



“I Feel All Alone Out Here”

Analysis of Audio Diaries of Bereaved Hospice Family Caregivers During the COVID-19 Pandemic

Djin L. Tay, PhD, RN ○ Casidee Thompson, ○ Miranda Jones, BS ○
Caroline Gettens, BS ○ Kristin G. Cloyes, PhD, MN, RN ○ Maija Reblin, PhD ○
Megan C. Thomas Hebdon, PhD, DNP, RN, NP-C ○ Anna C. Beck, MD ○
Kathleen Mooney, PhD, RN, FAAN ○ Lee Ellington, PhD

The COVID-19 pandemic has dramatically changed social life. This secondary qualitative analysis aimed to better understand the impact of the pandemic on bereaved hospice family caregivers' experiences of social connection and isolation in a time of social distancing and general anxiety. Six caregivers in 3 states recorded audio diaries (N = 59) between March 13 and May 15, 2020. Caregivers were, on average, 56.80 years old (SD, 14.22; range, 32-67 years old) and consisted of spouses (n = 2), adult children (n = 3), and a sibling (n = 1). Using NVIVO 12, caregiver diaries were coded for (1) “social connection” (n = 23), defined as being able to access or seeking informal or formal social support networks; (2) “isolation” (n = 17), defined as being unable or reluctant to access informal or formal social support networks, or feeling alone; and (3) “bereavement processes” (n = 147), informed by the dual process model of bereavement (restoration and loss-oriented stressors). Content analysis revealed that caregivers were able to connect with others despite physical distancing expectations, expressed loneliness and grief while in isolation, and described moving on in the face of uncertainty. Findings provide insight into how caregivers experienced bereavement

during the initial period of the pandemic and highlight implications for hospice bereavement services.

KEY WORDS

bereavement, cancer, COVID-19, family caregivers, hospice

On March 13, 2020, the United States declared a national emergency because of the global severe acute respiratory syndrome–related coronavirus 2 outbreak (commonly known as COVID-19).¹ The COVID-19 pandemic has been associated with fear of contracting and spreading infection, which has made mask wearing and social distancing widely recommended. These practices, in addition to the general fear and anxiety experienced across all levels of society, have dramatically disrupted social interactions and family processes,² contributed to poorer mental health,^{3,4} and impacted the delivery of health care services to patients and caregivers in the community.^{5,6}

Djin L. Tay, PhD, RN, is assistant professor, College of Nursing, University of Utah, Salt Lake City.

Casidee Thompson, is research assistant, College of Nursing, University of Utah, Salt Lake City.

Miranda Jones, BS, is study coordinator, College of Nursing, University of Utah, Salt Lake City.

Caroline Gettens, BS, is staff, Care Dimensions Hospice, Danvers, MA.

Kristin G. Cloyes, PhD, MN, RN, is associate professor, College of Nursing, University of Utah, Salt Lake City.

Maija Reblin, PhD, is assistant member, Department of Health Outcomes & Behavior, Moffitt Cancer Center, Tampa, FL.

Megan C. Thomas Hebdon, PhD, DNP, RN, NP-C, is T32 postdoctoral fellow, College of Nursing, University of Utah, Salt Lake City.

Anna C. Beck, MD, is director, Supportive Oncology and Survivorship, Huntsman Cancer Institute; and medical director, Community Nursing Services Home Health and Hospice, Salt Lake City, UT.

Kathleen Mooney, PhD, RN, FAAN, is distinguished professor, College of Nursing, and Louis S. Peery and Janet B. Peery Presidential Endowed Chair in Nursing, University of Utah, Salt Lake City.

Lee Ellington, PhD, is professor and Robert S. and Beth M. Carter Endowed Chair, College of Nursing, University of Utah, Salt Lake City.

Address correspondence to Djin L. Tay, PhD, RN, College of Nursing, University of Utah, 10 S 2000 E, Salt Lake City, UT 84112 (djin.tay@nurs.utah.edu).

