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Featured Article

Supporting dementia family care partners during COVID-19: Perspectives from hospice staff

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Introduction

Supporting families is a crucial aspect of care in hospice settings.^{1,2} Hospice is a care model that provides interdisciplinary team-based, person and family-centered care to individuals with a life-limiting illness (a six-month-or-less prognosis); and can be accessed both in private residences and long-term care settings.³ In addition to providing care to the patients, hospices provide supportive care to their families, called family care partners, through spiritual counseling, medical social services, respite services, and family grief and loss counseling before and after the patients' death.⁴

Coronavirus disease 19 (COVID-19), however, poses challenges to providing such support to family care partners of persons living with dementia.⁵ Persons living with dementia served in hospice, along with their families, have increased to nearly 45% of the hospice patient population.^{3,6} Persons living with dementia experienced an increase in deaths beyond anticipated projections (13% for Alzheimer's disease and 17% for other dementias) due to COVID-19 in 2020 and remained elevated (at least 11,000) in 2021.⁷ A recent consensus paper highlighted the importance of supporting dementia care partners at the end of their family member's life during the pandemic.⁸ Dementia family care partners are subject to heightened risk for anxiety, stress, and caregiver burden from lockdown and social distancing because persons living with dementia, especially those in the later stages,⁹ are at risk for increased behavioral symptoms, and negative psychosocial outcomes during COVID-19.¹⁰ Hospice staff play a crucial role in supporting dementia family care partners at the end of life. While previous research documents needs and resources to better serve persons living with dementia and their care partners during the pandemic, these studies were largely in long-term care,⁸ palliative care,¹¹ and community settings¹² with few studies focused on hospice.⁵

Previous research documents COVID-19 related changes in healthcare delivery, and corresponding challenges communicating with families. Initially, hospice organizations and staff faced

shortages of personal protective equipment (PPE), evolving COVID-19 policies regarding visit restrictions, and increasing the use of remote communication, such as telemedicine.⁵ Shortages of PPE and ventilators impeded healthcare providers' ability to effectively care for patients,^{13,14} including those in hospice.¹⁵ Providers and healthcare organizations scrambled to respond to evolving COVID-19 policies such as visit restrictions, which suboptimal in-person communication with families. Additionally, high staff turn-over and the swift re-organization of teams created barriers to building trust^{16,17} and communicating up-to-date patient information and COVID-19 protocols to families.^{4,4} As in-person hospice visits were curtailed due to infection risk, family care partners were forced to shoulder symptom management burden in isolation, and at times with limited support from telehealth solutions.^{18–21} As services shifted to telemedicine, hospice staff lost the ability to provide hands-on support to families during end-of-life care.¹⁵ Moreover, Crower et al.¹¹ found dementia family care partners experienced inadequate communication with healthcare professionals regarding their family members' end of life care during the pandemic and lacked support.

It is important to understand hospices' ability to support dementia family care partners during COVID-19 because family care partners are critical to implementing the care plan and patient safety at home and are an essential part of the hospice philosophy of caring for both the patient and the family.¹ Previous research documents COVID-19 related changes in care delivery, communication challenges, and the emotional impact on families. Few studies explore hospice staff's perceived ability to support dementia family care partners,¹⁵ with none identifying the alternative modes of communication used to support families receiving hospice services, and the additional resources hospice staff need. This understanding can inform hospice agencies' current provision of resources and training to better equip hospice staff to provide alternative modes of supportive communication to dementia family care partners as COVID-19 continues; and may also guide organizational planning for future pandemics.

Objective

The objective of this study is to explore the impact of COVID-19 on hospice support to family care partners of persons living with

Abbreviations: COVID-19, Coronavirus disease 19; PPE, Personal protective equipment

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dementia from the perspective of hospice staff, document alternative modes of communication provided during the pandemic, and identify needs for additional resources to better equip hospice staff to support dementia family care partners.

