

Original Article

The Lived Experience of Physical Separation for Hospice Patients and Families amid COVID-19



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Abstract

Context. Many hospice patients were physically separated from family members and healthcare professionals during the early COVID-19 pandemic.

Objectives. Researchers sought to describe the lived experience of physical separation for hospice patients and family caregivers who adhered to public health guidelines intended to limit the transmission of COVID-19 in the spring of 2020.

Methods. Researchers performed a secondary analysis of qualitative data collected during a multi-site clinical trial of an intervention that incorporated family caregivers into care plan reviews during biweekly hospice interdisciplinary team meetings. Twenty-eight adult family caregivers of hospice patients with cancer participated in at least one care plan review between March 7, 2020 and June 10, 2020. The final analytic dataset included the transcribed content of 60 care plan reviews, which were analyzed via reflexive thematic analysis.

Results. Hospice patients and their family caregivers experienced physical separation as interrupted care that resulted in the potential for unmet informational, functional, and social and emotional needs. Connection strategies employed to adapt to care interruptions and address patient and caregiver needs were not consistently effective.

Conclusion. Inclusive, innovative connection strategies are needed to ensure that high-quality end-of-life care is provided to hospice patients and their family caregivers when physical presence must be limited. *J Pain Symptom Manage* 2022;63:971–979. © 2022 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Caregivers, COVID-19, family, hospices, patients, social isolation

Key Message

This article describes the qualitative analysis of 60 hospice care plan discussions that illustrate the lived experience of physical separation for hospice patients

and families in the early COVID-19 pandemic. Findings point to the need for inclusive, innovative connection strategies to meet families' informational, functional, and social and emotional needs.

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Introduction

Although the World Health Organization acknowledged COVID-19 as a public health emergency of international concern as early as January 30, 2020,¹ daily life remained largely unchanged for many Americans until weeks later. On March 13, 2020, the U.S. President declared COVID-19 a National Emergency.² Not long after, many state and local governments issued stay-at-home/shelter-in-place measures aimed at slowing the spread of the virus. With little advance warning, large gatherings were banned; schools, restaurants, and gyms closed; and “non-essential” employees began working from home.³ The potentially damaging effects of social isolation, long known to be a risk factor for poor physical and psychological health among older adults, were quickly brought into focus.⁴ As was later opined, “The struggle to balance literal survival with all the things that make surviving worthwhile [had] never been so clear.”⁵

U.S. Hospice Care in the Early Pandemic

Although they would later play an essential role in the U.S. response to COVID-19,⁶ many American hospice providers cared for few, if any, COVID patients in the very early days of the pandemic. Then, as before, the typical U.S. hospice patient was an older adult with a life expectancy of six months or less who lived in a private residence or long-term care (LTC) facility and received significant support from unpaid family members and friends (commonly referred to as “family caregivers”).⁷ Federal regulations mandating biweekly hospice interdisciplinary team meetings, during which patients’ care plans are reviewed and updated, remained in place, although the meetings themselves moved online.⁸ In numerous other respects, however, changes were widespread. Unclear directives regarding patient contact, rapidly-changing state and local ordinances, insufficient supply of personal protective equipment, and growing fears amid rapidly increasing numbers of positive cases and deaths dramatically altered the landscape of U.S. hospice care.⁹

Among the most pronounced changes experienced by hospice providers and the patients and families they served in the spring of 2020 were restrictions on physical contact. As social distancing, defined as “remaining out of congregate settings, avoiding mass gatherings, and maintaining ... approximately 6 feet ... from others when possible,”¹⁰ became the norm, many patients and families limited contact with individuals outside of their homes. Some patients and family caregivers who lived in separate residences stayed apart from one another. This was especially true among patients living in LTC facilities, many of which restricted all visitors and non-essential personnel from entering the premises.¹¹

Many patients and their families also experienced separation from hospice care providers in the early pandemic. Lack of clarity and shifting guidance from regulatory bodies regarding the definition of “essential personnel,” coupled with wide variation in more localized interpretations of public health directives, led to uncertainty and frequent changes in rules governing facility visits by hospice providers.⁹ Hospice care for patients living in LTC facilities was commonly provided via telephone; direct care tasks that had previously been performed by hospice team members shifted to facility employees. In addition, lack of access to personal protective equipment occasionally limited home visits at the onset of the pandemic.¹² Understanding potential systemic deficiencies and being better equipped for socially distant care in preparation for future COVID-19 surges,¹³ emergencies, and other disasters can be important benefits of understanding patients’ and families’ experiences during this national crisis.

