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Original Study

Caring for a Relative With Dementia in Long-Term Care During COVID-19



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A B S T R A C T

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Objectives: The COVID-19 pandemic created unique stressors for caregivers of persons with dementia living in long-term care (LTC) facilities. The purpose of this qualitative study was to identify the challenges associated with caring for a relative with dementia in LTC during the pandemic, as well as resources, strategies, and practices caregivers found helpful in coping with COVID-19.

Design: This study was conducted within the context of an ongoing randomized controlled trial of a psychosocial intervention to support caregivers. Open-ended survey responses (n = 125) and semistructured interviews with a subset of the sample (n = 20) collected between June 2020 and June 2021 explored caregivers' experiences during COVID-19.

Setting and Participants: Participants included 125 family caregivers of persons with dementia living in residential LTC.

Methods: Thematic analysis was used to identify themes capturing caregivers' experiences.

Results: In addition to concerns about COVID-19 infection, participants reported key challenges such as the difficulty of maintaining contact with relatives because of visiting restrictions, lack of information about relatives' health and well-being, worries about overburdened LTC staff, impossibility of returning relatives home from the LTC facility, and fears about relatives dying alone. Participants also identified resources, strategies, and practices that they perceived as helpful, including effective infection prevention within the LTC facility, good communication with LTC staff, and creative strategies for connecting with their relatives.

Conclusions and Implications: This qualitative analysis informs recommendations for practice within LTC facilities, as well as supports that may help caregivers manage stressful situations in the context of COVID-19. Vaccination and testing protocols should be implemented to maximize family caregivers' opportunities for in-person contact with relatives in LTC, as alternative visiting modalities were often unsatisfactory or unfeasible. Informing caregivers regularly about individual residents' needs and status is crucial. Supports for bereaved caregivers should address complicated grief and feelings of loss.

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Residential long-term care (LTC) settings are “ground zero” for COVID-19 infections.^{1–4} As of September 2021, more than 675,000 infections and more than 134,000 COVID-19 deaths have occurred among US nursing home residents,⁵ representing approximately 2% of

total infections but more than 20% of total deaths.⁶ To mitigate infection spread, LTC facilities implemented initial lockdowns and ongoing visiting restrictions that have had unintended negative consequences, such as social isolation.^{7–11} Among LTC residents, those with dementia are especially vulnerable to infection and isolation, as they are less likely to understand and remember the purpose for social distancing and isolation procedures.¹² Such concerns remain relevant as novel variants and low vaccination rates contribute to outbreaks and reimplementations of stricter visiting restrictions in LTC.¹³

Though the effects of COVID-19 among LTC residents have received substantial attention, the experiences of family caregivers of LTC

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residents with dementia have not been sufficiently examined up to this point. Although not providing round-the-clock care, caregivers continue to play a critical role after the transition to LTC.^{14–17} They generally remain actively involved as coordinators and advocates for their relative's care, and regularly provide social interaction and assistance with activities such as feeding, bathing, and cleaning.^{18–20} Thus, the COVID-19 pandemic has caused disruption and added stress for caregivers, as their relatives are at greater risk of infection and mortality and opportunities to interact with residents have been limited.²¹ Family caregivers of LTC residents also face unprecedented end-of-life scenarios and bereavement without usual supports.^{22,23} Anecdotal evidence has revealed multifaceted challenges for caregivers of LTC residents with dementia at this time.²⁴ Though some literature has documented effects of COVID-19 on dementia caregivers, most research has focused on caregiving in community contexts, not LTC.^{25–31} Good-quality LTC care relies on a partnership between families and LTC facilities, and those partnerships have been strained and in some cases broken during the pandemic. Understanding the perspectives of LTC caregivers is critical for formulating LTC policy as the pandemic continues.

Most literature on caregiving for a relative with dementia in LTC during COVID-19 is limited to commentaries from experts, rather than empirical work with caregivers.^{21,32–34} Their recommendations provide helpful guidance, but it is crucial to systematically incorporate the perspectives of caregivers themselves into recommendations for LTC policy and procedures during COVID-19. Caregivers may disagree with experts about what practices are most beneficial to their relatives, and through firsthand experience, may identify problems with existing protocols that experts may not be aware of. The need to acknowledge family caregivers and include them as active partners in care planning has long been recognized as a critical unmet need in dementia care.^{35–38} Now more than ever, incorporating family caregivers' perspectives into research and practice is necessary to optimize care for the remainder of the COVID-19 crisis.

