

Failed Liminality and Disenfranchised Grief:

COVID-19 Deaths in Nursing Homes

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Abstract

One of the populations in the United States hit hardest by the COVID-19 virus were residents of nursing homes. Their deaths made the systemic problems and failed expectations of the nursing care industry more legible. In this paper, we draw on ethnographic research of COVID commemoration and activism, including an in-depth analysis of a podcast series on COVID grief, to analyze how survivors' experiences with care facilities exacerbated their suffering and altered expected ritual processes of death and mourning. Cultural expectations and social experiences in this case were not congruent. Thus, we argue that the traumatic nature of death and dying in a nursing home resulted in a failed liminal period, and subsequent "disenfranchised grief" (Doka 1989).

Introduction

According to a recent Kaiser Family Foundation report, more than 200,000 residents and staff have died from COVID-19 in long-term care facilities, constituting at least 23% of all COVID deaths in the U.S. (Chidambaram 2022). It is not enough to give statistics of these deaths, as each death holds a story and leaves behind grieving survivors. These deaths stand out for a fundamental failure of expected care, as nursing homes are predicated not solely on medical care, but on affective care.¹ However, the nursing home industry in the United States has been struggling with systemic issues affecting the quality of care for residents, including understaffing and underpayment,² corruption, the medicalization of elderly bodies, abuse and even murder (Baker 2007; Braithwaite 1993; Bostick 2006; Free 1996; Kieft 2014; Neumann 2020). These issues became even more apparent during the COVID-19 pandemic. Conditions in many of these care facilities worsened as the virus spread rapidly through them. The trust that families had in nursing homes was broken, as they were separated from their loved ones and were unable to provide support and care.

In this paper, we draw on ethnographic research of COVID commemoration and activism, including an in-depth analysis of a podcast series on COVID grief, where we analyze how survivors' experiences with care facilities exacerbated their suffering and altered expected ritual processes of death and mourning. Cultural expectations and social experiences in this case were not congruent. Thus by looking at nursing homes, we highlight one of the sources of suffering that is not immediately recognized without ethnographic review. We argue that the traumatic nature of death and dying in a nursing home resulted in a failed liminal period, and subsequent "disenfranchised grief" (Doka 1989). Survivor narratives then are met with politicized and contested knowledge about the pandemic, alongside the lack of accountability in the nursing home industry.

Methods

Within the larger study of COVID death and mourning undertaken by a team of student and faculty researchers at the George Washington University, the authors and colleagues have spent two years

gathering and analyzing ethnographic evidence of COVID grief and memorialization. We conducted numerous interviews, attended COVID bereavement group sessions, and analyzed podcasts. We listened to a total of 29 episodes from the podcast *For Those We Lost*, hosted by Jennifer Sullivan, who herself lost her mother to COVID in a nursing home. This podcast illuminated prevalent themes that characterize COVID loss and mourning,³ one of these being the shared traumatic experience of losing a loved one in a nursing home.⁴ We supplemented our analysis of the podcast with several interviews, including one with Sullivan to inquire more about her experience and how she came to start her podcast. This paper synthesizes our findings from both the podcast analysis and these qualitative interviews.

Liminality and Disenfranchised Grief

The concept of liminality refers to the temporal period between social statuses during key transitions in life that may necessitate rituals, often consisting of a physical or social separation from social structure (Gennep 1960; Horvath et al. 2018; Turner 1967).⁵ Liminality imbues the experience of transition with a shared discourse about the change in status (Turner 1967). In the context of the nursing home deaths, however, the podcasts provide direct insight into the traumatic nature of the transition from life to death, and the obstacles surviving relatives faced within the external pandemic environment, regarding how to manage COVID deaths.⁶ Thus, the grief these survivors experience becomes what scholar Kenneth Doka described as “disenfranchised grief”—that is, mourning that is not “openly acknowledged, publicly mourned or socially supported” (1989, 4) and instead becomes a time of suffering and conflict.⁷ For nursing home losses, grief is heightened through the traumatic nature of death, the lack of social support, and with little recourse for accountability. As these factors have yet to be repaired, and as the pandemic is still very much a present part of life, their disenfranchised grief exists as a state of failed liminality.