Study Purpose and Research Questions

The overarching purpose of the study described herein was to describe the lived experience of physical separation for hospice patients and their families during the early days of the COVID-19 pandemic. Specifically, researchers sought to illuminate patients’ and family caregivers’ perspectives and experiences by answering the following research questions: (1) How did physical separation affect hospice patients and their family caregivers? and (2) How did hospice providers, patients, and family caregivers attempt to adapt to the physical separation?

Methods

Data Source

Data analyzed in the present study were originally collected as part of a National Cancer Institute-funded multi-site clinical trial (R01CA203999; ClinicalTrials.gov identifier: NCT02929108; University of Missouri Institutional Review Board Project #2006270) conducted, in part, to determine the effect of participation in hospice interdisciplinary team (IDT) meetings on family caregivers’ distress (a detailed description of the trial, including a complete study protocol and additional outcomes of interest, has been previously published¹⁴). Inclusion criteria required that participants were English-speaking adults who were providing unpaid care to an adult with cancer receiving services from one of seven Missouri hospice sites. At the time of their enrollment in the original trial, all participants whose data were analyzed in the present study were providing care to a hospice patient living in a private

residence (e.g., house, apartment) or a LTC setting such as a skilled nursing facility. Multiple family caregivers per patient were allowed to enroll in the study.

Approximately one-third of the family caregivers taking part in the clinical trial participated by telephone or videoconference in biweekly IDT meetings during which their family member's plan of care was reviewed. These caregivers' virtual participation was not an adaptation to COVID-19; the study protocol was designed from the start to maximize accessibility for individuals who might find it difficult to leave home due to caregiving responsibilities. Hospice staff members' participation in IDT meetings, however, changed as a result of COVID-19. Prior to the pandemic, hospice nurses, social workers, chaplains, physicians, and other members of the interdisciplinary team attended meetings in person in the hospice agency office, where they used telephone or Zoom (San Jose, CA) to connect with family caregivers calling from home. By late March 2020, a statewide social distancing order was in place, and numerous counties had issued shelter-in-place orders. Nearly all hospice staff members had begun participating in IDT meetings from their homes. Like family caregivers, they connected with other attendees via telephone or ZOOM. Although patients whose family caregivers participated in the clinical trial were invited to participate in their care plan reviews, they rarely did so; none of the reviews analyzed in the present study included patients as participants.

The qualitative dataset analyzed in the present study consisted of the transcribed content of 60 care plan reviews that occurred during family caregiver-inclusive hospice IDT meetings between March 7, 2020 (when the first positive test of COVID-19 was announced in Missouri,¹⁵ the state in which the study was conducted) and June 10, 2020 (when researchers stopped recording hospice IDT meetings as part of the larger clinical trial). 28 family caregivers participated in at least one care plan review during this approximately three-month period of time (demographic characteristics of participating caregivers and their patients are provided in Tables 1 and 2). The duration of the care plan reviews ranged from two minutes and 53 seconds to 16 minutes and 28 seconds, with a mean duration of seven minutes and 11 seconds and a standard deviation of three minutes and 10 seconds.

Data Analysis

Researchers conducted a reflexive thematic analysis,¹⁶ following a predominantly inductive process in which themes were conceptualized as meaning-based patterns that were informed by the data rather than generated from an existing framework. This process consisted of six phases: becoming familiar with the dataset; coding the data; generating initial themes; developing and reviewing themes; refining, defining,