To address this important gap in the literature, we investigated caregivers' perspectives on the challenges they have experienced while assisting a relative with dementia in LTC during COVID-19, and the supports they have found helpful. Our analysis focused on 2 key questions:

1. What challenges did caregivers of a relative with dementia living in LTC experience during the COVID-19 pandemic?
2. What resources, strategies, and practices did caregivers perceive as helpful for addressing these challenges?

Methods

Participants

Participants were family caregivers who were currently participating, or had previously participated in a randomized controlled trial of a psychosocial intervention for dementia caregivers, the Residential Care Transition Module (RCTM).²³ Caregivers who remained enrolled in the parent study as of June 2020, and those who had previously completed the study but were not bereaved, were invited to complete the COVID-19–focused assessments. RCTM participants were recruited via newspaper advertisements and via the University of Minnesota Caregiver Registry (full recruitment details are available in the RCTM protocol paper).²³ To be eligible, caregivers had to identify as being the most involved with care provision or sharing the role equally, be English speaking, and be 21 years or older. Their care recipients needed to live in residential care with a diagnosis of Alzheimer's disease or Alzheimer's disease–related dementias (AD/ADRD), as reported by the caregiver. A total of 125 caregivers provided

qualitative data; full baseline demographic information is reported in [Tables 1 and 2](#).

Measures and Procedure

Qualitative data were collected via open-ended online or mail survey questions (n = 125) and semistructured phone interviews (n = 20). Combining these data sources promoted both broad representation of many caregivers' views and in-depth exploration of key cases to provide richness and depth.

Open-ended survey questions addressed caregivers' satisfaction with how their LTC facility handled COVID-19, changes in communication with their relatives, discussions with their relatives on advance care planning and goals of care, and general thoughts on how COVID-19 has affected their relatives and their caregiving experience. These open-ended survey items were administered beginning in June 2020 and ending in August 2021.

A subset of 20 participants, a sufficient sample size for interviewing,³⁹ was selected for in-depth semistructured interviews. Participants were purposively selected to capture a diverse range of experiences and contexts relevant to the pandemic (eg, large and small LTC facilities; care recipients who were infected with COVID-19 and those who were not; high and low levels of satisfaction with the facility's response). Interviews addressed how LTC facilities handled the COVID-19 pandemic, changes in caregiving routines, and resources that caregivers found helpful. Interview questions were developed based on emerging research and ongoing discussions in LTC communities about COVID-19 in spring 2020.^{24,40} The interview protocol is available in [Supplementary Material 1](#). Interviews were conducted from January 2021 to June 2021. Ethical approval was obtained from the University of Minnesota Institutional Review Board (STUDY1511S80406).

Analysis Plan

Thematic analysis was conducted using the 6 steps outlined by Braun and Clarke.⁴¹ Authors LLM, EAA, RWB, CMP, HS, BH, and JC read through an initial round of interview transcripts and open-ended survey responses to familiarize themselves with the data (step 1). They met to discuss initial codes that addressed the research questions (step 2). Additional subsets of the data were read through next to evaluate how well the initial codes applied to them. The group reconvened to compare interpretations and refine the coding framework. Each author then coded a subset of the qualitative data in NVivo 12 using the final code framework (step 3). Coded data were reviewed holistically to identify broader themes (step 4), which were further refined and named (step 5). The codes were then applied to all available data. Each interview transcript was double-coded, and discrepancies were resolved via group discussion. A portion of the open-ended survey responses (20%) were coded twice in order to evaluate interrater reliability; average Kappa across categories was 0.84 and average percentage agreement was 96%. The summarized themes were compiled for reporting (step 6).

Results

Caregivers' Challenges During the Pandemic

Here we report the main themes reflecting the difficulties that caregivers reported, in order from most to least frequently mentioned. Frequencies for each theme are reported in [Table 3](#).