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Research on the impact of the COVID-19 pandemic on caregiving has mostly been discussed in the health care facility or long-term care settings among active caregivers,⁷⁻⁹ but little is known about how the pandemic affects bereavement for hospice family caregivers (HFCs). Depressive symptoms are common in family cancer caregivers through the first year of bereavement,¹⁰ and approximately 1 in 10 adults experiencing bereavement will go on to develop prolonged grief disorder.¹¹ Depressive symptoms in bereavement can be buffered by emotional support from informal support such as through one's personal network and formal social support systems such as hospice bereavement services.^{12,13} Bereavement services, which are covered under Medicare's hospice benefit up to the first year of bereavement,¹⁴ include one-on-one or group therapy sessions, which may be particularly helpful for those with greater psychosocial support needs. In addition, returning to activities such as work and engaging in a process of meaning making,^{15,16} especially if the death was traumatic, can help individuals cope with bereavement. Holtslander et al's¹⁷ (2017) meta-summary of 47 studies identified a connection with both formal and informal social support networks as the most common facilitator of caregiver coping during bereavement. However, the need to curb the spread of the virus has required that close, in-person interactions with individuals outside one's household be limited, which could affect grieving among bereaved HFCs and negatively impact their ability to seek comfort in a time of crisis.

The dual process model of bereavement (DPMB) developed by Stroebe and Schut¹⁸ (1999) describes the processes by which individuals cope with loss-oriented stressors (eg, grief) and restoration-oriented stressors¹⁹ (eg, forming new identities or relationships) during bereavement and suggests that individuals cycle between loss-oriented and restoration-oriented stressors,¹⁸ instead of progressing through a linear process of stages as suggested by the Stages of Grief model.²⁰ However, the process of bereavement may be affected by disruptive life events, such as natural disasters and pandemics. Applications of the DPMB in disaster research have found that disasters can affect both loss- and restoration-oriented processes,²¹ and it is possible that the COVID-19 pandemic has similarly affected bereavement.

STUDY PURPOSE

The purpose of this secondary data analysis was to examine how the COVID-19 pandemic has impacted HFCs' ability to connect with informal and formal social support networks during bereavement. A secondary purpose was to explore other ways the pandemic has impacted bereavement. Understanding the impact of the pandemic

on HFC bereavement can provide insight into unmet needs for HFCs during highly stressful times.

METHODS

This study is a secondary qualitative analysis of audio diaries as part of a larger study on HFC interactions in home hospice. Institutional review board approval was obtained for the study before recruitment of participants, and an amendment was approved to analyze pandemic-related content in collected data.

Sample Selection, Study Design, and Participants

Hospice family caregivers of advanced cancer patients receiving in-home hospice services were purposively recruited for the primary study from hospices across 3 US states. After written informed consent, caregivers recorded audio diaries through a secure, automated interactive voice response system. Hospice family caregivers were randomized into 1 of 2 conditions (Table 1) where participants were asked to (1) elaborate on patients' and HFCs' symptoms or (2) talk about their thoughts and feelings related or unrelated to their role as caregiver. Hospice family caregivers who were randomized into the second condition continued to record diaries through the first 6 months of bereavement. Because this study was specifically interested in the bereavement experience, only recordings

TABLE 1 Automated IVR Audio Diary Script	
First 3 calls	"Taking time to reflect on how you are feeling can improve your health, this next part of the call is a time for you to think out loud. Please talk about what it is like to for you now. To do this, simply speak into your phone after you hear the tone. Tell me your deepest thoughts and feelings about what you are going through? Talk about good and bad things that happened today. If you are talking leads to other issues, that is fine. Do not worry if you say something you'd like to change, if you say 'um' or if you stutter, that is absolutely okay. It is fine to stop talking and then start again. Let yourself go and get in touch with your deepest thoughts and feelings. When you are finished talking press the '#' key. Remember, this is your time."
Subsequent calls	"At the tone, please talk about your thoughts and feelings about what you are going through. When you are finished talking press the '#' key. Remember, this is your time."
Abbreviation: IVR, interactive voice response.	



from HFCs assigned to the latter group were selected. An HFC who was a friend of the deceased was excluded because of the differences in bereavement experiences between kin and nonkin caregivers. Eligible HFCs ($n = 6$) were 18 years and older and were spouses, siblings, or nonparent family members of the hospice patient, who provided care to the patient during hospice. Hospice family caregivers who completed the baseline and longitudinal surveys from the parent study were compensated for their time, but participants did not receive additional compensation for recording audio diaries.