Table 1
Family Caregiver Demographic Characteristics

	Overall (n=28)
Age	
Mean (SD)	58.2 (12.3)
Median [Min, Max]	61.0 [34.0, 76.0]
Gender	
Male	8 (29%)
Female	20 (71%)
Race	
Black/African American	6 (21%)
White	22 (79%)
Ethnicity	
Non-Hispanic	25 (89%)
Hispanic	1 (4%)
Missing	2 (7%)
Relationship Status	
Single, never married	2 (7%)
Married or partnered	20 (71%)
Divorced or separated	2 (7%)
Widowed	2 (7%)
Other	1 (4%)
Missing	1 (4%)
Highest Formal Education	
High school/GED	4 (14%)
Some college/trade school	13 (46%)
Undergraduate degree	6 (21%)
Graduate/professional degree	5 (18%)
Employment Status	
Not employed/retired	15 (54%)
Employed part-time	3 (11%)
Employed full-time	10 (36%)
Annual Household Income	
Under \$20,000 per year	2 (7%)
\$20,000 to \$39,999	6 (21%)
\$40,000 to \$69,000	11 (39%)
Over \$70,000	6 (21%)
Missing	3 (11%)
Relationship to Patient	
Adult child	9 (32%)
Spouse or partner	11 (39%)
Other relative	3 (11%)
Other	5 (18%)

Note: Percentages may not total 100 due to rounding.

and naming themes; and describing themes in writing.¹⁶ Theoretically, the study was grounded in a critical realist approach, which acknowledges that an objective reality exists while also emphasizing that one's experience and understanding of that reality are shaped by language and culture.¹⁷ Accordingly, researchers sought to understand the reality of patients' and families' experiences, while also attending to the broader social context and ascribed meaning of those experiences.

First, each of the 60 transcripts was read by at least two researchers who made notes regarding their initial impressions of the data. Next, researchers used NVivo qualitative analysis software (QSR International (Americas) Inc., Burlington, MA) to label pertinent data segments with codes describing the segments' semantic (i.e., explicitly stated) meanings. After all the transcripts were coded, researchers collaboratively organized the coded data into candidate themes that captured the data's deeper, more implicit meanings. Researchers

Table 2
Patient Demographic Characteristics

	Overall (n=26)
Age	
Mean (SD)	72.5 (12.0)
Median [Min, Max]	72.0 [51.0, 94.0]
Gender	
Male	15 (58%)
Female	11 (42%)
Race	
Black/African American	5 (19%)
White	21 (81%)
Ethnicity	
Non-Hispanic	24 (92%)
Missing	2 (8%)
Relationship Status	
Single, never married	3 (12%)
Married or partnered	11 (42%)
Divorced or separated	2 (8%)
Widowed	9 (35%)
Missing	1 (4%)
Highest Formal Education	
Less than high school	5 (19%)
High school/GED	9 (35%)
Some college/trade school	9 (35%)
Undergraduate degree	1 (4%)
Graduate/professional degree	2 (8%)
Patient Residence/Location of Care	
Private Residence	19 (73%)
Long-Term Care Facility	7 (27%)
Primary Cancer ^a	
Brain Cancer	2 (8%)
Breast Cancer	1 (4%)
Gastrointestinal Cancer	6 (23%)
Genitourinary Cancer	6 (23%)
Gynecologic Cancer	2 (8%)
Lung Cancer or Mesthelioma	5 (19%)
Missing/Unknown	4 (15%)

Note: Percentages may not total 100 due to rounding.
^aPrimary cancer information was provided by study participants.
 No data were obtained from the medical record.

then reviewed each candidate theme by returning to the transcripts to ensure that the themes accurately reflected the data and provided valuable insight(s) into

hospice patients’ and family caregivers’ experience of physical separation during the early pandemic. Researchers named and provided definitions of themes retained beyond the candidate stage and, finally, created a visual map and corresponding written explanation that illustrated relationships among themes. Measures to enhance the trustworthiness of study findings included dual coding of all study data, multiple and repeated instances of peer debriefing, and maintenance of an audit trail comprising meeting notes and e-mail correspondence regarding analytic decisions in addition to a shared Box (Box, Inc., Redwood City, CA) folder containing all analytic files.

Reflexivity, the process of intentionally considering how researchers’ disciplinary, theoretical, and personal expectations and assumptions shape data analysis,¹⁶ was regularly practiced and discussed during research team meetings. Subjects that were the focus of reflexivity discussions included researchers’ professional backgrounds (nursing, research, education, social work), their prior experiences with death and dying, and their own social realities in the early days of the COVID-19 pandemic. The goal of reflexivity was to bring awareness to researchers’ responses to the data and to work together to utilize those responses as a resource to deepen rather than obscure an understanding of patients’ and families’ experiences.