Visiting restrictions

Caregivers frequently discussed difficulty with visiting restrictions (79% of surveys, 100% of interviews). They missed the sense of

Table 1
Baseline Caregiver Demographics

	Interview Participants (n = 20)	Open-Ended Survey Participants (n = 125)
Female	18 (90)	108 (86)
Age, mean (SD)	58.2 (7.2)	61.9 (10.3)
White	19 (95)	121 (97)
Married	19 (95)	100 (80)
Number of living children, mean (SD)	2.2 (1.7)	2.0 (1.6)
Bachelor's degree or higher	16 (80)	92 (74)
Annual income of ≥\$80,000 or more	9 (45)	61 (48)
Employed prior to COVID-19 pandemic	12 (60)	62 (50)
Spouse of care recipient	5 (25)	34 (27)
Adult child of care recipient	12 (60)	78 (62)

Unless otherwise noted, values are n (%).

closeness that came from face-to-face visits and physical contact: “You had moments that seemed like you could connect on some level with the simple things, like walks, activities, meals and that is so limited now. We were able to hug and hold hands and can't do that now” (ID214a, daughter-in-law, age 64 years).

Furthermore, caregivers noted that alternative modalities such as video and window visits were inadequate substitutes. Staff were often unable to assist with arranging calls owing to time constraints. Residents had difficulty using new technology or did not understand the need to avoid in-person contact, and failed attempts to communicate led to frustration or helplessness:

With the “remote” visits, I felt very distant and that my mother probably didn't really know I was there . . . I have to admit, I did window visits and [Z]oom visits less and less since it was depressing and since I wasn't sure it had any effect. (ID223, daughter, age 54 years)

Even after reopening, many caregivers felt frustrated by restrictions that limited their ability to interact with their relative. Social distancing measures still interfered with closeness and warmth, and scheduling constraints presented barriers to visiting:

Due to my full time work schedule and my relative's decline in cognition during the afternoon and evening, I feel much of the scheduling is working against me. I am restricted by the schedule only allowing a limited number of visitors in each area of the nursing facility. (ID43, daughter, age 49 years)

Care recipient isolation

Caregivers worried about their relative's social disengagement as a result of social distancing and quarantine practices (30% of surveys, 90% of interviews):

Social isolation has been devastating for Mom. She experiences depression, anger, and loneliness far more frequently. Lack of social stimulation has diminished her interest in activities that previously were engaging and stimulating. (ID247, daughter, age 69 years)

Disruption of care routines

Participants felt distressed at not being able to conduct their normal caregiving routines, such as providing meals, cleaning, or taking the resident on outings (30% of surveys, 90% of interviews). Similarly, residents had difficulty adapting to changes in their typical daily routines as a result of COVID-19:

The entire pattern changed at the facility. . . . I could not go in to see her personally. . . . No more dining together. All activities

Table 2
Baseline Care Recipient Demographics

	Interview Participants (n = 20)	Open-Ended Survey Participants (n = 125)
Female	9 (45)	83 (66)
Age, mean (SD)	80.0 (9.0)	82.4 (7.8)
White	18 (90)	121 (97)
Married	10 (50)	50 (40)
Widowed	9 (45)	60 (48)
Number of living children, mean (SD)	2.9 (2.4)	3.2 (1.9)
Bachelor's degree or higher	7 (35)	52 (42)
Annual income of ≥\$30,000	12 (60)	74 (59)
On Medicaid	4 (20)	37 (30)

Unless otherwise noted, values are n (%).

changed, the schedule changed, and I understand that it had to. But she was confused. I didn't know what I was going to do. She needed me with her. (ID188, wife, age 67 years)

COVID-19 infection concerns

Caregivers reported fears of COVID-19 infection within the LTC facility (31% of surveys, 80% of interviews). Such concerns included fear that relatives might become infected, fear that staff may introduce COVID to the facility by violating safety protocols or avoiding vaccines, and fear about inadvertently exposing residents to infection themselves. As one participant stated, “It was just constant, like, ‘I hope he doesn't get it. I hope he doesn't get it. I hope he doesn't get it.’ You know, ‘Please let him be safe!’ It was a lot more stressful” (ID178, niece, age 41 years).

Needing information

Caregivers reported feeling uninformed about their relatives' needs (27% of surveys, 65% of interviews). Without opportunities to observe, caregivers found themselves wishing for detailed, day-to-day information on their relative's status. As one participant expressed, “I have missed being able to visit my husband and check on how he is doing. I haven't been able to monitor his cleanliness and the cleanliness of his room, or check on what he needs to have me bring him” (ID79, wife, age 81 years).

