



# Engaging with Discomfort: Thanatological Social Movements and Public Death Education

by Kaitlyn L. Kinney

Death is not just the end of life; death is also a complex and cultural phenomenon. As such, the shifting boundaries between life and death call for a reexamination of existing social norms and practices and the various educational resources surrounding death and dying in the United States. This is essential because death is not usually spoken of in our everyday lives. Instead, it is surrounded by silences that emerge from how death became displaced from vernacular discourse during the early 20<sup>th</sup> century with the creation of hospitals, funeral homes, professional death workers, and rapid advancements in medical science and technology (Cann 2014, Faust 2008, Rosenow 2015). These silences and displacements created a problematic deathscape—the places (conceptually, physically, and virtually) associated with dying and death that are imbued with various meanings and associations.<sup>1</sup>

Discontent with the contemporary U.S. deathscape serves as the catalyst for the emergence of grassroots groups, practices, and expressions that I term *thanatological social movements*. In discussing these groups, I employ “thanatological” versus “thanatocultural”. Thanatoculture broadly defined encompasses the cultures of death and dying shaped by the deathscape they resonate within. Thanatological is derived from “thanatology”—the science and study of death and dying from multiple disciplinary perspectives to educate others regarding death. Important to my framework is that an educational motivation drives these groups in their advocating for *thanatocultural* change. Thanatological social movements are folk groups whose shared beliefs and identities are situated around initiating cultural, political, and social change in the ways we communicate about, practice, and perceive death and dying. How people come to join and identify as being part of these thanatological folk groups relates directly to their everyday online interactions. Digital spaces and interactions facilitate experiential learning and connection in navigating together how to accomplish their advocacy. Folklore is uniquely equipped for contributing to this dynamism occurring within the U.S. deathscape in relation to the performance of death communication and education because our field provides a framework for acknowledging and responding to the ways death remains meaningful to people across shifting spatial and temporal contexts.

This brief survey of thanatological social movements provides folklorists useful entrée to consider the importance of the U.S. deathscape vis à vis disciplinary genres of performance and narrative (among others). This overview also shares with fieldworkers a potential starting point for researching this work and, for educators, offers four great resources that can be incorporated into classroom work. The movements outlined below indicate that death’s displacement and its silences

do not erase the cultural and personal connections we have to the deceased and dying. The increase in these communities is in part directly tied to a need for more informal death education that is public-facing and easily accessible and embraces the cultural and personal aspects of these experiences as teachable moments. In creating and using digital spaces and resources, individuals are beginning to move past the effects of institutional and professional structures that have unintentionally created silences surrounding death to mitigate this.

These digital spaces allow for the potential of verbal and nonverbal communicative interaction between and among thanatological social movement participants as death educators. These online interactions additionally facilitate the potential for these educators to connect with others outside their thanatological folk groups in their performance of public death education. The liminal nature of these virtual places allows these performers to pull from familiar communicative strategies, while also creating their own grassroots methods to speak of death in the pursuit of public death education. Through these grassroots methods, folklorists can better understand how digital engagement for education allows for the public mapping of “liminal spaces of emotion and affect” through these expressions of death communication within the changing American deathscape (Maddrell and Sidaway 2010).

The four social movements below range in scope and history spanning the past 30 years. Beginning with Death with Dignity, established in 1994, we can see how these movements create space and community for people in the U.S. in the form and performance of public death education. Thanatological social movements highlight how people work to change the deathscape, and how we can reflexively learn from the sharing of one another’s experiences. Demonstrating together, we can all learn how to engage with the discomfort of death in our everyday lives.

### **Death with Dignity (est. 1994)**

The [Death with Dignity](#) movement seeks to change the current experience of death in this country by advocating for the freedom of all terminally ill Americans to make their own end-of-life decisions (e.g., how they die; promoting death with dignity laws around the nation; and providing information, education, and support about death with dignity as an end-of-life option). This social movement presents didactic educational resources about physician-assisted death along with experiential, vernacular, and performance of personal experience narratives online through the “[Stories](#)” community archive on their website. Here participants practice “grassroots activities of documenting, recording, and exploring community heritage in which community participation, control, and ownership of the project is essential” (Flinn 2007, 153). Since 2013, Death with Dignity has successfully collected and archived 95 stories of terminally ill patients, loved ones, medical experts, and survivors. As a digital community archive, Death with Dignity connects people seeking and needing these resources. The intertwining of public education and folklore in Death with Dignity’s “Stories” archive creates an important resource for folklorists and educators because it documents the complexities of the American deathscape through the sharing of participants personal experiences.