Material and methods

Design

This is a mixed methods analysis of a cross-sectional survey study from June 1–July 15, 2020 that occurred as a process evaluation of a 25-site pragmatic clinical trial, The Hospice Advanced Dementia Symptom Management and Quality of Life Trial (ClinicalTrials.gov Identifier: NCT04175977). During this time, the trial was paused due to COVID-19 from April 2020–February 2021. The pragmatic trial is still ongoing at the time of this paper; it tests the effectiveness of a quality improvement program, Aliviado Dementia Care–Hospice Edition, on antipsychotic and analgesic use in persons living with dementia; hospice continuous, inpatient, and respite care hours provided; rate of permanent institutionalization and site of death; and bereaved caregiver satisfaction. The conduct of the pragmatic trial was approved by the lead institution's institutional review board.

The quality improvement program intervention consists of interdisciplinary dementia care training; a toolbox of symptom assessments, treatment algorithms, care plans, and caregiver education materials; clinical workflow changes; a mobile health application for remote access to the toolbox materials; and mentorship on intervention implementation and quality improvement processes.^{41–43}

At the time of the survey, five hospice sites, located in Nevada, North Carolina, Maryland, California, and Florida, had partially or fully implemented the quality improvement program. The cross-sectional survey, consisting of both open- and close-ended questions, was conducted to assess (1) any continuation of implementation of the quality improvement program components when the study was on pause (e.g., “Have you used any Aliviado Care Plans with persons living with dementia?”) and (2) the impact of COVID-19 on hospice care to persons living with dementia and family care partners. We refer to this cross-sectional survey as COVID-19 survey for simplicity hereafter.

The mixed methods analysis reported in this paper uses a qualitative-dominant, mixed-methods concurrent nested design²² to integrate selected open- and close-ended questions from the COVID-19 survey. In a concurrent nested study, qualitative and quantitative data are collected simultaneously, but one method dominates the other that is embedded within. In this mixed methods analysis, qualitative data stemmed from the two open-ended survey questions: “How has COVID-19 affected your ability to support the family caregivers of your patients living with dementia?” “What additional resources would you like us to provide to help you support the family caregivers?” Quantitative data was obtained using an embedded, close-ended matrix question to explore the modality and frequency of supportive communication: Respondents were asked, “How often do you use each of the communication mode below to support the family caregivers of your hospice patients during the COVID-19 pandemic (Modality options: Telephone call, Video call, Email consultation, Text message, In person, Other. Frequency Options: Daily; A few days a week; Weekly; A few days a month; Rarely; Never.)” In this study, we deviate from the term “family caregiver” originally used in our COVID-19 survey, to “family care partner” to better reflect family members' diverse roles and experiences of partnering in care with hospice staff and persons living with dementia.

Participants

Because the quality improvement program was agency-wide, all administrative, management, and clinical staff who were 18+ from

the five sites ($n = 656$ total) were eligible for participation in the COVID-19 survey.

Procedures

A link to the COVID-19 online survey was emailed to all eligible employees identified by the five sites ($n = 656$) with up to three reminders. The COVID-19 survey was collected once between June 1 and July 15, 2020 with no late submissions allowed. Each respondent who submitted a completed survey received a \$50 honorarium.

Data Analysis

Qualitative and quantitative data were first analyzed separately and then compared, related, and integrated. For qualitative data, we applied *conventional content analysis*,²³ which is appropriate when there is limited literature or existing theories on the phenomenon of interest. All responses to the open-ended questions were first reviewed in their entirety, open-coded using key words in the quotes whenever possible, and then grouped into preliminary themes by the first author to generate an initial codebook. All responses to open-ended questions were then divided into three equal sections; each section was independently coded by a second coder using the initial codebook. The first author and the three secondary coders met weekly to discuss coding discrepancies and iterate the preliminary themes until consensus was reached and the codebook finalized.

To enhance credibility, findings from the COVID-19 survey were triangulated against related themes identified from meeting minutes of monthly champion calls and quarterly champion surveys in the parent trial. Each hospice designated a group of interdisciplinary champions to facilitate implementation of the quality improvement program. Champions met monthly by Zoom/telephone with study staff to discuss implementation barriers and achievements, as well as provided anonymous feedback on the quality improvement program in the quarterly champion survey. Meeting notes from monthly champion calls and quarterly champion surveys were examined for COVID-19 related themes to corroborate findings from the COVID-19 survey (triangulation).