Isolation and Death Without Dignity

When families admit a loved one to a nursing home, they assume that they will be able to maintain social interaction with them and be there in their final moments. During COVID, nursing homes prohibited loved ones from visiting in person, often without updating them on the status of their resident’s health. In the *For*

Those We Lost podcast series, Maureen in Washington⁸ was locked out of her husband's nursing home without advance notice. She told Sullivan that she would sit outside his window for hours, regardless of the weather. When the nursing home had a COVID outbreak, they failed to notify loved ones for days.⁹ This isolation remained in place, regardless of whether their loved one was dying, as was the case for Sullivan. "I just wanted her to have someone with her at the end, and I thought that was going to be me...it really breaks my heart that she died all by herself in the middle of the night with people who had masks on... she probably had no idea what was going on."¹⁰ Such separation from loved ones and denial of presence during their final moments violated the terms of liminality as the expectation to be with a loved one, and engage in the process of death as a transition, was not met.

Nursing home conditions produced deaths without dignity, due to both the isolation and the apparent negligent treatment residents received. Across the country, testimonies from residents and workers detail a lack of PPE and testing, disorganized quarantine procedures, and overcrowding of patients, leading to a failure to deliver care (Khim 2020, 2021; Neumann 2020; New York Times 2020). Debra from Florida¹¹ notes that her 55-year-old brother Bobby contracted COVID while he was living in a nursing home. Debra explains he was feverish, delirious, and had a severe cough, but the workers, she said, made no attempt to improve his condition. A few days later, a nurse told her that Bobby had been found dead on the floor, alone in his room. "I can never accept that Bobby being such a good person died a very cruel and horrific death" (Episode 25, Sullivan, 2022). This inability to "accept" the conditions of death reflects the unexpected status of the bereaved, as they were unable to digest the reality of the death itself. Thus, in their retelling of these final terrible moments, these survivors have given voice to a disenfranchised grief that in turn complicates their ability to acknowledge the loss of their loved one and contributes to a failed liminal stage.

Furthermore, it was not merely the isolation and nature of nursing home death that contributed to this prolonged liminal stage, but also the treatment of the deceased's body after death. Maureen from Washington shares that the nursing home immediately asked for her to send a funeral home to pick up her husband, who was found "dead...laying in the room with two other guys. And they had opened the window.

. . . So the breeze is blowing across his dead body onto these other two men.” According to Maureen, the funeral director said he had never seen such a “chaotic and awful situation” (Episode 2, Sullivan, 2021). In her narrative, death is rendered as a site of potential COVID contagion that disrupted traditional funeral, burial, and mourning rituals. This deprivation of care and ritual produces the failed liminal stage, as mourners cannot reckon with the transition from life to death. As Bari in Pennsylvania stated clearly, “I still, eighteen months later, can’t process it” (Episode 12, Sullivan, 2021).

Rejected Resocialization and Lack of Accountability

An imperative stage of transition is the resocialization, or reintegration state (Turner 1967), but for nursing home COVID bereaved, the exit from the liminal stage is obstructed. Survivors note that nursing homes minimized their losses as a way to escape accountability for negligent treatment. Indeed, some politicians and media have falsely compared COVID-19 to the flu, as a virus dangerous only for the elderly and those with underlying conditions. As this misconception spread, so too did justification of nursing home deaths. Debra in Florida often received questions such as, “Are you sure Bobby had COVID? Did he have underlying conditions? How old was he? Are you sure he didn't die of pneumonia?” (Episode 25, Sullivan 2022). As Debra said, “They minimized it. They downplayed it. And meanwhile, family after family were losing loved ones.” Experiences such as Debra’s reflect the ways in which the country’s nursing home population was marginalized.¹² The lack of acknowledgment of loss from the public heightens mourners’ disenfranchised grief, because their loved ones’ lives are discounted and minimized. This places mourners in a failed liminal stage, as the individual expectations of grief are contested by the collective.