### **Death Café (est. 2011)**

[Death Café](#) creates and provides spaces where individuals can come together and explore their anxieties and experiences of death and dying. These collectives attempt to recenter death

communication outside expert discourse with a very simple premise: Creating a space where people meet, eat, drink, and discuss death to help people “make the most of their finite lives” (About: Death Café).

Death Café also created a digital platform where one can find resources to help navigate the processes of death, dying, and grief, as well as death communication education for learning to articulate these experiences. Death Café encourages active community engagement; individuals can share death-related thoughts, resources, and links and transmit shared experiences among one another directly on the site. Like many communities over the last two years, the café shifted to online gatherings to mitigate the effects of the Covid-19 pandemic. Importantly, this move creates spaces for community members to discuss the deathscapes perpetuated by the global pandemic.

During the virtual October 2020 American Folklore Society (AFS) Annual Meeting, I organized a modified Death Café with several other folklorists who have a key interest in the intersections of folklore and death. Working closely with AFS, in our Death Café we introduced the purpose; discussed our work on the intersections of death and folklore; and opened the floor for attendees to share thoughts, reflections, and experiences. Janet Langlois, a renowned legend scholar who herself was dying from breast cancer, took the first brave step in engaging with the discomfort of discussing our own mortality stating that “Death is an intertwining, a braided connection that is personal, familial, and professional.” She used this space to openly discuss how her own encounters with death shaped her work on deathbed visions in hospice care.

Janet passed in May 2021, but the legacy she left behind as a human being will reverberate throughout time and space. The intimate sharing of her personal experiences inspired moving conversations about the ways folklore can contribute to the practice of death communication and education in relation to our own experiences, and these conversations are continuing.<sup>2</sup> The following year, in 2021, several folklorists who organized or attended the virtual AFS Death Café came together again for further discussion about death and folklore. While this was a traditional panel hosted face-to-face, the question-and-answer portion became a place to begin to speak of death in relation to our personal experiences and reflect on how we are observing these thanatocultural changes in our daily lives.

### **Death Positivity / Order of the Good Death (est. 2011)**

Death Positivity is perhaps the most well-known among the thanatological social movements. In particular, this community tackles what it means to have a good death by addressing the need for reform within the funeral industry, writing that “the public has reluctantly accepted that a funeral will mean huge expense, few opportunities for participation, and little space for grief” (The Order of the Good Death: About). Caitlin Doughty, a funeral director, is instrumental in creating [The Order of the Good Death](#). Doughty’s highly subscribed YouTube documentary series with 1.83 million followers, [Ask a Mortician](#), answers questions about death history, the funeral industry, and mortality. Understanding that death’s negative connotations within the U.S. deathscape is “not a fun, sexy topic for advocacy”; this momentum grew into the Death Positive movement (Order of the Good Death: About).

Death positivity invites an openness about death and encourages engagement. YouTube user SpaceTypo demonstrates this in their [video](#) discussing death positivity, stating that this movement does not “shame you for wanting to be curious about death and it’s okay to explore these subjects and question them” (How Death Positivity Affected Me 2020). Measuring informal engagement online with this thanatological social movement through hashtag searches on #DeathPositivity and #DeathPositive on social media platforms indicates a rise in visibility of this kind of death education. Social media practices like #DeathPositivity allow researchers and educators to analyze the vernacular communicative pathways being actively created online within these communities and to stay current with the dynamism occurring within the American deathscape. However, folklorists and other educators should also consider what skills they can learn from these thanatological social movements and their digital vernacular practices. Doing so teaches us how to better frame our own digital performances in these spaces to network with participants of these communities and directly support public death education efforts through interacting with their content.

### **Collective for Radical Death Studies (est. 2019)**

The [Collective for Radical Death Studies](#) (CRDS) is unique as a thanatological social movement. It directly addresses silences within formalized death education, highlighting how this affects everyday conceptualizations and communications. While death is often attributed to being the “great equalizer” because we will all physically die someday, CRDS acknowledges the unequal experiences of death. Death studies are often situated around white middle- and upper-class experiences; marginalized communities and *their* experiences are too often left out of this discourse. Seeking to bridge this gap, this thanatological social movement consists primarily of death scholars, students, funeral directors, skilled death workers, trained death practitioners, and activists who all see death work as social justice work, antiracism work, and work that addresses marginalized communities. Folklore is equipped to contribute to this discourse through how we are able to navigate the adaptation and performance of tradition within formalized death education and the informal public education performed by these groups online.

