


Changes to Family Caregiving of Older Adults and Adults with Disabilities during COVID-19

Gerontology & Geriatric Medicine
Volume 7: 1–8
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DOI: 10.1177/23337214211002404
journals.sagepub.com/home/ggm


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Abstract

The strict restrictions to reduce the spread of COVID-19 have disrupted the lives of many at-risk people and their family caregivers. This study explored how family caregivers perceived that family caregiving had changed during COVID-19 and the strategies they used to cope with these changes. We conducted 52 semi-structured interviews with family caregivers of adults over age 65 or adults with disabilities and analyzed the data through an inductive thematic analysis. Caregivers perceived the largest COVID-19-related caregiving changes to be limited social and physical contacts, changed caregiving tasks, reduced services and supports, and a new focus on vigilance and safety. Caregivers made numerous changes to caregiving, including keeping connected, keeping relatives occupied, getting support and services in new ways, and reducing caregiver stress.

Keywords

family caregivers, supports, older people, aging, connections, technology

Manuscript received: December 7, 2020; **final revision received:** February 10, 2021; **accepted:** February 19, 2021.

Introduction

The stringent restrictions enacted to protect at-risk people from COVID-19 have also disrupted their lives and those of their family caregivers. Researchers are now exploring the psychological and social impacts of these restrictions, particularly the effects of isolation (Luchetti et al., 2020). While family caregivers provide the majority of care to these at-risk people regardless of setting (AARP, 2020), and there has been much attention to the changes in family caregiving in newsletters and editorials (Hado & Friss Feinberg, 2020; Ickert et al., 2020; Lightfoot & Moone, 2020), there has been little research into the nature of these changes. The few studies about family caregiving during COVID-19 have used existing panel studies to examine caregiver stress, mental health, and supports (Altieri & Santangelo, 2021; Cohen et al., 2020; Gallagher & Wetherell, 2020; Park, 2020; Savla et al., 2020), but none have studied the nature of caregiving changes. To get a better understanding of caregiving during COVID-19, we used a qualitative approach to study how family caregivers of older adults or adults with disabilities perceived that family caregiving had changed during COVID-19 and what strategies caregivers used to cope with these changes.

Methods

We gathered data through semi-structured interviews with family caregivers to explore the complex phenomena of family caregiving during the COVID-19 pandemic, allowing for rich narrative responses and subsequent coding into themes. Our multilingual research team included two faculty members, four graduate students, and one undergraduate student, and all participated in data collection and data analysis. The University of Minnesota approved this study.

We recruited 52 family caregivers of adults over age 65 or adults with disabilities in the upper Midwest region in the United States using convenience sampling primarily through emails to caregiving networks and social media posts. Participants could be caring for relatives living in their own home, in the caregiver's home

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Table 1. Demographic Characteristics of Family Caregivers.

Characteristic	Family caregivers	
	N	%
Age of caregiver		
20–44	9	17.3
45–54	11	21.2
55–64	14	26.9
65–74	15	28.8
75+	3	5.8
Gender		
Male	8	15.4
Female	44	84.6
Race/ethnicity		
White, non-Hispanic	34	65.4
Black, non-Hispanic	6	11.5
Asian	6	11.5
Hispanic	5	9.6
Care recipient		
Father	6	11.5
Mother	18	34.6
Spouse/partner	10	19.2
Son	5	9.6
Daughter	3	5.8
Others	10	19.2
Residential setting		
Own home	6	11.5
Caregiver's home	25	48.1
Long-term care setting	21	40.4
Language		
English	37	71.1
Somali	5	9.6
Korean	5	9.6
Spanish	5	9.6

or in a long-term care facility. See Table 1 for description of sample.

We utilized a semi-structured interview guide for this study that was developed based on a current review of the literature and pre-tested with seven community members. We asked participants a series of questions regarding the types of care they had provided before and during the COVID-19 pandemic. The 25 to 60 minute interviews were conducted by research team members over a video platform from May to September of 2020, and English interviews were transcribed, with each interviewer reviewing transcripts. Somali, Spanish and Korean interviews were conducted, translated and transcribed into English by bilingual interviewers who were certified translators.