Member checking was conducted by two authors during monthly champion calls following the administration of the COVID-19 survey to verify the main findings. Quantitative data (participant characteristics and the closed-ended question on communication mode and frequency) were analyzed using descriptive statistics in STATA/IC 15.1. Qualitative and quantitative analysis results were then compared to identify whether findings converged or diverged.

Results

Participant characteristics

Initially, there were 133 survey entries. After removing duplicates ($n = 4$) and unsubmitted surveys ($n = 28$), 101 respondents (95% female; 71% white/Caucasian; mean age: 49 years old) were included in data analysis. The respondents were of diverse job titles and disciplines. See [Table 1](#) for a summary of participant characteristics.

Qualitative findings

Our analysis of qualitative responses identified four main themes: (1) *changes in quantity and quality of care*, (2) *perceived emotional toll on families and impact on service utilization*, (3) *resources needed*, and (4) *perceived resilience*.

Table 1
Respondent characteristics (n = 101).

Variable	n	%
Age: mean years, range	49.2	25-70
Gender	93	100
Female	88	95
Male	4	4
Prefer not to answer	1	1
Race	93	100
White/Caucasian	66	71
Black/African American	17	18
Hispanic/Latino	8	9
Asian/Pacific Islander	2	2
Discipline	100	100
Nursing	48	48
Social work	20	20
Certified nursing aide/home health aide	24	24
Spiritual care/Chaplaincy	7	7
Medicine	1	1
Employment	92	100
Full time	84	91
Part time	8	9
Education	92	100
High school	6	6
Vocational program/associate degree/some college	37	40
Bachelor's degree	27	29
Master's degree/advanced degree	22	24
Site	101	100
I	41	41
II	9	9
III	12	12
IV	5	5
V	34	34

Note. Missing data: Of the 101 respondents, 100 provided their discipline information, 93 answered the questions about gender, 92 provided their employment and education information, and 90 provided their age information.

(1) Changes in quantity and quality of care.

Fifty-two respondents discussed changes in the amount and the quality of care, including the following subthemes: *mode, frequency, and/or duration; visit restrictions negatively affected quality of care; increase in remote communication; and COVID-19-related safety procedures.*

Most respondents reported changes in care delivery *mode, frequency, and/or duration* in response to COVID-19, in both long-term care facilities and private homes. Changes around in-person visitation included the reduced number and length of visits as well as limited visiting hours. Many respondents reported that these *visit restrictions negatively affected quality of care*, especially around psychosocial support and therapeutic relationship-building. Specific therapeutic elements missing that were reported by respondents included “supportive presence”, “non-verbal cues to show empathy”, and “human touch.” One home health aide said, “Yes, I and my patients’ families always like to give and receive hugs and the no touch is really hard for them.” Other negative consequences of visit restrictions included families’ lack of understanding of the patient’s plan of care and hospice staff’s inability to be physically present during end-of-life support. A nurse said, “If the patient is in a facility, there is less communication with families, families lack understanding on what is [the] patient’s plan of care.” One social worker said, “It can be a challenging at times, if the patient is in a long-term facility, you can’t be there at time of death or when the patient is declining because families and facilities are prohibiting visits.”

On the other hand, many respondents reported *an increase in remote communication* between family care partners and hospice interdisciplinary team members to compensate for decreases in face-to-

face visits and the limited communication from long-term care facilities to families. A nurse said, “With the decrease in visits, more time is required in phone and text conversation to give caregivers reassurance and support.” The limited communication from long-term care facilities is exemplified in the quote below from a social worker:

The main thing I’ve noticed is our family caregivers feel out of the loop regarding the care of their loved ones. Some facilities do better at communicating than others, but I would say that the caregivers feel distrustful of the care their loved ones are receiving at the facilities now that they cannot visit and ‘keep an eye’ on things.

