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**Caregiving in Times of Uncertainty:
Helping Adult Children of Aging Parents Find Support during the COVID-19 Outbreak**

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Abstract

The COVID-19 pandemic, which is especially dangerous to older people, has disrupted the lives of older people and their family caregivers. This commentary outlines the adaptive and emerging practices in formal supportive services for family caregivers, the changing types of support that family caregivers are providing to their older relatives, and the ways family caregivers are seeking informal caregiving support during the COVID-19 outbreak.

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COVID-19, first diagnosed in Wuhan Province in China in 2019, is especially dangerous to older people because of age-related health conditions and age-related declines in their immune systems. Early studies put the mortality rate of COVID-19 for people between ages 70 and 79 years at 8%, and for those over age 80 at 14.8% (Wu & McGoogan, 2020). In the United States, The Centers for Disease Control and Prevention (CDC) (Centers for Disease Control, 2020) estimates that eight out of ten deaths have been among people ages 65 and older. Older adults living in long-term care facilities, such as nursing homes or assisted living facilities, are at a very high risk for mortality from COVID-19, particularly with asymptomatic or presymptomatic workers inadvertently spreading the virus in the facilities (McMichael et al., 2020). While national data were unavailable as of early May 2020, seven states reported more than half of their COVID-19 deaths were residents of long-term care facilities (Kaiser Family Foundation, 2020), with some states reporting much higher rates, such as in Minnesota where about 80% of its deaths were from long-term care facilities (Minnesota Department of Health, 2020).

In response to older people's higher chances of complications from COVID-19, the CDC (Centers for Disease Control, 2020) has recommended older people living in community settings to stay home as much as possible, and when venturing outside, to practice "social distancing." The CDC's (Centers for Disease Control, 2020) guidance to long-term care facilities urged facilities to restrict visitors unless visiting a dying relative, screen workers and residents for symptoms, require workers to wear cloth masks, and limit activities for residents. When long-term care facilities have COVID-19 within their facility, they are advised to separate those with and without COVID-19 through quarantines and cohorting, which often results in residents being mostly confined to their rooms. While all of this is challenging for older people living in the community and long-term facilities, it also can create enormous stress and challenges for their caregivers. This commentary outlines adaptive and emerging practices in formal supportive services for caregivers, the changing types of support that family caregivers are providing to their older relatives, and the ways family caregivers are seeking informal caregiving support during this global pandemic. Information was obtained from professional and personal experience, feedback from interactions with over 670 caregivers through a series of webinars co-presented by the authors at university and nonprofit venues, and discussions with caregivers in several online elder caregiving support groups hosted by the authors.

Family caregiving

An estimated 41 million family caregivers provide 34 billion hours of care to other adults in the United States. This care is valued at over 470 USD billion annually (AARP Public Policy Institute, 2019). Caregiving touches nearly all Americans in some way. Rosalyn Carter is famously quoted as saying, "There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver (Snelling, 2012)." The care provided informally by family can take many forms, such as providing assistance with activities of daily living or offering social and emotional support. The care can occur in a variety of settings, including a care receiver's home, the caregiver's home, an assisted living establishment, or a nursing home. Family caregivers

provide, on average, 20 hours per week of care for a period of nearly 5 years, with roughly one-third providing care to more than one older person living in the community (Gaugler & Kane, 2015). Trends in family caregiving of older people living in the community show declines as the population ages and successive generations have less children (Stone, 2015), which can put more responsibility on a smaller number of caregivers, as well as an increased reliance on formal systems to provide care. With COVID-19, family caregivers of older adults in community settings are often providing this care from a distance.

Family members also provide care to older relatives living who are living in long-term care settings, including nursing homes and assisted living facilities. These caregivers spend about as much time with their relatives as do those caring for those in community settings (Port et al., 2005). As there are significant staffing shortages in long-term care settings (Geng et al., 2019), which have been exacerbated by COVID-19 (Mettler et al., 2020), family caregivers of those living in formal settings might feel extra stress worrying about the care their family member is receiving and a sense of helplessness at their lack of ability to monitor their care.

Supportive services for caregivers during COVID-19

Crucial to successful caregiving is the utilization of supportive services designed to decrease burden, stress, depression and burnout (Iecovich, 2008). While studies about caregiving and COVID-19 are not yet available, it is highly likely that due to a combination of social distancing, shelter-in-place or stay-at-home orders, and the disproportionate impact of the virus on older adults, caregivers of adults living both in community and long-term care are in need of different types of formal caregiving supports. The following details the emerging changes to formal supportive services during the COVID-19 crisis.

The 2000 Older Americans Act reauthorization included a provision to support informal caregivers known as the National Family Caregiver Support Program (Title III-E). The passage of Title III-E acknowledged the crucial role caregivers play in the lives of older Americans. Funding through the Older Americans Act flows to states and area agencies on aging, who then develop relationships with providers in the community to offer direct support to caregivers.