We conducted an inductive thematic analysis following the guidelines proposed by Braun & Clarke (2006) to explore themes related to changes related to two categories: caregiving during COVID-19 and coping with caregiving changes. We reviewed each transcript and assigned initial codes based on concepts that emerged from the narrative. Codes were noted in an Excel spreadsheet with corresponding quotes. Upon completion of

the initial coding of all transcripts, researchers met to establish a final coding framework. The initial coders then re-coded all the transcripts with the final coding framework, and then a second researcher independently verified the coding. The codes were then grouped into themes and sub-themes, with the research team distilling the descriptions of the themes. We pulled out the quotes related to each sub-theme into a separate spreadsheet to assist with the final analysis. All transcripts were reviewed a final third time by the first author to verify and clarify the established themes and sub-themes.

There are several limitations to this study. First, the findings cannot be generalized to the larger population. However, as this study aimed to gain an initial understanding of caregiving changes during a contemporary crisis, the tradeoffs seemed acceptable. Second, we used a research team to conduct interviews and analysis. As recommended by Boutain and Hitti (2006), we trained interviewers, conducted practice interviews, used a semi-structured interview guide, and had all team members participate in data collection, which to help mitigate this limitation. A final limitation to our study is that it included caregivers of both older people and people with disabilities. While many of these issues overlap, a future study should examine the nuanced issues of caregivers of younger adults with disabilities.

Findings

We organized the findings into two categories: changes to caregiving during COVID-19 and coping with caregiving changes. We found four broad themes under each category, each containing several sub-themes (See Table 2).

Changes to Caregiving during COVID-19

The first category focused on changes that caregivers experienced during COVID-19. Family caregivers were asked to discuss how caregiving had changed since the start of the pandemic. Caregivers outlined numerous changes to their caregiving tasks, which we grouped into the following four sub-themes: *limited social and physical interactions*; *changed caregiver tasks*; *reduced services and supports*; and *vigilance about safety*.

Limited social and physical interactions. The first theme, described by all of participants, was how COVID-19 had greatly *limited social and physical interactions* of both care recipients and caregivers in all settings. The four sub-themes were: no in-person contact; no physical contact; smaller social networks; and changed social interactions.

No in-person contact. Nearly all of those caring for family members with whom they did not live described the lack of in-person contact as being one of the most difficult changes related to COVID-19. For many, they

Table 2. Themes and subthemes exploring the changes and coping mechanisms of family caregivers during COVID-19.

Changes to Caregiving	Coping with Caregiving Changes
Limited Social and Physical Interactions <ul style="list-style-type: none"> • No in-person contact • No physical contact • Smaller social networks • Changed social interactions 	Keeping Connected <ul style="list-style-type: none"> • Keeping Connected through Technology • Alternative in-person visits • Sending letters and gifts • Connecting more often • Enlisting staff
Changed Caregiving Tasks <ul style="list-style-type: none"> • Less social stimulation and exercise • Monitoring from afar • Practical caregiving changes • Changed schedules 	Keeping Loved Ones Occupied <ul style="list-style-type: none"> • Technology for entertainment • Other activities
Reduced Services and Supports <ul style="list-style-type: none"> • Changes to health care • Fewer formal caregiving supports and activities 	Getting Support and Services in New Ways <ul style="list-style-type: none"> • Technology for support and services • Hiring staff • New shared caregiving arrangements • Advocating and monitoring • Moved family member
Vigilance about Safety <ul style="list-style-type: none"> • Masks and physical distancing • Keeping the home safe 	Reducing Caregiver Stress <ul style="list-style-type: none"> • Self-care • Adapting to new routines • Dealing with guilt

went months without seeing their relatives at all. This was a dramatic change for caregivers, many who had described visiting their relatives regularly and providing important care and social stimulation.

No physical contact. In addition to the lack of in-person contact, a number of caregivers discussed how difficult it was not to have physical contact with their relatives, such as hugging or holding hands. This was especially the case for those caring for older relatives with dementia, who described physical touch as one of their key ways of interaction. For example, a caregiver caring for his 92-year-old mother in a memory care facility said:

I feel deprived of just being able to sit with her and I can't really talk to her. . . we would just sit there and I would just sit there and kind of rub her back and chat with her, and I am sad I can't do that anymore.