Results

The Lived Experience of Physical Separation: Interrupted Care

Data indicated that, for many hospice patients and their family caregivers, the early days of the COVID-19 pandemic were shaped by physical separation:

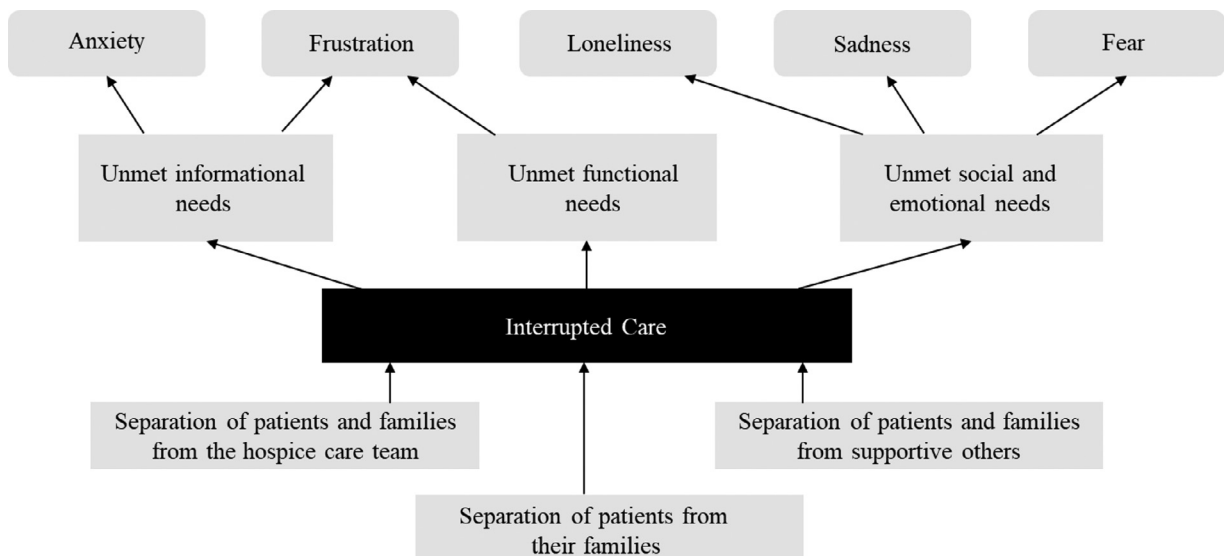


Fig. 1. Visual map.

separation from the hospice care team, separation from a broader network of support, and/or separation from one another. Each of these types of physical separation was, to varying degrees, described as an interrupted pathway of care. Thus, analysts determined that the essential experience of physical separation for hospice patients and families in the early days of the COVID-19 pandemic was *interrupted care*, shown in Fig. 1 in relationship to three potential consequences of care interruptions: *unmet informational needs* (leading to *anxiety* and *frustration*), *unmet functional needs* (also resulting in *frustration*), and *unmet social and emotional needs* (prompting feelings of *loneliness*, *sadness*, and *fear*). Each of these potential consequences is described below, along with a discussion of connection strategies employed in an attempt to adapt to the care interruptions introduced by COVID-19. *Interrupted care*, determined to be the defining feature of the experience of physical separation for patients and families, is not described below as a separate theme; rather, examples of care interruptions are interwoven with discussion of their potential consequences and the strategies employed to avoid them.

Unmet informational needs. Discussions in hospice IDT meetings highlighted the degree to which, prior to the COVID-19 pandemic, physical visits served as an important opportunity to gather information on patients' care and wellbeing. Removed from physical contact, family members of patients residing in LTC facilities reported feelings of *anxiety* ("concern [for patient] welfare") and *frustration* ("trying to manage [care] from afar"). Members of the hospice team who were unable to visit patients in LTC facilities typically sought patient updates by placing telephone calls to facility staff members; however, those calls often went unanswered or unreturned. Even when patient updates were successfully relayed via telephone, the lack of information obtained "face-to-face" was frequently noted as problematic. As a result, the information hospice teams were able to share with patients' family members during IDT meetings was limited. Speaking with a patient's family member, a nurse explained, "[At the next IDT meeting], we may not have a whole lot more to say, unfortunately, because of the lockdown. But, like I said, we are trying to stay in contact with [the patient's facility]."