Eligibility for Title III-E mirrors most of the Older Americans Act Titles with some uniqueness. Services are available to people 18 years and older providing care to someone 60 years and older or someone of any age with dementia. The program also supports relative caregivers 55 years and older who are providing care to children or adults with disabilities (Administration for Community Living, 2019). Also similar to the other Titles, a Title III-E provider cannot charge for services, but can request either a voluntary contribution or utilize a quasi-sliding fee scale known as cost-sharing. Services cannot be denied due to a caregiver's inability or unwillingness to pay. The CARES (Coronavirus Aid, Relieve and Economic Security) Act included an additional 100 USD million for Title III-E (Administration for Community Living, 2020).

Services available under Title III-E are comprehensive and include coaching and counseling, support groups, education, respite care, adult day services, and supplemental services. Supplemental services are services that often target the care receiver, but benefit the

caregiver in some way. For example, a care receiver may need their lawn mowed and the primary caregiver may not be able to provide this service, but it is crucial in order for the caregiver to continue to provide care. Another agency could be engaged to offer the lawn mowing service as a way to support the caregiver so they can continue to provide other care.

The response to COVID-19 has greatly affected the delivery of formal systems and supports for caregivers. For example, one crucial support for caregivers is adult day services, where an older adult attends a day program that provides socialization and health related services. Adult day services provide critical respite for caregivers who may be employed or have a number of other tasks that need to be accomplished (such as grocery shopping, medical appointments, caring for young children, etc.). In many states adult day services have been closed due to stay-at-home orders, such as in Minnesota, where all 225 adult day service programs were closed, displacing thousands of older adults, many of whom experience cognitive and memory impairment, who attended adult day programs during the week. Service providers have needed to innovate quickly and continue to practice nimble, flexible project management to continue to support caregivers. The following is a case example of how one service provider has adapted its services to provide caregiving support.

Adaptation and innovation in service delivery

FamilyMeans is a nonprofit social services agency in Washington County in Minnesota. As a recipient of an Older Americans Act Title III-E contract, the organization provides a comprehensive array of services and supports for caregivers. During the COVID-19 crisis and stay-at-home orders, FamilyMeans caregiver support staff have begun to initiate a number of telesupport services including:

- Conducting caregiver consultation over phone, Skype or Zoom. Anecdotally, themes of increased stress due to stay-at-home orders, lack of in-person respite, and facility visiting restrictions have begun to emerge.
- Contacting individual clients via phone and writing notes to ensure needs are being met and connections continue.
- Providing in-home respite through volunteers over telephone and videoconference. One volunteer found a streaming movie that a particular care receiver would enjoy. They watched it simultaneously while the caregiver had a break for a couple of hours.
- Offering online videos with messages from staff for respite care participants. The videos are 20 minutes long and offer some social interaction and familiar faces for people with memory loss.
- Holding Memory Cafes via zoom. Memory Cafes are lunches supported by local restaurants for people living with dementia and their caregivers. With restaurants closed, these Cafes have moved to a virtual setting.
- Holding Zoom coffee breaks with staff where anyone can join for drop-in support.
- Increasing e-mail communication to weekly posts which include ideas for activities that can be done from home (such as exploring a live eagle cam, online exercise classes, and a self-care resource developed by mental health staff).

Services funded by Title III-E may differ in availability and response to COVID-19 and connecting caregivers to local supports is necessary. Finding a caregiver support provider is a phone call or mouse click away. Nationally caregivers can contact the Eldercare Locator which can connect them to local information and assistance programs offered through states and area agencies on aging.

Informal caregiving supports during COVID-19

Caregivers of older people living in community and long-term care settings are also changing the types of support that they provide to older relatives as well as the ways that they are seeking informal support for themselves in response to COVID-19. The following details some of the emerging types of informal care that caregivers are providing from a distance, ways caregivers are seeking their own support, and examples of caregiver individual and systems advocacy to bring awareness to the impact of COVID-19 on senior care communities.