Caregivers described this type of human connection as something that could not be replaced by staff. A caregiver of her 89-year-old mother in a memory care unit explained:

It's different when . . . somebody else is providing that care. You know, she likes having her back scratched. You know whenever we see her. . .and I did ask the nurse to offer to scratch your back sometimes but I don't know if it's happening.

Some caregivers broke facility rules just to have some physical contact, such as one caregiver who described hugging her mom when a staff member had turned

away: "So, we had our masks on, and we all reached out to give her a hug. Oh yeah!"

Smaller social networks. Caregivers of family members living with them described how social distancing had led to smaller caregiving support networks. While over half of the participants typically shared caregiving, COVID-19 often led to one caregiver providing the bulk of in-person caregiving. For example, a caregiver of an 81-year-old mother said, "My siblings used to come and help, but now no one can come from the outside into the house. We stopped people from coming into the house."

Changed social interactions. Caregivers discussed how both the caregiver and the care recipient now had limited social interactions. Care recipients had limited interactions because of their high risk for COVID-19 complications, and caregivers often limited their own interactions to keep their relatives safe. For those living together, this often involved isolating together. Caregivers caring for families members in facilities described their worries about the dramatically decreased social interactions of their family members and its impact on their mental health. Some worried that staff, no matter how conscientious, could not provide the same loving care that families provided. A caregiver of an 84-year-old mother living in a facility related: "So I know she sees people, but it's a whole different experience. It's more coming in to give her medication or help her go to the bathroom, that kind of thing."

Changed caregiving tasks. Most caregivers discussed their *changed caregiving tasks*, and many lamented that

they were no longer able to do many of their typical caregiving tasks due to the COVID-19 restrictions. For many, this was extremely difficult, as family caregiving was an essential part of the care their relative received and an important part of the caregivers' lives. One caregiver of an 85-year-old father summed up the changes:

I don't think that that people outside of living in this situation understand, even if somebody is in long term care, how much the family does for individuals. . . that you're going in there and you're going through his mail, you're cleaning up his room, you're making sure they're taking care of him, you're bringing him snacks, you're taking him out, you're talking to the staff, you're keeping an eye on things, and none of that is happening now.

The following describes the four sub-themes related to changed caregiving tasks: less social stimulation and exercise; monitoring from afar; practical caregiving changes; and changed schedules.

Less social stimulation and exercise. Participants caring for family members in all settings discussed that prior to COVID-19, one of their key caregiving tasks was to provide social stimulation and exercise. For those caring for family members in facilities, they were no longer able to provide this type of care and were concerned that facilities could not fulfill these tasks. For those providing care in the community, they were no longer able to provide the same types of community inclusion and exercise for their relatives, such as going to a mall, restaurant, or park. For example, a caregiver of his 67-year-old mother said: "Especially in the summer, we would take her to the park or other places for her to walk around and exercise . . . we haven't taken her out since the disease started."

Monitoring from afar. For some participants providing caring for relatives in long-term care, one of their key caregiving tasks was to monitor their relatives' care. Since COVID-19, they were no longer able to monitor the type, amount, or quality of services being provided, and some felt the staff communication was not detailed enough. Some described looking for clues to the type of care a relative was receiving through generic communications with staff or during video chats, wishing they had a better handle on the type of care being provided. This uncertainty was unsettling. For example, a participant who cared for her 86-year-old mother said, "We are not sure about her condition or her needs . . . it's hard to check. That's the most difficult thing."

Practical caregiving changes. Participants also discussed practical changes in their caregiving tasks, such as having to figure out new ways to obtain medicine, supplies, or food for their relatives; or arranging telehealth visits instead of in-person visits. This included arranging home delivery of many items that they used to pick up, and also delivering supplies to long-term care

facilities in new ways. Some participants described this initially as stressful, but none described this as an ongoing challenge. In fact, for many, they shared how they enjoyed spending less time driving as a caregiver than they had before the pandemic.

Changed schedules. Finally, some talked about how their own changed schedules had affected the type of caregiving tasks could do. Many talked about how they were now working from home, were homeschooling their children, and/or had new people living in their homes, which made caregiving more challenging. While some who were caring for their relatives in their own home described spending more time at home as useful for providing care, others talked about how they had much less time to engage in caregiving tasks because they were so busy with a new, hectic schedule.

Reduced services and supports. The third major theme was *reduced services and supports*. The two sub-themes included changes to health care and fewer formal caregiving supports and activities.