In response, family care partners relied on hospice interdisciplinary teams for updates on their loved ones in a facility. Hospice nurses were able to enter facilities with restrictions or perform telehealth sessions; other disciplines including social workers and chaplains then helped relay patient updates to families.

Conversely, despite hospices’ ability to ramp up remote communication and bridge the communication gap between facilities and families, many respondents recognized limitations in these alternative communication modes. In fact, these communication modes were subject to most of the missing therapeutic components described earlier. One nurse clinical educator stated, “. . . while phone calls provide some support it is not the same as being there in person.” A nurse case manager commented, “There is no way to support someone other than a video chat as pts (sic) are isolated. This is not sufficient and is complicated the grief processes of all involved.” Some respondents also mentioned difficulty in performing home assessments remotely, getting family care partners to “open up,” or building trust and rapport over the phone. Additionally, certain technology such as video calls could be confusing to patients with cognitive impairment. A social worker said, “My team’s nurses assist with video calls, but the video calls don’t usually work all that well with our patients with dementia.” In sum, these quotes underscore challenges related to remote communication and technology during COVID-19, including barriers building rapport and providing comfort to family care partners of persons living with dementia receiving hospice services.

Apart from changes in care delivery mode and frequency, some respondents also reflected on how *COVID-19-related safety procedures* affected care delivery. Some respondents noticed that the use of PPE introduced an additional barrier to care. A social worker said, “When I do visits in person, I have to wear a mask and they don’t recognize me, and the masks scare some of them.” Others commented on family care partners’ distrust of PPE: a nurse team leader said, “Families are afraid of health care workers to come in their homes even with PPE.” Conversely, one home health aide cautioned that PPE could create a false sense of safety: “As long as I have my mask, most patients/families/caregivers are fine. They don’t know that I have to use a mask all day - they think I am wearing a fresh one each time I walk into a home.” Furthermore, a nurse case manager voiced her concerns related to COVID-19 safety procedures with the Centers for Disease Control and Prevention (CDC)’s response to COVID-19:

The CDC has been conflicting with their education to the public regarding masks. This is an airborne illness and they have not effectively educated the public or healthcare professionals with the studies provided to indicate the virus is airborne for 3-6 hrs. People are confused and terrified in society. Our organization initially stated we did not have to wear a mask. I ready (sic) the studies out of Italy and I knew it was airborne. I knew people were positive and asymptomatic. The studies were available and the CDC failed.

This quote exemplifies the challenge of safety procedures such as social distancing protocols, masking, and PPE that affected care delivery to family care partners, due to inconsistencies or outdated information provided on a national and an organizational level.

(1) Perceived emotional toll on family care partners and impact on service utilization.

While describing changes in quantity and quality of care, 29 respondents emphasized their *perceived emotional toll on family care partners and (its) impact on service utilization*. This theme encompassed text describing family care partners' psychological responses (e.g., stress, anxiety, grief, etc.) to COVID-19 and related safety precautions, as well as their consequent behavioral responses in using or abstaining from hospice services with the subthemes: *emotional responses* and the *impact on service utilization*.

Many respondents highlighted family care partners' *emotional responses* (e.g., stress, anxiety, grief, etc.) to COVID-19 and related safety precautions. A social worker commented on the increased anxiety in family care partners due to visit restrictions, "family caregivers are extremely anxious about not being able to visit their loved one." A nurse case manager expressed that "Families are grieving pts (sic) are grieving and this will go down in history as a horrible pandemic to endure."

Many respondents also described how family care partners' emotional responses *impacted service utilization* (e.g., refusing visits, refusing respite, turning to spiritual support, etc.). A nurse team leader noticed that "For home patients they [family care partners] are scared to use respite and outside resources due to the virus." This quote describes a decrease in the utilization of services, due to fear of COVID-19. In contrast, a social worker commented, "I am spending more time supporting my families by phone, recognizing their stress levels and anxieties are high due to not being able to see their loved ones in person." This quote describes an increase in service utilization to address family care partners' high stress levels and anxieties. Some respondents also noticed that family care partners became more receptive to hospice spiritual care. A chaplain commented, "I find that family members who have loved ones in a facility are more open to chaplain support because they are worried."