Providing informal caregiving from a distance

Staying connected

Caregivers have quickly adopted new ways of connecting with older relatives, often supported with new technology. While family caregivers already used telephone and/or video calls to connect with their older relatives, often to supplement in-person visits, this now has become the main way many caregivers are staying connected with their relatives in community or long-term care settings. Video calls have become especially popular, with caregivers using these calls to substitute for in-person visits, as well as a means to reduce the social isolation of older people who are not able to participate in their typical social activities. Older residents might have their own tablets, such as an iPad, use a specially designed tablet geared toward older people, such as GrandPads, or use facility owned tablets. For those living in facilities, workers can help residents establish connections with these devices. Caregivers can also use these, or other devices, such as laptops, for playing interactive games together, listening to concerts or shows together, or doing other online activities together. Some caregivers and older relatives are not as comfortable with smart phones or tablets, or are not able to afford this type of technology, and instead rely on traditional phone calls. Caregivers are making use of lower-technology too, such as letter writing or setting up penpals with family members, friends or grandchildren. There are also a variety of new ways to connect in-person, while maintaining social distancing. For example, some long-term care facilities are arranging window-greetings, where caregivers stand outside the window and either wave or talk on the phone with their older caregivers, and family members are visiting their older relatives through various forms of distant visits (driving their cars by the facility while honking, singing to residents who are standing on a balcony, etc.)

Arranging delivery of essential items

Family caregivers have also taken on the responsibilities of arranging for delivery of essential items, such as food or medication. For those caring for residents living in the community, this activity keeps their older relatives from having to shop or otherwise venture in the community. Family members might be doing the errands themselves, or arranging for a delivery service to

send needed items. Family caregivers caring for those in long-term care settings also are delivering essential items, including items that the long-term care facility is no longer able to procure during the pandemic.

Providing activities and information

Caregivers are also providing activities to loved ones that can help reduce social isolation and fill the void left by the cancellation of their typical activities. The types of activities are personalized based on their loved one's interests and cognitive ability. Examples include books, puzzles, craft materials, and devices for watching movies or shows or listening to audio books. For those with more significant cognitive decline, activities could include a portable music player with a playlist of their loved one's favorite songs, photobooks or videos of family or friends, or fidget blankets. Caregivers are also providing information to their older relatives about COVID-19, such as the latest news on transmission, prevention and treatment, or state and local ordinances, particularly for those who are not able to access news and information online.

Thanking long-term care workers

As caregivers are no longer able to visit long-term care settings during the Covid-19 crisis, the workers in these facilities are having to take on an additional supportive role. Workers, who are often risking their own health to provide care for residents in long-term care settings, have become the main source of social interaction for residents, particularly in facilities where residents have been quarantined in their rooms. Caregivers are providing support for these workers in a variety of ways, such as sending thank you notes or small gifts.

Monitoring from afar

One key activity that family caregivers typically do for older relatives in long-term care facilities is to monitor the quality of care they are receiving. Caregivers are having to find new ways to monitor when they are not able to visit, such as through increased communication with workers and their supervisors, or monitoring while connecting with their loved one through video or phone chats.

Taking action

Some family caregivers have been involved in advocacy efforts related to protecting loved ones during the COVID-19 outbreak as well as protecting and supporting their paid caregivers. This advocacy has been at multiple levels, including advocating at the institutional level for long-term care facilities to adopt procedures to protect residents, such as requiring all workers in a nursing home to wear masks or increasing transparency about the number of residents who have tested positive for COVID-19; or at the state level, such as demanding that states include protections for residents of long-term care facilities or provide COVID-19 testing at all facilities throughout the state. Family caregivers have become community organizing and advocacy leaders for protecting older people during COVID-19. Community advocacy activities have included petitioning stores to have special hours or to require masks, organizing mask drives to provide personal protective equipment for senior care workers, or leading parades and concerts outside senior communities. Other caregivers have taken their voices to the media, contacting reporters

to publicize the COVID-19 outbreaks in long-term care facilities and pointing out the lack of a swift government response. They have shared both positive and negative experiences in news articles and blogs. All of these can lead to policy changes and help build community and support during uncertain times.

Getting informal caregiving support during COVID-19

While formal aging services programs are adapting to provide formal support for caregivers during the COVID-19 outbreak, caregivers are also finding new ways to get informal support for themselves. Many caregivers rely only on informal supports for their caregiving, while others rely on a combination on formal and informal supports to assist them in caregiving (Chow et al., [2010](#)). The following describes key ways family members are seeking informal supports.

Coordinating with other family members and friends

Caregivers of older adults have always had to coordinate and negotiate caregiving responsibilities with other family members and friends, and other families and friends are often the main source of caregiving support. During COVID-19, the focus of this coordination and support has changed. Caregivers are now having to coordinate care from a distance, such as scheduling regular communication through phone or video to help reduce social isolation. This can also involve having families and friends making important decisions regarding whether to remove their family members from a long-term care facility because of the dangers of COVID-19, often with very incomplete information. Some extended families are developing COVID-19 plans to assist them in providing care and making decisions from a distance.