In addition to *unmet informational needs* related to routine patient care and wellbeing, hospice providers and family caregivers were sometimes without information on significant patient-related events. As one example, a patient who had fallen in a LTC facility was unable to receive an x-ray to determine if any of her bones were broken. A hospice nurse provided the following information: "[Patient] had a fall last week, and her right arm started to hurt, and there are no x-ray technicians that can go into the facility because they're

out with COVID too. So, we didn't do x-rays. We just controlled the pain with Tramadol, 50 mg, every six hours." The patient's family caregiver provided additional information, reporting that, "Apparently, she was seen [in the facility] by a physical therapist, and they suspect that the arm is actually broken in two places."

While most examples of *unmet informational needs* were identified during discussions of care plans for patients residing in LTC facilities, physical separation sometimes resulted in *unmet informational needs* for patients and families living in the community. e.g., a family caregiver whose brother was receiving hospice services was made aware of a recent fall during an IDT meeting. She stated, "[My brother] never told me [he fell]. I told him, 'You've got to let me know [if] anything happens when I'm not there,' [but] he doesn't like to worry me."

Unmet functional needs. The potential for *unmet functional needs*, defined as a lack of support in completing activities of daily living (e.g., bathing, eating) or instrumental activities of daily living (e.g., housecleaning, meal preparation), was not often discussed during hospice IDT meetings. Despite its infrequency in the dataset, this theme was retained in the final analysis due to many functional needs' inherently physical nature and the pronounced challenges patients and families encountered when trying to address them amid the physical separation introduced by COVID-19. Most statements comprising this theme pertained to LTC facilities' policies limiting visits from hospice home health aides. At the time the data were collected, most aides were providing "supply delivery only" to LTC facilities. Responsibility for personal care (e.g., assistance with bathing) had shifted to the LTC facility staff. Following this change, family caregivers questioned the frequency with which patients were receiving personal care, particularly given the additional demands placed on LTC facility staff. One caregiver explained, "I'm sure it's hard for [facility staff] too, with everything that's going on, and they can't have family in, and they can't have any of the friends or people who used to come in and try to support [residents]. They have to do it all themselves now." Although they acknowledged the additional stressors facilities faced, caregivers were nonetheless *frustrated* by the possibility that their family member was receiving insufficient care.

Only one instance of *unmet functional needs* was identified in the transcripts of care plan discussions involving family caregivers of patients receiving care in the community. In that instance, a social worker summarized an earlier discussion with a patient and family caregiver: "The family . . . had a housekeeper that was coming in and [she] happened to share . . . that she thinks this COVID thing is just a joke, so they are going to find [a] different [housekeeper]."

Unmet social and emotional needs. Data suggested that patients' and family caregivers' social and emotional needs were inextricably linked. Thus, the third theme identified in the dataset was labeled *unmet social and emotional needs*. Discussions in hospice IDT meetings frequently centered on the social isolation and resulting *loneliness* and *sadness* of hospice patients residing in facilities that were limiting residents' interactions with one another and not allowing visitors. For example, one nurse reported, "[Patient] is feeling a little depressed due to eating in the room and not [being] able to go outside the room and interact with other residents." IDT meeting participants wondered aloud about the cognitive effects of social isolation for such patients. During one exchange, a patient's family member asked, "The mental slipping—is that part of her disease process?" After explaining that, indeed, cognitive changes could be a result of the patient's disease process, the hospice nurse added, "I'm sure this isolation is hard on [residents]. [They're] not communicating with others, not seeing others. They're out of their routine. Some of it could be that too."