Care Recipient's health deteriorating

Several participants felt that their care recipient's mental, physical, or cognitive health precipitously declined as a result of the pandemic (26% of surveys, 70% of interviews). For instance, one caregiver noted that several residents' cognitive status seemed to have worsened substantially:

I noticed that my mom really had sort of declined cognitively from where she was before . . . a lot of [residents] had a severe decline, and it's hard to tease out whether it's the dementia itself or if it was the lack of stimulation from visitors. (ID164, daughter, age 65 years)

Concerns about staff

Some caregivers expressed worry on behalf of LTC staff, recognizing that many LTC facilities were understaffed and staff members were overly stressed (15% of surveys, 40% of interviews). These strains on staff were perceived as negatively affecting residents as well. As one participant stated:

Staff was short. At one time, 15 staff members were out with COVID. The ones remaining on duty were overworked and stressed. They didn't and couldn't care for residents the way they needed to. (ID195, wife, age 67 years)

Table 3
Qualitative Coding Themes

Theme	Frequency in Interview Transcripts, n (%) (n = 20)	Frequency in Open-Ended Surveys, n (%) (n = 125)
Challenges		
Visiting restrictions	20 (100)	99 (79)
Care recipient isolation	18 (90)	37 (30)
Disruption of care routines	18 (90)	37 (30)
COVID-19 infection concerns	16 (80)	39 (31)
Needing information	13 (65)	34 (27)
Care recipient's health deteriorating	14 (70)	32 (26)
Concerns about staff	8 (40)	19 (15)
Grief	8 (40)	16 (13)
Impossibility of returning care recipient home	11 (55)	9 (7)
Inconsistent policies	8 (40)	12 (10)
End-of-life concerns	5 (25)	15 (12)
Resources, strategies, and practices		
Infection control within the LTC	18 (90)	66 (53)
Good communication with LTC Staff	18 (90)	51 (41)
Maintaining contact with care recipient	13 (65)	26 (21)
Staff engagement with residents	12 (60)	15 (12)
Social support	14 (70)	3 (2)

Grief

Coping with bereavement and loss was often especially difficult during the pandemic, as discussed in 13% of surveys and 40% of interviews. Participants described feeling that they had lost precious time with their care recipient. One caregiver noted that the pandemic “just robbed me of so much time with her, and I don't know how the end would've played out. Obviously she's gonna pass away at some point, but the pandemic absolutely caused her death, because it sped it up” (ID213, daughter, age 54 years).

Impossibility of returning care recipient home

Although several caregivers reported they had considered removing their relatives from the LTC facility and caring for them at home instead, most felt it would not be possible (7% of surveys, 55% of interviews). Some expressed frustration at others' perceptions that this would be a natural solution to the problem of rapidly spreading infections in LTC:

This isn't a puppy. . . . [We] would still have to have caregivers come in the house, they would expose him and me to COVID. . . . And what if I got COVID and died and he didn't? I mean, so yeah, I can always bring him home, but how do you care for somebody alone? You can't, that's why he's in a facility. (ID191, wife, age 63 years)

Inconsistent policies

Caregivers reported frustration at inconsistent application of COVID-19 preventive measures across institutions and across individuals (10% of surveys, 40% of interviews). Caregivers often felt frustrated that others could visit their relatives at other LTC facilities, when they were unable to do so:

I see how differently different places have handled visits or the lack thereof, and it's hard not to be jealous sometimes. . . . if she had lived at [other nearby LTC facility], they have a completely different category of caregivers now. . . . that can come in for up to three hours at a time. (ID213, daughter, age 54 years)

Participants also noted that rules were sometimes inconsistently applied within a facility: “[The facility has] a no visitor policy and yet

my one sister will go there to drop stuff off and they'll say, ‘Do you want to come in?’ . . . She's the lucky one” (ID238a, daughter, age 56 years).