Collectively, these responses show the situational nature of family care partners' emotional and behavioral responses ranging from increased care partner anxieties leading to service refusal for home-based hospice care to increased utilization of hospice services (more support calls and updates) for those with persons living with dementia in long-term care facilities.

(1) Additional resources needed.

Forty-two hospice staff identified additional resources needed to support family care partners, which can be categorized into: (1) *information*, (2) *respite care*, (3) *supplies*, (4) *education and training*, (5) *support groups and grief support*; (6) *stress management and self-care*; and (7) *other*. Hospice staff identified a need for additional information involving online and printable resources for family care partners during the pandemic. A social worker requested "Information to cope

with COVID-19 stressors." Additionally, hospice staff requested increased resources for respite care including local grants and programs to provide relief to family care partners and tips on how help them prepare. One home health aide wrote "Seeking more volunteer assistance & how to get more support to assist them [family care partners] for respite periods." Hospice staff also highlighted a need for supplies (e.g., PPE) and devices for virtual services. A nurse wrote "providing families with more mask and hand cleaners." Moreover, hospice staff requested education and training on communication and symptom management to better support family care partners. One case manager commented "video learning, examples of behavior management w/ dementia patients." Support groups and grief support requests highlighted needs for peer and professional support. One social worker requested more resources related to "Caregiver burn out, grief support, caregiver self-care. Caregiver emotional support." Calls for more stress management and self-care resources from hospice staff included a need practical tools and resources to better support family care partners during the pandemic. A home health aide requested, "more coping skills for stressful days." Lastly, other resources identified were a chief medical officer's request for "tools for care coordination."

Perceived resilience

This theme contains descriptions of hospice staff's self-appraisal of little to no change in their *ability* to support family care partners, in the face of COVID-19. Twenty-two hospice staff across disciplines (nurses, social workers, chaplains, and aides) declined the impact of COVID-19 on their ability to support family care partners; and nearly two thirds of them (N = 14) merely provided a brief response of "no" or "none". For the remaining respondents, they attributed their resilience, or invulnerable ability, to specific settings (e.g., inpatient unit), job roles ("no effect on my on-call role"), or ability to fulfill an essential need such as patient updates. A nurse case manager said: "It has not affected my ability to support the family. As a matter of fact, the family relies on the RN to provide the much needed (sic) updates on their loved ones."

Quantitative findings

To improve our understanding of hospice staff's communication to support family care partners during COVID-19, including different communication modes used by skilled hospice employees (i.e., non-aides) and their frequency of use, we embedded a quantitative matrix question to explore this subtopic further. As shown in [Table 2](#), the most *commonly used* communication mode overall (i.e., ever used during COVID-19 in contrast to "never") was "telephone call" (95% used it to any extent vs. 5% "never"), followed by "in-person" communication (90% vs. 10%), "video call" (66% vs. 34%), "email consultation" (55% vs. 45%), "text message" (49% vs. 51%) and "other" (41% vs. 59%). The most *frequently used* communication mode was "telephone call"

Table 2
Supportive communication by mode and frequency (n = 76 skilled hospice employees).

	Daily, n (%)	A few days a week, n (%)	Weekly, n (%)	A few days a month, n (%)	Rarely, n (%)	Never, n (%)
Telephone call (n = 74)	25 (34)	15 (20)	9 (12)	19 (26)	2 (3)	4 (5)
In person (n = 73)	18 (25)	8 (11)	14 (19)	16 (22)	10 (14)	7 (10)
Text message (n = 74)	6 (8)	8 (11)	2 (3)	7 (9)	13 (18)	38 (51)
Video call (n = 74)	2 (3)	6 (8)	7 (9)	9 (12)	25 (34)	25 (34)
Email consultation (n = 73)	2 (3)	6 (8)	2 (3)	10 (14)	20 (27)	33 (45)
Other-optional (n = 54)	6 (11)	4 (7)	7 (13)	1 (2)	4 (7)	32 (59)

Note. This was a matrix question and a couple of people only selected "Other" and therefore, even though 76 respondents answered this question, the total number of responses received for each communication mode was fewer than 76.