Analytic Strategy

Qualitative content analysis was conducted using NVIVO 12 Plus.²² Using a team coding approach,²³ team members coded all collected data with the codes. Codes (“social connection,” “isolation”) were developed by the first author and refined through team discussions to answer the study aim. “Social connection” was coded when HFCs mentioned being able to or had access to their informal or formal social support networks such as family members, friends, colleagues, or hospice bereavement services. “Isolation” was coded when HFCs were unable to access their informal or social support networks, or mentioned loneliness or being alone. “Bereavement processes” were guided by the DPMB and included restoration-oriented and loss-oriented stressors.¹⁸ *Restoration-oriented stressors* referred to HFCs’ return to their precaregiving life, taking on new roles or identities, engaging in constructive activities, focusing on the positive aspects of life, and distracting themselves from dwelling on grief, whereas *loss-oriented stressors* referred to grief, breaking bonds that tied the caregiver to the deceased, denial, or avoidance of restoration-oriented activities.

The coders also applied pandemic-related subcodes: (1) pandemic-related social connection or (2) pandemic-related isolation when caregivers spoke directly about the pandemic, such as “There’s a lot of social isolating right now because of the coronavirus, but I met with a group of friends on Zoom today...so I do feel pretty connected” or “A little isolated because of COVID-19.” These codes were also applied when caregivers indirectly mentioned the pandemic (eg, “I’ve been able to visit my mother and my youngest brother and my nephews at appropriate social distances”). Disagreement in coding was resolved at team meetings, and the analytic process was documented in an audit trail (Table 2).

RESULTS

A total of 59 audio diaries (range, 1–42) were collected. Table 3 reports the demographic characteristics of HFCs ranging between 2 and 7 months post bereavement (mean [SD], 4.17 [1.94]). Participants consisted of children ($n = 3$), spouses or partners ($n = 2$), and a sibling ($n = 1$) of the

deceased, with a mean (SD) age of 56.80 (14.22) years (range, 32–67 years; 1 missing).

Of the 59 diaries, $n = 32$ diaries (54.24%) contained references about the pandemic (eg, COVID, COVID-19, coronavirus situation, virus, pandemic). All HFCs made at least 1 pandemic-related reference in their audio diaries. “Social connection” was coded 23 times (12.3%), “isolation” was coded 17 times (9.1%), and “bereavement processes” were coded 147 times (78.6%). Within these codes, recurring topics raised by the caregivers included connection despite physical distancing, loneliness, and grief in isolation, and moving on in the face of uncertainty.

Connection Despite Physical Distancing

Hospice family caregivers described not being able to visit distant family over vacations and being unable to access entertainment or recreation due to the pandemic. They also described strategies such as staying 6 ft apart, quarantining before visiting vulnerable family members, and using videoconferencing to overcome social distancing barriers. A widowed husband described building a new relationship in the context of social distancing:

The past 24 hours although we kept six feet apart, I had a walk with someone today who is obviously interested in building a relationship with me. I’m not sure how much I return that interest. I’m not sure there’s a big spark there but she’s really a nice person.

The need for connection was even stronger in the context of the pandemic because some HFCs struggled to make sense of the changes in their life and the new state of society:

Well, I have been feeling kind of down the last couple of days, cried a few times thinking about momma wishing she was here so I could talk to her about everything that was going on in this country.

It was particularly hard for this participant who became closer to her mother because of caregiving and had lost both parents within a short period:

I’ve been uh...anxious and worried a lot in the last 24 hours and I’m sure this damn pandemic virus is a part of it but I miss my mommy and I want to talk to her...it makes the whole thing worse having gone through the death of both my parents in the last year and it just magnifies everything and being the caregiver for my mom brought me so much closer to her and that made it even harder to let go so ya, I’m not doing good today. That’s all.

Going back to work represented a return to a “normal life” for some HFCs. However, the need for physical



TABLE 2 Themes and Exemplars

Theme	Description	Subcodes and Exemplars
Connection despite physical distancing	The pandemic necessitated different means by which HFCs connected with their personal and formal support systems (eg, friends, families, coworkers, bereavement services).	Social connectedness: "I was able to visit with my daughter and grandson and son-in-law and we had a good hour or so together and it was very nice. We cannot stop yakking when we are together. So that was good. Good to be around people you love." Pandemic-related social connectedness: "I was able to work remotely and had several video phone team meetings which makes you feel not as alone because of this isolation that we are going through."
Loneliness and grief in isolation	Pandemic-related concerns contributed to the inability or conscious choice to avoid in-person interactions that may have intensified feelings of loneliness or instances of being alone.	"A little down being home by myself last night." Pandemic-related isolation: "I just feel isolated and hospice canceled their counseling session that I had signed up for."
Moving on in the face of uncertainty	Pandemic-related concerns affected HFCs' ability to return to a "normal" life or engage in activities, and grieve. However, HFCs also identified positive aspects of losing a family member before the pandemic.	Loss-oriented stressors: "I've been uh anxious and worried a lot in the last 24 hours and I'm sure this damn pandemic virus is a part of it but I miss my mommy and I want to talk to her and I just I cannot." Restoration-oriented stressors: "I'm also a runner, and I was getting ready to run in the [large marathon] marathon in honor of my husband and raising money for [large hospital], and we learned today that that's going to be postponed until September due to the coronavirus."