Digital spaces are instrumental for CRDS as they collectively work toward providing resources and online engagement in multiple ways to develop a radical death studies canon. This organization came into existence because of conversations that began on Twitter in 2018, highlighting how informal encounters online can form these thanatological communities. Death Studies advocate and historian Kami Fletcher states, “For myself and a lot of my colleagues, Twitter is a nice academic Rolodex where we can easily talk to each other, and people can engage with us who are in the field of death studies. Academia is a privileged world, and Twitter offers a way for anyone to directly engage with academics” (Allis 2020). The Twitter conversations expanding on Fletcher’s tweet resonated with many educators, resulting in CRDS’ creation. CRDS created highly accessible education resources online, such as the Death Canon—a [collection](#) of source material, blog posts, YouTube videos—and an online book club called [#RadDeathReads](#). Yet, CRDS participants also continue to use social media platforms to share their stories to navigate together how to speak of death as experienced within marginalized communities.

Thanatological social movements and their digital practices create spaces where community knowledge and vernacular death communication are jointly developed. Their performance online

highlights the importance of reflexivity to enact thanatocultural change within the American deathscape. There is more work to do for folklorists and educators to contribute to these discourses. The four thanatological social movements surveyed provide a helpful entry point for us to learn from and support public death education.

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### Endnotes

- 1 This definition of “deathscape” is based on cultural geographers Maddrell and Sidaway’s discussions (2010). They conceptualize deathscapes primarily in reference to places of memorialization for the dead for the living (2016, 5). I have recontextualized this definition here to be more inclusive of: 1) the ways these “places” are conceptualized and used (not just memorialization) and 2) how the persons interacting and using these deathscapes may better incorporate the perspectives of individuals who are dying.
- 2 To learn more about Janet’s life and work, please read these beautiful tributes to her from the [International Society for Contemporary Legend](#) and in the [Journal of American Folklore](#).

### Works Cited

- Allis, Ellary. 2020. Interview. Kami Fletcher. Is Death “The Great Equalizer?” African American Deathways and Inequality in America. *Seven Ponds Blog*, Accessed June 15, 2022, <https://blog.sevenponds.com/professional-advice/is-death-really-the-great-equalizer-african-american-deathways-and-inequality-in-america>.
- Cann, Candi K. 2014. *Virtual Afterlives: Grieving the Dead in the Twenty-First Century*. Lexington: University Press of Kentucky.
- Death Café. About. Accessed May 28, 2022, <https://deathcafe.com/what>.
- Death with Dignity. About. *Death with Dignity*. Accessed June 9, 2022, <https://www.deathwithdignity.org>.
- Faust, Drew Gilpin. 2008. *This Republic of Suffering: Death and the American Civil War*. New York: Alfred A. Knopf.
- Flinn, Andrew. 2007. Community Histories, Community Archives: Some Opportunities and Challenges. *Journal of the Society of Archivists*. 28.2:151-76.
- Maddrell, Avril and James D. Sidaway. 2010. *Deathscapes: Spaces for Death, Dying, Mourning, and Remembrance*. Farnham, Surrey, UK: Ashgate.
- Rosenow, Michael K. 2015. *Death and Dying in the Working Class, 1865-1920*. Champaign: University of Illinois Press.
- Spacetyo. 2020. How Death Positivity Affected Me. *YouTube*. Accessed June 5, 2022, <https://www.youtube.com/watch?v=ga0w80mBNpU>.

### Urls

- Collective for Radical Death Studies <https://radicaldeathstudies.com>
- Collective for Radical Death Studies. Death Canon <https://radicaldeathstudies.com/death-canon>
- Collective for Radical Death Studies. #RadDeathReads <https://radicaldeathstudies.com/decolonizing-death/raddeathreads>
- Death with Dignity <https://deathwithdignity.org>
- Death with Dignity. Stories <https://deathwithdignity.org/stories>
- Death Café <https://deathcafe.com>
- International Society for Contemporary Legend. Janet Langlois Obituary <https://contemporarylegend.org/2021/05/25/in-memory-of-janet-l-langlois/?fbclid=IwAR2GBRYiDJFjCAy25UEwBB8InYuSjx99UPn2pZxqHFOjuMZuvcmpl-AV3Uc>
- Journal of American Folklore*. Janet Langlois Obituary <https://muse.jhu.edu/article/848311/pdf>
- Order of the Good Death <https://www.orderofthegooddeath.com>