The prospect of LTC facility residents dying without family members or hospice providers present resulted in *fear* for many patients and family caregivers. One patient was described as voicing concerns about "how hospice [would] interact with her" if they could not be physically present when she died. The patient's nurse explained, "She doesn't want to suffer at the end of her life. She doesn't want to be looking for air. We . . . educated her on [her] medications, and she said she won't be able to ask for medicine. And I said, 'Don't worry. You'll be on a . . . schedule, so you won't have to ask.'" The patient was also described as "very anxious" about not being able to see her daughter at the end of her life. The patient's daughter replied, "God, I hear it in her voice when she talks to me. I just try to reassure her that regardless of me not being in [her] presence, I'm there." Another family caregiver discussed her fear that her father would be alone in his final hours: "To be honest with you, I really I don't know what to expect. I don't know what I should be asking for. I don't know what I want. I just don't want him to lay there and die alone."

Physical separation also resulted in *unmet social and emotional needs* for patients' family members, which were mentioned repeatedly in hospice IDT meetings. One family caregiver's experience mirrored many others. The caregiver explained, "I just really miss my mom. We talked to her and that's fine, but I just want to see her. I haven't been able to see her in almost two months, I just want to see her face." Another caregiver inquired about the anticipated length of COVID restrictions: "How long do they anticipate this COVID thing going on, or do they know? . . . It's been a long time since I've seen

[patient], and he's the only family I've got left." *Unmet social and emotional needs* were experienced by patients and families in the community as well. One family caregiver discussed her young granddaughter's reaction to being required to socially distance from her dying grandfather: "She's just still very tiny and very much a hugger and cuddler . . . The most difficult thing so far has been that we can't be with her, I'm just very concerned because she's definitely Papa's girl."

Connection Strategies

While precautions to prevent the transmission of COVID-19 interrupted existing pathways of care, hospice providers, patients, and family caregivers developed new connection strategies in an attempt to adapt to these changes and prevent unmet needs. Examples included calling rather than physically visiting LTC facilities, visiting LTC residents through windows in their rooms or common areas, identifying in-home service providers who were adhering to public health guidelines, and facilitating video-calls. While many of these strategies were described as less than ideal, they nonetheless allowed a substitute form of connection, information gathering, and provision of care.

These strategies were not without their challenges. During numerous IDT meetings, hospice providers indicated that their calls and emails to LTC facilities often went unanswered or unreturned. Family members reported a lack of support from LTC facility staff in the facilitation of video-calls, and several hospice patients lacked the technology (i.e., Internet-enabled smartphones or electronic tablets) needed to place or receive the video-calls. During one care plan discussion, a nursing supervisor indicated that hospice providers who were able to enter LTC facilities were not allowed to use their work-issued phones to facilitate video-calls because "they're not secure." As a result of these challenges, the effectiveness of attempts to prevent unmet needs was mixed.

Discussion

Study findings indicate that hospice patients and their family caregivers experienced physical separation in the early days of the COVID-19 pandemic as interrupted care that resulted in the potential for unmet informational, functional, and social and emotional needs. Discussions that took place during regularly scheduled care plan reviews also underscore the limited effectiveness of connection strategies employed to adapt to care interruptions and meet patients' and family caregivers' needs.

These findings shed light on numerous opportunities to strengthen hospice organizations' emergency preparedness plans¹⁸ in anticipation of future COVID-

19 surges¹³ and other catastrophic events. Expanded use of telehealth applications, which have been found to be feasible and acceptable for conducting hospice reauthorization visits¹⁹ and facilitating group support for hospice family caregivers,²⁰ could reduce or eliminate unmet information needs and provide socially and emotionally supportive interactions when physical presence is not possible; however, these applications must be designed and delivered in an inclusive manner that ensures equitable access, lest they exacerbate existing disparities in healthcare processes and outcomes.²¹ Hospice patients and family caregivers who, like individuals described in this study, do not possess Internet-enabled smartphones, tablets, or computers, will likely need to be provided with the requisite technologies and support for their use.