(34% used it daily and 20% a few days a week), followed by “in-person” communication (25% daily and 11% a few days a week), “text message” (8% daily and 11% a few days a week), and “video call” and “email consultation” (3% daily and 8% a few days a week for both communication modes).

Integration of qualitative and quantitative findings

To generate more complete insight into hospice staff’s supportive communication to family care partners, qualitative and quantitative results were compared, related, and integrated. In this study, qualitative and quantitative findings regarding changes in care delivery converged and complemented each other; no divergence was found (Table 3). Quantitative data revealed that text messages were the third most frequently used form of supportive communication and qualitative data affirmed the use of text messages to communicate with families and provided contextual information for the communication, such as “to give caregivers reassurance and support”.

Discussion

This study examined the impact of COVID-19 on hospice staff’s perceived ability to support family care partners of persons living with dementia. Qualitative findings underscored hospice staff perceived *changes in quantity and quality of care*, the *emotional toll on family care partners and impact on service utilization*, and *additional*

resources needed, while some reported *perceived resilience*, or self-appraisal of little to no impact of COVID-19 on their ability to support family care partners. Our qualitative and quantitative findings converged and collectively pointed to decreased face-to-face visits in facilities and private homes compensated by increased use of alternative care delivery modes, especially telephone support calls. To our knowledge, this is one of the first studies to examine hospice staff’s perceived ability to support family care partners of persons living with dementia during COVID-19 and the first to explore the various modes of communication utilized and additional resources needed. Our findings can inform hospice agencies’ current provision of resources to bolster their staff’s ability to support dementia family care partners during COVID-19, as well as inform organizational planning for resources to provide better support to families using alternative communication modes (e.g., text, phone, virtual visits) current and future pandemics.

Our findings affirm previous research documenting changes in care delivery. Specifically, our findings regarding increased remote communication align with Rogers and colleagues’⁵ national survey of hospice agencies that found a decrease of in-person visits and an increase in telemedicine. While previous research has explored communication interventions employed during COVID-19, no studies have documented the alternative communication modes and frequencies utilized by hospice staff to support family care partners of persons living with dementia such as telephone, telemedicine, and texting. This is important to consider as understanding how hospice

Table 3

Integration of qualitative and quantitative findings on main supportive communication modes and frequencies.

Mode	Frequency: A=Daily; B=A few days a week; C=weekly; D=A few days a month; E=rarely; F=Never						Convergent/Divergent	
	A	B	C	D	E	F	Number of times mentioned in open-ended responses	
Telephone call	n = 25 (34%)	n = 15 (20%)	n = 9 (12%)	n = 19 (26%)	n = 2 (3%)	n = 4 (5%)	n = 13	Convergent: Both qualitative and quantitative findings suggested that telephone was the most commonly used mode of communication during COVID-19.
In person	n = 18 (25%)	n = 8 (11%)	n = 14 (19%)	n = 16 (22%)	n = 10 (14%)	n = 7 (10%)	n = 31 (All about limitations and restrictions)	Convergent: In-person visits mentioned in the qualitative data were all around visit restrictions. Quantitative results also indicated that in-person visitation was not the most commonly or frequently used mode of communication.
Text message	n = 6 (8%)	n = 8 (11%)	n = 2 (3%)	n = 7 (9%)	n = 13 (18%)	n = 38 (51%)	n = 1 (“With the decrease in visits, more time is required in phone and text conversation to give caregivers reassurance and support.”)	Complimentary: Quantitative findings suggested that text message was the 3 rd most frequently used communication mode (8% daily and 11% a few days a week). The frequency of use would not have been correctly estimated if without quantitative data because text conversation was only mentioned once in the qualitative data. Conversely, the only relevant qualitative quote clearly stated that decreases in visits contributed to increases in text conversation.
Video call	n = 2 (3%)	n = 6 (8%)	n = 7 (9%)	n = 9 (12%)	n = 25 (34%)	n = 25 (34%)	n = 6 (video call, FaceTime, or telehealth)	Convergent: Video call was the 3 rd most frequently mentioned in the qualitative data and also the 3 rd most commonly used according to the quantitative findings (66% used it to any extent). However, the uptake of video calls (34% never used it) was still lower than expected. Qualitative findings helped to explain this lower-than-expected uptake rate (“My team’s nurses assist with video calls, but the video calls don’t usually work all that well with our patients with dementia.”). In addition, member checking revealed that: (1) some families were in the rural area and did not have stable internet access, which limited the use of video calls; and (2) one small community-based hospice chose not to implement video calls due to limited resources.
Email consultation	n = 2 (3%)	n = 6 (8%)	n = 2 (3%)	n = 10 (14%)	n = 20 (27%)	n = 33 (45%)	Not mentioned	Complimentary: Email was not mentioned in the open-ended responses but was captured by the quantitative data.

