end of life care.

An overwhelming majority of respondents (92.3%) have NOT completed a social media will / digital will outlining their wishes about their social media and online accounts following their death. Professionals should learn about the resources available to assist in planning for their digital assets - see DigitalLegacyAssociation.org & MyWishes.co.uk (8)

The pandemic has provided new and unique opportunities for end of life professionals to have conversations with people about the potential role / use of technology (digital and social media) in commemorating those who have died as well as helping people to cope with grief. Professionals have a responsibility to learn about these topics and to incorporate it in their work with the dying and the bereaved. (3)

People use thanatechnology for multiple reasons while coping with death and grief, and digital and social media has had an important role in helping people to participate in services for those who have died during the pandemic.

69% of respondents felt it would be very or somewhat important to be able to watch a live video stream of a funeral if they were not able to attend in person.

The social etiquette (netiquette) around digital and social media when dealing with death and grief has changed during the pandemic (Sofka, 2021).

References

- Digital Legacy Association: Digital Death Survey <https://digitallegacyassociation.org/about/reports-2/>
- Digital Legacy Association: Digital Assets & Digital End of Life Conversations Framework <https://digitallegacyassociation.org/wp-content/uploads/2017/07/Digital-Assets-and-Digital-Legacy-Framework-April-2018-1.pdf>
- James Norris - (2018) Your digital legacy: an emerging aspect of advance care planning <https://www.rcplondon.ac.uk/news/your-digital-legacy-emerging-aspect-advance-care-planning>
- James Norris (2020) End of Life Communication: utilising technology during the COVID-19 pandemic (Royal College of Physicians Commentary Magazine)
- Sofka, C.J. (1997). Reference for Death Studies article.
- Sofka, C.J., Cupit, I.N., & Kilbert, K.R. (2012). Death, dying, and grief in an online universe. Springer Publishing.
- Sofka, C. (2021). Netiquette regarding digital legacies and dealing with death, tragedy, and grief. <https://www.siena.edu/files/resources/netiquette-social-media-and-grief.pdf>
- MyWishes care planning application - www.MyWishes.co.uk