Abbreviation: HFCs, hospice family caregivers.

distancing and the widespread encouragement of work-from-home policies posed initial barriers to connecting with others:

I was really looking forward to going back to working in my office eventually you know—after my mother passed away and now that she has gone—and this coronavirus thing has taken off I can't work in my office.

Technology quickly bridged the gap for many to resume work from their homes, allowing caregivers to return to their careers and connect with colleagues: "I was able to work remotely and had several video phone team meetings which makes you feel not as alone because of this isolation that we are going through." The ability to see friends, coworkers, and family helped provide a sense of connection despite HFCs not being able to connect with society in daily life such as attending church, recreating, and going out to restaurants and entertainment venues.

However, pandemic-related social distancing also offered HFCs an easy excuse for bereaved HFCs to disengage from their social networks if they did not feel like it, which an HFC had to consciously overcome:

Sort of self-isolating due to the coronavirus. Kind of withdrawing socially and not wanting to connect with people at all. I'm trying to work on that today. Just in terms of internet participation and reaching out to people. Both friends and family and business as well.

Loneliness and Grief in Isolation

Sadness, grief, and loneliness were often discussed in the context of being alone. As this widow described, "In the last 24 hours [I'm] sort of feeling a little down. A little isolated because I still...mean because of COVID-19. Trying to cope with some of that loneliness and frustration." This inability to connect with others in a face-to-face setting, although manageable for some, was harder for others—in particular, those who already were dealing with negative emotions. A caregiver described her difficulty accessing formal support during this time:

I just feel isolated and hospice canceled their counseling session that I had signed up for so I don't know I just feel all alone out here and I don't like it. But I understand it's the coronavirus...there is nothing anybody can do.



TABLE 3 Demographic Characteristics of Family Caregivers

Demographics	Sample (N = 6)	
	Mean (SD)	Range
Age, y	56.80 (14.22)	32-67
Length of bereavement, mo	4.17 (1.94)	2-7
	n (%)	
Race		
White	5 (83.33)	
Multiple races	1 (16.67)	
Ethnicity		
Hispanic/Latino	2 (33.33)	
Non-Hispanic/Latino	4 (66.67)	
Sex		
Female	5 (83.33)	
Marital status		
Married/domestic partnership	4 (66.67)	
Single (never married)	1 (16.67)	
Separated/divorced/widowed	1 (16.67)	
Religious preference		
No religious preference	2 (33.33)	
Catholic	1 (16.67)	
Protestant	3 (50.00)	
Highest level of schooling		
Some college or vocational school	3 (50.00)	
College graduate (4 y)	1 (16.67)	
Graduate or professional degree	2 (33.33)	
Employment status		
Not employed	1 (16.67)	
Part-time	0 (0.00)	
Full-time	5 (83.33)	
Relationship of the caregiver to the patient		

(continues)

TABLE 3 Demographic Characteristics of Family Caregivers, Continued

Demographics	Sample (N = 6)	
	Mean (SD)	Range
Child	3 (50.00)	
Spouse	2 (33.33)	
Sibling	1 (16.67)	
Annual household income		
\$25 000-\$39 999	1 (16.67)	
\$40 000-\$49 999	1 (16.67)	
\$50 000-\$74 999	1 (16.67)	
\$75 000 or more	3 (50.00)	
Overall health		
Excellent	1 (16.67)	
Very good	1 (16.67)	
Average	4 (66.67)	

Being socially disengaged and physically distanced could have also possibly contributed to less healthy coping: “I had a little too much to drink last night by myself and I ended up crying a lot which is ridiculous. The drinking, not the crying.”

Moving on in the Face of Uncertainty

HFCs often described anxiety and stress when talking about the COVID-19 pandemic:

I have been having a really hard time sleeping the last couple days. I'm just stressed out about work and everything going on with the coronavirus. Making sure my mom doesn't get infected. Just that everything's taking care of. It's just a lot of stress.