staff communicated with family care partners of persons living with dementia to improve care during the pandemic can better inform more family- and patient-centered approaches during COVID-19, future pandemics, and the changes that may be retained following transition from pandemic to endemic as part of routine care, including a strong likelihood that telehealth provisions will be extended beyond the public health emergency.²⁴ This is juxtaposed, however with a new Centers for Medicare and Medicaid Services quality measure implemented in 2022 that quantifies face to face visits by providers, nurses and social workers in the last three days of death.²⁵ These and other regulatory changes expected in 2023 will require ongoing training and support above what we found in this study.

Moreover, our findings around remote communication and PPE underscore the tension between supporting safety and fostering communication with families that are echoed in previous research. For instance, Gergerich and colleagues²³ cautioned that hospice staff's use of telehealth created challenges building rapport with families, while PPE during in-person visits introduced an additional communication barrier. Yet, the use of telehealth and PPE are important for the safety of family care partners, hospice staff, and persons living with dementia, who are especially vulnerable to COVID-19.²⁶ Additionally, we found family care partners' views of PPE use by hospice staff varied, ranging from distrust to overconfidence. This may have resulted from variations and controversies that existed in infection control recommendations around PPE use in the first year of the pandemic.²⁷

In response to COVID-19, family care partners utilized hospice services differently ranging from actively refusing home visits and respite care to reduce risk of exposure to increasing telephone support; and emotionally, experienced heightened stress, anxiety, and grief. Heightened stress and anxiety of dementia family care partners during the pandemic has been reported in community²⁸ and hospice settings.⁵ For family care partners of facility patients, particularly, not being able to see their loved ones and receiving regular communication from the facility raised their anxiety and stress levels, which in turn led to family care partners' reliance on hospice interdisciplinary teams for patient updates and emotional support. Challenges communicating with families arising from social distancing restrictions are not isolated, as providers across healthcare settings struggled to provide patient information and updates to families.^{29–32} Yet, we found that hospice staff in general expressed a positive view on the amount of support calls provided and their ability to bridge the communication gap between the family care partners and the facility. Particularly, chaplains were pleased that family care partners became more receptive to spiritual care (support calls from chaplains). Family care partners' greater use of religious support to cope during COVID-19 was also reported in a nationally representative internet sample.³³

Family care partners play a central role in the care of persons living with dementia, and the quality of the clinician-family care partner relationship is especially important for this population. Despite the amount of support calls provided to and appreciated by family care partners reported in the current study, our findings also highlight many detrimental effects of COVID-19 on clinician-family care partner relationship building, mediated through a change in clinicians' ability to be physically present.³⁴ Many respondents reported barriers to establishing affective and relational components of the clinical relationship remotely, including the use of touch to support families. This finding is also supported by Rogers and colleagues,⁵ who found that hospice staff noted an increase in family bereavement needs, citing a loss of support and physical touch as contributing to this need. Moreover, challenges building rapport can also hamper hospice interdisciplinary teams' ability to have difficult conversations and establish the trust necessary to address sensitive subjects such as

end-of-life care in the midst of COVID-19.³⁵ While Wittenberg et al.³⁶ identified strategies to support healthcare providers' communication with families during COVID-19, strategies specific to dementia and hospice are scarce. Our findings broaden understandings of hospice staff's need for increased resources to communicate and support families of persons living with dementia during COVID-19.