Changes to health care. Caregivers were worried both about cutbacks to health care services which could impact their relatives' health, and possibilities of their relative contracting COVID-19 while receiving services. Some caregivers described delaying in-person health care because of COVID-19 restrictions on accompanying family members, particularly care recipients who did not speak English. For example, one caregiver caring for her 80-year-old mother said, "They used to say she had to go to the hospital alone, and no one could go with her, even if she needed an interpreter. They said they would provide the interpreter."

Even when some of the restrictions were temporarily lifted, some caregivers were leery of in-person services, worrying about the possibilities of their relative catching COVID-19 while seeking treatment. For example, one caregiver of her 81-year-old mother said: "We are afraid to take her to the doctors or other places we used to take her. Now we use the telephone when she needs the doctor. The doctor sends what she needs when we call him, because we're afraid of taking her places, or of people coming to us."

Fewer formal caregiving supports and activities. Most participants described using less formal supports for caregiving. While the majority of those caring for folks in the community were not using formal caregiving supports, those that were discussed how these supports were altered or eliminated. Some also talked about how they were cautious with getting in-home help, as they worried that staff would bring in the virus. Others described how certain in-home services had been temporarily eliminated, such as a visiting minister to provide pastoral care, or a nurse to provide medicine checks. Caregivers providing care in their homes described how most

of the in-person activities were no longer available, such as singing groups, sports, arts and crafts classes, social activities, or memory cafes. Some activities were now offered online, which caregivers appreciated, but online activities did not provide the caregivers the same type of respite.

Vigilance about safety. The final theme related to changes to caregiving was a new caregiving role that emerged during COVID-19: *vigilance about safety*. Participants were generally aware of the dangers of COVID-19, as all of their family members had at least one risk factor for severe COVID-19. The two sub-themes they discussed related to vigilance were: masks and physical distancing, and keeping the home safe.

Masks and physical distancing. Caregivers discussed how they had taken on a new role of reminding their relatives and visitors to wear masks and stay more than six feet away. For those caring for relatives with cognitive disabilities, this became an important caregiving task. As one caregiver said:

I'm the one who reminds him to wear a mask. He doesn't remember, and he probably wouldn't remember to keep his distance. So he'll reach out to shake hands with somebody, and I have to remind him not to do that.

Some caregivers reported not leaving the house because it was so difficult for their relatives to understand and follow safety protocols.

Keeping the home safe. Many caregivers described how vigilant they have become in keeping COVID-19 out of the home, such as banning all visitors. Others talked about extensive cleaning that they would do to keep their relatives safe. People described actions such as changing all their clothes when returning to the house, wiping off all items that entered the house, including groceries and take-out food, and hanging signs around the house with safety instructions. One participant described her caring for her 80-year-old mother as follows, "We keep cleaning all the time until our hands hurt. We cleaned before too, but it's a lot more now. We even clean the keys when somebody comes home from the outside."

Coping with Caregiving Changes

The second category includes four themes related to coping with caregiving changes during COVID-19. These themes are: *keeping connected*, *keeping loved ones occupied*, *getting support and services in new ways*, and *reducing caregiver stress*. The following details these themes and sub-themes.

Keeping connected. The most common theme discussed by participants was *keeping connected*. Caregivers were creative in keeping connected with their relatives, and

keeping their relatives connected with others. The following details the five sub-themes related to keeping connected, including keeping connected through technology, alternative in-person visits, sending letters and gifts, enlisting staff, and connecting more frequently.

Keeping connected through technology. The most common way participants kept connected was through technology. Many caregivers discussed video chatting with their relatives themselves, and/or arranging technology-assisted communication for their relatives with other family or friends. For many, this technology worked well, and for some it increased their connections. For example, a caregiver said, "we FaceTime, and in some ways I see her face more." People discussed this video contact as especially crucial for those who have difficulty talking on the phone. While nearly every participant discussed technology as an option for keeping connected, some discussed how their relatives had difficulty with the technology or were uncomfortable talking over video. For example, one caregiver of her 86-year-old mother said, "We tried to do video chatting. But, mom has serious dementia so there was no reaction, and we just saw the wall . . . so, it did not work that well."