Sometimes this anxiety overshadowed their grieving:

My mother who is 87 and lives in another state has been very, um, has been ill with severe back pain and I can't visit her, uh, because of the coronavirus.... I'm sort of more focused, or equally focused, on that as...with my husband's loss.

In addition, the pandemic resulted in the delay of an event that an HFC had planned to attend to recognize the memory of her husband:



I was getting ready to run in the [large marathon] marathon in honor of my husband and raising money for [large hospital], and we learned today that that's going to be postponed until September due to the coronavirus.

However, the pandemic also brought positive aspects to HFCs' experience such as a sense of relief that their family member died before the onset of the pandemic: "I can definitely say, with certainty, that I am grateful now that he died when he did due to the craziness going on."

In addition to the struggles faced by the general public such as fear of contracting COVID-19 and the economic impact of the pandemic, caregivers also had to contend with their bereavement journeys:

Not certain what is going to happen with this coronavirus. I know two people who have gotten it and I'm very concerned about what is going to happen for them. Concerned about my income, concerned about my job, concerned about everything. These are difficult times and added to that is trying to come accustomed to what has become my life... whether I'm going to be alone the rest of my life or find someone.

Aside from the psychosocial aspects of bereavement, the timing of the pandemic clashed with what was already a stressful period for family members. This caregiver described being unprepared for the paperwork involved with the death of a family member:

I'm at the stage now where I am dealing with the paperwork and oh my gosh it sucks. I really wish hospice would do some kind of just a general prep of survivors, for this is what your need to go to social security and this is what you're gonna need for the bank and yada yada yada because I gotta tell ya dealing with bureaucracy is very, very frustrating and that's you know on top of the grief I am experiencing it just is not fun. I wish someone had warned me what is coming.

Overall, this analysis of bereaved hospice caregivers' audio diaries demonstrated that the COVID-19 pandemic has had a distinct effect on HFCs' bereavement experiences and has implications for HFC adjustment. These diaries highlighted the experiences of struggling to cope and successful adaptation to grief and loneliness, seeking comfort from others, returning to a new normal, and framing new identities in light of the COVID-19 pandemic.

DISCUSSION

To this team's knowledge, this is the first study that examined how HFCs experienced the initial onset of the COVID-19 pandemic. Although these diaries were collected

as part of a larger study, these particular diaries provided unique insight^{24,25} on the unanticipated effects of the COVID-19 pandemic on bereaved HFCs, adding to the trustworthiness of the data. The longitudinal nature of this qualitative study during a unique time in history is also a strength of this study.

The Need for Connection

In general, the results indicated that, for most caregivers, COVID-19–related perceived isolation was temporary. Although HFCs faced barriers in connecting with their social support networks, many of these barriers were overcome with either technology or other social adaptations. Social connection with others is a critical aspect of adjusting to bereavement¹⁰ and may be accessed in various ways formally, such as in-person support, online support groups, and telehealth-delivered support. Although technology may have enabled HFCs to engage with new or multiple forms of connection in this sample, it is important to note that not all HFCs may have access to the technology, skills, or Internet connectivity to access social support using online platforms. It may be helpful for clinicians to assess for digital literacy, in addition to routine assessments,²⁶ among bereaved caregivers because technology can help reach individuals who are socially or geographically isolated. As health care services pivot to telehealth platforms because of the pandemic, this vital delivery of formal social support is now more critical than ever. Telehealth group-based support services have been shown to improve mental health outcomes for HFCs²⁷; however, this pandemic has highlighted the need for telehealth service infrastructure to be part of a proactive approach to emergency situations and the need for a trained workforce that can deliver care through online platforms.²⁸

The Need to Support Isolated Caregivers

This study observed that pandemic-related physical distancing promoted more opportunities for HFCs to be alone. Not only were HFCs restricted in their social interactions with their family, friends, and hospice services, but they were also unable to engage in activities they were looking forward to such as going to museums, playing golf, or simply being back in the office. For caregivers who were already struggling with loss, isolation may have added to negative emotions. It was noted that the caregiver with the most observed emotional distress also recorded the most diaries. This finding is supported by research that suggests that individuals who are having greater difficulty with coping seek help more often than those who are less affected.^{29,30} It is possible that, although it was not intended as an intervention, the automated audio diary may have provided HFCs an outlet to express their emotions in a time where other social support systems were unavailable. Although hospices typically send out



condolence cards or letters, follow-up calls, and educational materials to support caregivers up to a year after the death of a hospice patient as part of bereavement services,³⁰ future considerations for supporting caregivers may include activities that encourage constructive processing of negative feelings outside formal services, such as audio diaries or reflective journaling. Providers should also recognize that individuals do not linearly progress through grief and, for some, may be an enduring state. Thus, hospice providers need to help caregivers identify their social support networks that can continue the support of HFCs outside formal services or refer caregivers to ongoing grief support programs.