Although most hospice staff described differences in how they supported family care partners during COVID-19, some perceived little-to-no change in their ability to support family care partners. Among those who reported little-to-no change, some attributed it to their work setting (e.g., hospice house) or job role, which inherently did not require frequent interactions with family care partners. Others considered their ability unaffected because they could continue supporting family care partners through support calls. Still, others confirmed their ability was unaffected without further explanation. These findings suggest that not all hospice staff experienced reduced ability to support dementia family care partners during COVID-19 and some even experienced resilience.

Implications for COVID-19 restrictions and mandates

While our findings occurred during the first year of the pandemic, the hospice agencies we initially surveyed are continuing to experience varying safety procedures/policies and staffing shortages as COVID-19 continues. On September 9th, 2021, the White House released an executive order requiring the COVID-19 vaccination for all federal employees.³⁷ This caused political divisiveness across the nation, and we are seeing the effects of the disharmony coupled with strain of the pandemic in the extreme form of staffing turnover³⁸ and vaccine hesitancy in healthcare assistants.³⁹ Also, most facilities have started regulating visitation access again. It is becoming near impossible to be inclusive in mandating the new federal policy in states where unvaccinated loved ones and clinicians are compulsorily being isolated as well as depleted with an already understaffed healthcare workforce. Consequently, hospice agencies must provide clear organizational communication regarding COVID-19 policies and mandates to staff to support retention.⁴⁰ Our findings also highlighted hospice staff reported video calls (Zoom and FaceTime) could be confusing to people living with dementia. More research is needed to understand how to make these common video technologies more user friendly for hospice recipients living with dementia or develop alternative video-technologies that are better suited for this population. Moreover, our findings underscore a need for resources to bolster hospice staff's ability to support family care partners of persons living with dementia in hospice, including information, family respite, and support groups to address the emotional toll of the pandemic. Implementation of these resources can better prepare hospice agencies and staff to support family care partners of persons living with dementia during COVID-19 and can guide organizational preparedness plans for future pandemics.

Limitations

This study has several limitations, including the use of a convenience sample, modest response rate, and the cross-sectional design. The use of an online survey instead of interviews/focus groups also presents a limitation in our ability to probe participants to elaborate more based on their free text responses. Despite these limitations, our sample includes respondents diverse in disciplines, job titles, hospice settings, and geographical regions, which likely improves our findings' generalizability. The use of member checking, triangulation, and incorporation of both qualitative and quantitative data helped construct a fuller picture of how COVID-19 affected hospice staff's ability to support dementia family care partners.

Conclusions

Most hospice staff reported differences in their ability to support dementia family care partners during COVID-19, resulting from visit restrictions, use of PPE, barriers to establishing trust and rapport remotely. Moreover, staff reported family care partners' emotional and behavioral responses and additional resources needed to provide support. COVID-19 related reductions in face-to-face visitation were mainly compensated by increased hospice telephone support calls. Hospice interdisciplinary teams played a vital role in supporting family care partners' greater informational, emotional, and spiritual needs during COVID-19, mainly resulting from limited access to their facility-dwelling loved ones due to pandemic precautions and associated stress. Hospices should consider staff's different perceptions of their ability to support family care partners when distributing resources and education. Staff who expressed concerns about remote relationship-building may benefit the most from guidelines for telehealth and family communication during COVID-19 and future pandemics. Future research should further explore the interrelationship among hospice setting, job role, modality and frequency of care delivery/communication, and staff's actual and perceived ability to support dementia family care partners during pandemics and other crises. Future research should also compare staff and family care partners' perceptions of the support provided and received, as well as investigate whether hospice staff who interact with family care partners regularly but perceive little-to-no effect of COVID-19 on their ability to support family care partners possess additional resilient or protective factors.

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Data availability statement

The data that support the findings of this study are available on request from the corresponding author.

Clinical trial registration: <https://clinicaltrials.gov/ct2/show/NCT04175977>

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