Several states adopted immunity laws after the start of the pandemic, making it much more difficult for the bereaved to seek accountability from nursing homes.¹³ Unlike a hospital or other medical facilities, nursing homes are not under obligation to release documents about past patients.¹⁴ Maureen explained that, after her husband’s death, she wrote to the nursing home facility and reached out to her local and federal representatives. “I’d get generic, boilerplate replies...I just begged [my representative], I said, please. I know she's a busy woman, but please put this under her nose... I think our nation considers nursing homes

just a dirty little secret. And if we don't talk about it, we don't have to think about it" (Episode 2, Sullivan 2022). Mourners of nursing home deaths experience a lack of transparency and accountability, leaving bereaved with unanswered questions about how their loved one died and who can be held responsible. The unanswered questions, lack of transparency, and accountability, denied the bereaved participation in the ritual process, or even knowledge about how their loved one transitioned from life to death.

As we heard repeatedly in the podcasts and in our broader research on commemorative practice, families distinguished COVID deaths in nursing homes for the failures associated with them: unmet expectations of affective care during the pandemic and as their loved one was dying; restrictions that kept them from being at their loved one's side as they died; and that, in the face of immunity laws, many were denied answers and accountability. Families were left with uncertainty and confusion about the treatment their loved ones received and the state of their death, conditions that characterized nursing homes across the country well before COVID hit (Neumann 2016). These failures shape the families' liminal stage of mourning.

With the public insistence for social conditions to return to "normal," mourners such as Debra from Florida express frustration with the systemic failures they experienced. "For us, it's always going to be there, we're always going to have this grief and this prolonged grief that we've been going through, and a loss that left so many questions and anger..." (Episode 25, Sullivan, 2022). Beginning with the premise that reckoning with death requires that survivors manage the transition from life to death, we have argued that COVID deaths in nursing homes reveal a failed liminal process, which itself has become a distinct source of suffering during the pandemic.

Endnotes

1. Affective care focuses on uplifting feelings, moods, and attitudes of residents.
2. Nursing home employees are disproportionately made up of women of color, often immigrants, and often from lower-class backgrounds. See:
<https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts/>
3. The categories analyzed for the podcast were recurring or striking themes, notable quotations with timestamps, key words, and dates of recording and publication.
4. Of the podcasts we listened to, Bari in Pennsylvania, Debra in Florida, Maureen in Washington, and Lauren in New Jersey, experienced a COVID loss in a nursing home.
5. Examples of key life transitions: from childhood to adulthood, from single to married, and life to death.
6. During the pandemic, scholars from a range of disciplines employed the concept of liminality to observe the production of collective and “pedagogical” (Bell 2021) transitional spaces that are characteristic of the COVID-19 experience. These include the space between the virtual and physical, the warped passing of time, the waiting for the passage of the virus, and the transformative patterns of socio-political thought (Bell 2021; De Wiele et al. 2021; Jamjoom 2021). In these studies, “liminality” serves primarily to index states that are aberrant, “abnormal,” or temporarily aberrant, and thus strays from the usage Turner intended .
7. As Clifford Geertz showed in his classic analysis of a failed funeral in Java (1973), cultural expectations and actual social interactions are rarely congruent.
8. In the *For Those We Lost Podcast*, each episode is named as “(Interviewee) in (State of Residence). Throughout the essay, we follow this same naming structure with the link to the podcast after first mention.
9. <https://podcasts.apple.com/us/podcast/for-those-we-lost/id1580833473?i=1000531757041>
10. Jennifer Sullivan, interview by *Rituals in the Making* team, Sept. 20, 2022.
11. <https://podcasts.apple.com/us/podcast/for-those-we-lost/id1580833473?i=1000567410191>
12. For more information on the marginalization of the elderly, see Beth Baker, *Old Age in a New Age: The Promise of Transformative Nursing Homes*. Nashville, TN: Vanderbilt University Press, 2011.
13. Edelman, T. “Immunity for Long-Term Care Facilities during the Coronavirus Pandemic.” Center for Medicare Advocacy. Center for Medicare Advocacy, July 22, 2021.
<https://medicareadvocacy.org/ltc-immunity-during-covid/>.
14. “Ahead of Hearing, Select Subcommittee Releases New Evidence of Dire Conditions at For-Profit Nursing Home Chains in 2020.” *Select Subcommittee on the Coronavirus Crisis*, September 2022.
<https://coronavirus.house.gov/news/press-releases/clyburn-corporate-nursing-home-pandemic-analysis>.
15. Our National Science Foundation research grant can be found at:
<https://cic-apps.datascience.columbia.edu/grants/419>

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