End-of-life concerns

Participants reported that end-of-life care was complicated by COVID-19 (12% of surveys, 25% of interviews). Several expressed worry that their relatives might die alone, or that they would never get to visit their relatives again before they died:

Thinking that you're going to lose your loved one and not be able to be by their side and let them know that you love them and be able to help them through that last moment of their life and have them feeling alone and abandoned, that was something that was a real big fear for me. (ID223, daughter, age 61 years)

Resources, Strategies, and Practices

Infection control within the facility

Caregivers reported appreciating the preventive measures that facilities implemented to prevent and control COVID-19 infection, such as social distancing and vaccinations (53% of surveys, 90% of interviews). For instance, one participant noted, “His facility acted early with strict measures for distancing, mask wearing, etc., so we felt confident” (ID227, daughter-in-law, age 54 years).

Good communication with LTC staff

Participants reported that staff members who made efforts to communicate actively with families, especially those who communicated specific details about individual residents, contributed to their peace of mind (41% of surveys, 90% of interviews):

During the week after she tested positive they called me just about every day. . . . I was concerned a little bit, but when they started calling me every day about what was going on with [her symptoms], that took care of those concerns. (ID198, son, age 43 years)

Maintaining contact with care recipient

Caregivers often reported using new ways to remain connected with their relatives, such as sending letters, setting up video visits, installing cameras and communication devices in their relative's room (21% of surveys, 65% of interviews). As one participant expressed, “You had to just sort of get creative. You had to be more overt about your efforts to stay connected, to know what was going on” (ID204, daughter, age 58 years).

Staff engagement with residents

Caregivers appreciated staff members' efforts to keep residents cognitively and socially active during the pandemic (12% of surveys, 60% of interviews). One caregiver described examples of engagement with residents in her father's LTC facility: “Efforts are made to engage with residents by a traveling snack cart, additional check-ins with residents, arranging virtual visits or in person socially distanced visits when COVID numbers allow” (ID39, daughter, age 59 years).

Social support

For many participants, emotional support and empathy from family, friends, and support groups were important in coping with the pandemic (2% of surveys, 70% of interviews). As one participant reported, “I had an informal network of friends that made up a support group because we were all advising each other, leaning on each other. So, I never felt alone” (ID221, daughter, age 60 years).

Discussion

This study represents an important contribution to understanding the effects of the COVID-19 pandemic on family caregivers of LTC residents with dementia. The findings emphasize the need to better integrate family members' perspectives and input into formal care delivery in LTC. COVID-19 laid bare how family caregivers are simply not acknowledged as key facets of LTC delivery in residential settings, as was evident in participants' discussions of disrupted care routines, lack of information and opportunities to interact, and residents' health deteriorating as a result.

A significant contribution of the current study is that families themselves emphasize a number of potential recommendations that could bridge this chasm. Notably, the resources, strategies, and practices that caregivers identified were aligned with the challenges they reported. The areas of (1) visitation and communication with care recipients, (2) protection from COVID-19 infection, and (3) communication and support from LTC staff emerged as underlying dimensions across our themes. Caregivers' experiences ranged on a spectrum across these dimensions, with many reporting significant challenges in these areas, and a smaller set reporting resources, strategies, and practices that helped them cope with such challenges.

Current advice from clinicians and experts did not always align with caregivers' recommendations. For example, several published commentaries have emphasized alternative visiting modalities,^{9,21} but participants frequently felt such workarounds were inadequate. The majority of participants (79% in surveys) discussed visiting restrictions as a key stressor, and only 21% highlighted alternative visiting modalities as a helpful strategy. Instead of focusing on communication workarounds, maximizing opportunities to visit in-person with the help of consistently enforced vaccination⁴² and testing may be more helpful to family caregivers.^{32,34} As LTC facilities navigate emerging COVID-19 outbreaks, prioritizing in-person visits will be crucial for maintaining residents' well-being.¹¹

Communication from LTC has always been very important to families,²⁸ and is likely even more critical during a pandemic. Within this sample, 27% of survey respondents felt distressed at a lack of information about their relative, whereas 41% felt reassured by effective communication from staff. Our findings concur with expert advice to keep families informed about LTC residents' care.²¹ LTCs should communicate at least weekly about their processes regarding resident care and visitations by families.²² Importantly, LTCs should also have consistent individual communication with families discussing their relative's health status and needs to the greatest extent possible. We encourage facilities to strive to provide regular, individualized communication, recognizing that such communication during pandemic conditions may be difficult in many cases and impracticable in some. Nonetheless, given families' emphasis on the importance of regular, personalized communication, this would benefit residents and families presently and post-pandemic.