“It’s a Tough Time” for HFCs

The COVID-19 pandemic potentially contributes to a higher risk of prolonged grief.³¹ Aside from being increasingly isolated from others, the anxiety and stress experienced by HFCs concerning the pandemic may have added to HFCs’ current stress. Some HFCs described being overwhelmed by stressors such as dealing with the legal and administrative work associated with the death of a family member, continuing to care for an elderly parent, and other daily stressors. These accounts highlight that the bereavement stress may be heightened in times of crisis, as this caregiver stated, “It’s just a tough time right now.” Whereas some caregivers may benefit from psychosocial support, others may have unmet needs for legal, financial, and administrative assistance to help them navigate the other more pressing stressors of bereavement, which underscores the importance of social workers in the care team. This highlights the importance of providing education and referrals to family members struggling with the logistical considerations of funeral arrangements and settling estates, which hospices are in a prime position to provide educational and formal support.

Some other HFCs expressed that the stress and anxiety from the pandemic competed for their attention and that they had less time to dwell on their grief. Avoidance of negative emotions may be a reason HFCs chose not to engage with the audio diaries, as this HFC stated: “I know I have not checked in in quite some time. After my father’s passing and doing everything...taking care of everything that needed to be taken care of. It was difficult to keep thinking and rehashing all of it.” However, avoidance of these negative emotions may not be healthy in the long run—as avoidance or delay in grief work has been associated with complicated grief.³² During bereavement, members of the hospice team should watch for signs of avoidance of grief, which is characterized by an avoidance of going to places or engaging in activities that evoke memories of the deceased or avoid losses of others in their network such as going to funerals.³²

Limitations

This study specifically sought to understand the acute impact of a pandemic on bereavement; therefore, data collection of diaries was limited. As such, there is no information about the bereavement experiences of the HFCs who did not participate in the audio diaries and how their bereavement experiences differed from this sample. This may have limited the team’s ability to examine more fully the impact of the pandemic on bereavement. In addition, the sample was small, relatively homogenous in racial and ethnic composition, and there was an underrepresentation of male HFCs. Nevertheless, the uniqueness of the data was a strength.

Practice Implications

The COVID-19 pandemic has greatly impacted the delivery of bereavement services such as in-person support groups and one-on-one grief counseling sessions, which are a cornerstone of hospice care.³³ In-person connections and face-to-face interactions can be critical for many experiencing loss, particularly for those who rely on these programs and support systems to process their grief. Although HFCs in the participating hospices were able to access telehealth services soon after services were disrupted, it is important to note that the quality of bereavement services is inconsistent across hospices,³⁴ and services such as screening family members for depression after the patients’ death and providing one-on-one or group counseling services are often only offered to those who are seen as at a greater risk for poorer mental health.³⁰ Thus, an area of exploration could be the concept of universal precautions of conducting depression screenings and offering counseling after bereavement.

CONCLUSIONS

This study is one of the first to describe HFCs’ accounts of their bereavement during the COVID-19 pandemic using the DPMB, which has been applied to study bereavement in natural disasters. McManus et al (2018) found that, in natural disasters, disasters that have a toll on human life but not physical infrastructure tend to prompt loss-oriented processes (such as grieving the loss of life), whereas disasters that have a more visible toll such as in the case of destruction to buildings tend to prompt restoration-oriented processes (such as a focus on rebuilding).¹⁶ With the increased demands on home hospice services, the lack of personal protective equipment, the need for stringent infection control, and the greater needs of patients and active caregivers, the support of bereaved HFCs may be overlooked.

Bereaved HFCs’ grieving can be complicated by daily stressors and inadequate support from the health care system.²⁷ Audio diaries provided valuable insight into the thoughts and feelings of bereaved HFCs as they processed their bereavement experiences and may have offered an



outlet for HFCs to express their emotions at a time where other support systems were unavailable. This study highlights the need for increased psychosocial and digital literacy assessment; unmet needs for education for the legal, logistical, and financial aspects of bereavement; and the need for flexible and responsive support engaging both informal and formal networks during the COVID-19 pandemic.

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