Alternative in-person visits. Most participants also discussed various types of alternative in-person visits, both for those living in facilities or the community. The most common type of alternative in-person visits were "outdoor visits," remaining physically distanced and wearing masks. This included visits at a facility patio or courtyard or in the caregivers' backyard or deck. The other common type of alternative in-person visit was a "window visit," where a family member could visit with others through a closed or open window. They also described "drive by visits," where family or friends could drive by a facility or home and wave, or "hand off visits," where their family member could briefly visit family or friends when they handed off a present. Many of those caring for relatives in facilities expressed relief when these types of visits were allowed, and dread about the coming winter when such visits might not be possible.

Sending letters and gifts. Some caregivers described sending letters and gifts to their relatives from whom they were physical distancing as a means to stay connected. One participant related that she started a letter drive for her mother, enlisting grandchildren and other letters to send letters. For relatives who couldn't read, some sent picture books or scrapbooks as a way for their loved ones to feel connected during lockdowns.

Connecting more often. Some caring for relatives from afar stated that they tried to connect more often with their relatives, particularly when their relatives were in isolation. As caregivers often were not able to do some of their other caregiving tasks, connecting became one of the main types of caregiving. For example, a caregiver

of her 97-year-old father who lives in a facility said, “The only way I can do anything is to call him, which I do.” This caregiver also explained that she tried to arrange for others to call as well. She said, “He has two grandkids and I’ve asked them to call him every so often just so he hears from somebody else besides me.”

Enlisting staff. The final sub-theme was enlisting staff to help them connect with their relatives. For many of those whose family members had memory loss and were living in facilities, they were not able to connect without the assistance of staff. For example, one caregiver described making arrangements with a staff member that assists her mom with toileting. She said, “So my mom picks which daughter she wants to FaceTime with, and the woman pushes the button.” Some discussed their hesitation to ask staff to help with communication, worrying that it was not technically the staff’s job to help with communication.

Keeping loved ones occupied. The second theme related to coping with caregiving changes was *keeping loved ones occupied*. The two sub-themes that comprise this theme are technology for entertainment and other activities.

Technology for entertainment. Many participants reported buying or borrowing technology for their loved one so that they could watch shows, listen to the radio, do exercises, or play games. For example, one caregiver described how a radio provided his relative with some entertainment. He said,

“You know, you’re just lying there, and you’re blind and you have nothing to do except for thinking in your head. That’s the deal, but getting news and listening to news and stuff, music, [it’s a] big deal to her.”

Some caregivers also discussed how their family members were able to be more engaged in community activities or social activities through the use of technology. For example, one family caregiver said that his husband was now able to attend church services remotely, while another discussed how her mother was attending social groups online.

Other activities. Participants also devised other activities to try to keep their relative entertained when they were socially distancing. This included printing out photos, making activity books, or sending treats and food. For example, one caregiver of her 89-year-old mother said: “I’ve just tried to send some things to my mom . . . little treats that we bring, or send her flowers, just to try to brighten her day.”

Getting support and services in new ways. The third theme in this category was *getting support and services in new ways*, much of it through technology. Most of our caregivers had never or rarely used formal caregiving support

services before COVID-19, and continued to rely on informal caregiving support. The five sub-themes were technology for support and services, hiring staff, new shared caregiving arrangements, advocacy and monitoring, and moved family member.

Technology for support and services. Many participants discussed how they were getting supports and services for their relatives through telehealth for a wide range of services and therapies, ranging from general visits with the doctor to visits with specialists and therapists. Telehealth was generally viewed as positive by participants, who appreciated that their family members could get the services they needed without the risk of their family members contracting COVID-19.

While the majority of participants were not connected with formal caregiving support, some discussed how they were able to get caregiving support online. This included online support groups for caregivers, social media groups, apps to arrange caregiver support, and online memory cafes where caregivers participated together with the care recipients.

Hiring staff. Some caregivers described needing to arrange for new types of assistance in caring for their relatives, particularly hiring new staff. Some described needing to replace staff who had quit because of COVID-19, and others had to hire new staff because of their increased amount of caregiving they were providing. Some participants reported difficulties in hiring staff, and others described worries that staff would bring COVID-19 into the house.