These findings also reinforce expert commentaries highlighting the challenges of bereavement during COVID-19,⁴³ which were mentioned by a minority of participants (13% in surveys), but with intense emotionality among those who were affected. Pandemic conditions may exacerbate families' perceptions of neglect and lack of respect for residents at the end of life, factors that strongly influence satisfaction with end-of-life care.⁴⁴ The loss of a relative under conditions of isolation and quarantine can contribute to severe and prolonged grief.^{23,45,46} Outreach to bereaved caregivers to ensure access to support services may facilitate recovery from traumatic losses.

Most participants were highly educated, affluent, and White; therefore the concerns reported here may not reflect the perspectives of caregivers with diverse backgrounds. Indeed, recent research suggests that the effects of COVID-19 are more severe for low-income

caregivers.²⁹ Further research on the experiences of diverse caregivers is critically needed.

Conclusions and Implications

The challenges and strategies reported by participants may inform improved support for caregivers throughout the remainder of the COVID-19 crisis, and in the LTC context more broadly. The discrepancies we found between caregivers' and experts' perspectives highlight the need to create more robust, family-centered models of LTC where caregivers are effectively integrated into policy development and care. Such models would help avoid adverse consequences not only in the current crisis but also beyond the pandemic when caregivers' perspectives are potentially neglected in LTC.

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Supplementary Material 1. Semistructured Interview Guide

1. First, I'd just like to get a broad view of how things have unfolded for you and your relative over the past several months, since the start of the COVID-19 pandemic. Can you tell me the story of what has happened for you and your relative, starting before the COVID-19 pandemic (about January-February, 2020), and bringing us up to the present?
2. What are some of the main challenges or concerns that have come up so far regarding caring for your relative?
3. How are you coping with these challenges and concerns? What strategies, if any, have been helpful to address these challenges?
4. Now, I'd like to talk about how your relative's long-term care facility has been handling the COVID-19 pandemic. What are some of the ways the facility has tried to prevent or slow the spread of COVID-19?
 - a. Probe: How worried are you about your relative getting sick from COVID-19?
 - b. Probe: Have these facility measures impacted your level of concern (ie, made you feel more or less scared)?
 - c. Probe: Has the facility "reopened" or lifted any restrictions that were previously in place? If so, what effect did reopening have on you and your relative?
5. How has the facility been communicating COVID-19-related plans and updates with you?
 - a. Probe: Has the communication been adequate? Why or why not?
6. How is the facility keeping your relative engaged while practicing social distancing?
7. What have you liked or disliked about how your facility is handling the situation?
8. What would you change about how your facility is handling the situation?
9. Are you concerned about being able to continue paying for care?
10. Now, I'd like to learn about how your relative has been affected by these changes. How has your relative's day-to-day routine been affected by COVID-19?
 - a. Probe: By any procedures implemented by the facility? Remind of any procedures listed earlier if needed.
11. How has your relative handled the changes in daily living, care, and visiting?
12. How has your relative's health and well-being changed since the start of COVID-19?
13. Next, I'd like to hear about how you've been affected in your role as a caregiver. How has your ability to be a caregiver for your relative been impacted by COVID-19?
 - a. Probe: Are you providing more or less care?
 - b. Probe: Any different care roles or activities you've taken on?
14. How have interactions with your relative changed?
15. How have your feelings of stress or burden changed as a result of the COVID-19 pandemic?
16. Has not knowing when or if these restrictions will change affected you?
 - a. Probe: How long are you comfortable with going without seeing your relative?
 - b. Probe: What are your thoughts about the tradeoff between quality of life (for example not being able to have visitors) and resident safety?
17. In this last section, I'd like to hear more about what kinds of resources have been helpful to you during this time. What resources have been most helpful?
 - a. Probe: What other resources do you wish you had access to?
18. *For participants still enrolled in the treatment group beyond March:* Did you find that talking with [name of study interventionist] was helpful for dealing with COVID-19? In what ways?
19. *For all participants in treatment group:* In what ways, if any, did things you learned from the RCTM help you in coping with the COVID-19 pandemic or in being a caregiver to your relative during the COVID-19 pandemic?
20. Is there anything else you would like to add about your COVID-19 experience as a caregiver of someone in a residential facility?