LTC facilities, chronically short-staffed even before the pandemic, are now experiencing a full-blown workforce crisis.²² Expecting individual support for residents wishing to place or receive video-calls is likely unrealistic for the foreseeable future, a reality that further underscores the need for telehealth solutions that take into account users' varied functional abilities. Expansion of telehealth for LTC facility residents receiving hospice services could have other benefits as well. For example, access to patient portals, which allow authorized users to securely access information regarding patients/residents' healthcare and status, could significantly decrease unmet information needs among family caregivers and hospice providers, who would otherwise be waiting for returned phone calls and emails; however, to date, patient portal adoption has been limited in both hospice²³ and LTC.²⁴

Finally, study findings emphasize the need to support hospice patients and family caregivers residing in the community, many of whom are separated from important sources of support when physical separation is required. These individuals' experiences of anxiety, fear, and frustration amid physical separation highlight the need for more widespread implementation of interventions such as online groups and virtually-provided therapies, which have been identified as promising facilitators of social and emotional support for hospice families.^{20,25} Additional research and clinical innovation is needed to identify strategies to meet patients and caregivers' functional needs in the community, which have traditionally been met using physical means.

Study Limitations

Study findings should be interpreted with a number of study limitations in mind. First, as with all secondary data analyses, this study was limited by the constraints inherent in the existing data, which were originally collected for a purpose other than addressing the present study aims. Primary data collection might have

afforded researchers the opportunity to interview or otherwise obtain data directly from patients rather than relying upon family caregivers' and hospice team members' perceptions of patients' experiences. In addition, in their review of the transcribed content from care plan reviews, researchers noted several experiences (e.g., communication challenges) that were described but not explicitly linked to COVID-19. In those cases, researchers erred on the side of caution and did not attribute these experiences to the pandemic, possibly omitting data that did in fact speak to the study's research questions. Having direct access to participants in the care plan reviews would have allowed researchers to inquire as to whether specific experiences were perceived as related to COVID-19, reducing the risk of failing to analyze relevant data. It would also have allowed researchers to explore potential linkages among experiences that were not described in the existing dataset. e.g., while no existing data linked unmet social and emotional needs to experiences of frustration, it seems likely that some participants would have identified a relationship between the two if they had been directly asked. It is also reasonable that a lack of help with functional needs—e.g., help with walking or bathing—might have led to a fear of falling or injury, a possibility about which researchers might have inquired if data were originally collected to address the present study's research questions. Similarly, patients and family members described attempted connection strategies that were largely practical in nature. Primary data collection would have permitted questioning to determine if emotional adaptation was a part of their experience as well. Second, while infrequently the case, poor audio quality during IDT meetings held as part of the original trial occasionally resulted in inaudible meeting content that was unable to be transcribed and made available for the present analysis. Third, while the study was longitudinal in nature, it was limited to the very early days of the pandemic. Much has changed since that time. As of the date of this writing, LTC facilities have re-opened to visitors and external healthcare professionals,²⁶ and stay-at-home/shelter-in-place orders have largely been replaced by community and employer-based policies mandating or encouraging preventive measures such as vaccination, wearing of face masks, and hand washing.²⁷ Although the future of telehealth remains uncertain, a number of provisional policy changes have reduced barriers to remote communication and provision of care.²⁸ While these changes have improved the lives of many hospice patients and their families, they are either impermanent or dependent upon the continued success of public health measures to control the spread of COVID-19, an outcome that many experts regard as uncertain.²⁹ These study findings underscore the need for innovative, forward-thinking solutions

that can be quickly activated in response to physical separation when needed.

Conclusion

Hospice patients and their family caregivers experiencing physical separation are at heightened risk of unmet informational, functional, and social and emotional needs, resulting in anxiety, frustration, loneliness, sadness, and fear. Inclusive, innovative connection strategies are needed to ensure that high-quality end-of-life care is available when physical presence must be limited.

Public Access Statement

The NIH Public Access policy applies to any peer-reviewed manuscript that is accepted for publication on or after April 7, 2008 that arises from direct funding from an NIH grant or cooperative agreement active in Fiscal Year 2008 or beyond. This policy states: "The Director of the National Institutes of Health ("NIH") shall require in the current fiscal year and thereafter that all investigators funded by the NIH submit or have submitted for them to the National Library of Medicine's PubMed Central an electronic version of their final, peer-reviewed manuscripts upon acceptance for publication, to be made publicly available no later than 12 months after the official date of publication: Provided, that the NIH shall implement the public access policy in a manner consistent with copyright law."

Disclosures

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