New shared caregiving arrangements. Some caregivers reported getting more support from relatives and friends than before, and related stories of family members helping out by engaging in regular calls or outdoor visits. One caregiver of her 85-year-old husband said, “I have engaged an adult granddaughter to walk with him once or twice a week.” However, not all caregivers who sought assistance from their friends and family members were successful. A caregiver of her 89-year-old mother living in a facility said, “I tried to reach out to family members to connect her with other family members. And they did that for about a week and then they stopped again.”

Advocacy and monitoring. Some caregivers of those in facilities discussed increasing their advocacy related to the safety and care of their relatives, including general safety related to COVID-19 and personal concerns on behalf of their relatives. Participants were particularly concerned that facilities would not be able to replace the care that family members typically provided. For example, one caregiver of her 98-year-old mother said, “I wrote a five page letter about this to the assisted living center about the things we’re doing to assist our mom. If you aren’t going to let us come in, you have to assume these responsibilities.”

Moved family member. A few caregivers shared that they had moved their relatives from their facility because of worries of their loved one catching COVID-19 and the decreased quality of life their relative would have living in a facility with extreme safety protocols. For example, one caregiver said that she had moved her 78-year old parents to live with her in a cabin. Others related that they had considered moving their relatives, but decided against it, which caused them enormous guilt. For example, one participant said she thinks to herself:

Oh maybe I should be doing more, maybe I should have gotten him out of that place, and brought him to our house. So there's that kind of stuff that goes through your mind. But. . . you know, I really don't have the space. We would probably kill each other. . . it just wouldn't work, and he wouldn't get the care he's getting there.

Reducing caregiver stress. The final theme in this category was *reducing caregiver stress*. The subthemes included self-care, adapting to new routines, and dealing with guilt.

Self-care. A few of the caregivers discussed how they intentionally took time to take care of themselves while caregiving during COVID-19. The caregivers took care of themselves in a variety of ways, such as through taking outdoor group classes, exercising, or scheduling breaks for themselves. Caregivers also gave themselves permission to be stressed, recognizing that COVID-19 was an exceptionally difficult time, such as a caregiver who said the following:

Just to be more compassionate with myself that this isn't normal. This is not typical. This is not, you know, there's nothing wrong with you, you were trying to adapt to something that's weird and crazy and makes no sense.

Adapting to new routines. Participants discussed how they had to adapt to new caregiving routines during COVID-19. For some, this meant that they had much more free time as they could no longer do visits in facilities, and others were caregiving at home now all the time. For example, one woman providing care for her 76-year-old husband said, "This is my joke because we've never been puzzle people, but we've actually done two puzzles."

Dealing with guilt. Some caregivers discussed needing to deal with guilt about their diminished caregiving during COVID-19. Some felt that they might not be doing enough for their relatives or that they were not making the right choices for their care. Some described guilt at not being able to provide the type of care that they had been providing in the past.

"She can't read anymore. She can't watch TV, and I find myself wishing she would just pass peacefully during the night. . . what's the point, your very low quality of life. . . you feel guilty as hell saying that."

Some of participants related that they dealt with their guilt by participating in COVID-19 relief activities, such as mask making or organizing events for facilities.

Discussion

Caregivers uniformly described the greatly diminished social and physical interactions with their family members as a key way caregiving had changed. Caregivers were also no longer fulfilling many of their regular caregiving tasks, and some of these tasks, such as providing social and mental stimulation, were not being provided by others. In addition, both informal and formal supports for caregiving were reduced, requiring in-home caregivers to take on more responsibilities. Conversely, those caring for family members in facilities were having to care completely from afar. All of these changes are likely related to the increased caregiving stress and decreased caregiver mental health found in the panel studies (Cohen et al., 2020; Park, 2020).

Caregivers in our study were resourceful, finding new ways to interact with their family members, keep family members occupied, and get health care and support. While many of these innovations involved technology, technology did not work for all participants. Caregivers also discussed several COVID-19-specific caregiving tasks, including monitoring from afar and vigilance about safety. Despite this resourcefulness, some felt guilt based on their perception that they were not caring appropriately for their relatives.

Conclusion

While there is a growing body of research exploring the correlations between caregiving during COVID-19 and the well-being of family caregivers, the findings from this study help us to understanding caregivers' perceptions of the nature of these changes and can help inform the design of interventions geared to better support family caregivers, particularly during times of crisis.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Center for Healthy Aging and Innovation, University of Minnesota.

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