Online informal support

As in-person support groups are not available, many formal services have developed telephone or video support groups for caregivers. Another type of informal, peer-led support group has emerged: support groups on social media platforms. These support groups, which are not facilitated by service providers or long-term care facilities, can give caregivers a more open forum to not only provide each support, but to assist caregivers who might be frustrated with facilities or service providers. Using social media for social support is particular relevant for caregivers who are seeking caregiving support for the first time during stay-at-home orders, as this type of support is available in real-time, and also can lead to a sense of empowerment among participants who can share and access resources through these venues (Ammari & Schoenebeck, [2015](#)). The informal COVID-19 era caregiving support groups on social media have also fostered advocacy on behalf of older family members. This type of support, while useful, is only accessible to those who have the appropriate technology.

Recognizing competing responsibilities

Caregivers are also recognizing the competing sources of stress during the COVID-19 crisis. Not only are they worried about providing care from a distance to their older relatives, they are also worried about the health of their family members who are at a high risk of death if they become infected with COVID-19 because of their age and/or age-related health conditions. For those whose loved ones are living in long-term care facilities, there is the compounded stress of the

high rates of COVID-19 within such facilities. With the required social distancing, family caregivers can have a heightened sense of helplessness because they are not able to protect their family members or provide the type or amount of care that they want to provide. In addition, caregivers might simultaneously be adjusting to working at home, caring for children who are home from school, coping with losing their job or some of their income due to state or city stay-at-home rules or the economic downturn, and/or experiencing serious financial problems. Caregivers also worry about becoming infected with COVID-19 themselves, or about other family members and friends. All of these stressors make caregiving for older family members during this global pandemic difficult.

Conclusion

There is much we do not know about the course of this pandemic and the long term impacts on our communities, and gerontological research efforts on the effects of COVID-19 on caregiving are just beginning. We know that COVID-19 will continue to transform the delivery of long-term services and supports, including caregiver support, as well as the ways we interact with our loved ones into the future. For older adults and their caregivers, social distancing and fear may also continue when many have returned to work and the social distancing restrictions are lifted. Gerontological research is needed to examine which types of formal caregiving supports are needed and most effective during crises such as COVID-19, and which emerging caregiving supports should be retained after this crisis ends. The field of social work must be particularly attuned and sensitive to the needs of family caregivers who may be experiencing added burden, stress, and depression, and the differences in needs based on a variety of family circumstances. Connecting caregivers to formal supports like the Title III-E network, as well as offering suggestions for continued connection with their family members and for finding informal sources of support, is helpful both during the global pandemic and after.

References

- AARP Public Policy Institute . (2019, November). Valuing the invaluable 2019 Update: Charting a path forward . Washington: AARP Public Policy Institute. <https://www.aarp.org/content/dam/aarp/ppi/2019/11/understanding-the-contributions-of-family-caregivers-infographic.doi.10.26419-2Fppi.00082.003.pdf>
- Administration for Community Living . (2019). National family caregiver support program. Washington: Administration for Community Living. <https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program>
- Administration for Community Living . (2020, March 29). Supporting community living during COVID-19: CARES act and civil rights protections . Washington: Administration for Community Living. <https://acl.gov/news-and-events/announcements/supporting-community-living-during-covid-19-cares-act-and-civil>
- Ammari, T. , & Schoenebeck, S. (2015, April). Networked empowerment on Facebook groups for parents of children with special needs. In Proceedings of the 33rd annual ACM conference on human factors in computing systems . Seoul, South Korea. (pp. 2805–2814).
- Centers for Disease Control . (2020, April). Older adults: Coronavirus disease 2019 (COVID-19) . Atlanta: Centers for Disease Control. <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/older-adults.html>
- Chow, J. C. C. , Auh, E. Y. , Scharlach, A. E. , Lehning, A. J. , & Goldstein, C. (2010). Types and sources of support received by family caregivers of older adults from diverse racial and ethnic groups. *Journal of Ethnic & Cultural Diversity in Social Work* , 19(3), 175–194. <https://doi-org.ezp3.lib.umn.edu/10.1080/15313204.2010.499318>
- Gaugler, J. E. , & Kane, R. L. (Eds.). (2015). *Family caregiving in the new normal*. Academic Press.
- Geng, F. , Stevenson, D. G. , & Grabowski, D. C. (2019). Daily nursing home staffing levels highly variable, often below CMS expectations. *Health Affairs* , 38(7), 1095–1100. <https://doi-org.ezp3.lib.umn.edu/10.1377/hlthaff.2018.05322>
- Iecovich, E. (2008). Caregiving burden, community services, and quality of life of primary caregivers of frail elderly persons. *Journal of Applied Gerontology* , 27(3), 309–330. <https://doi-org.ezp3.lib.umn.edu/10.1177/0733464808315289>
- Kaiser Family Foundation . (2020, May 2). COVID-19: Confirmed cases and deaths by state . Washington: Kaiser Family Foundation. <https://www.kff.org/health-costs/issue-brief/state-data-and-policy-actions-to-address-coronavirus/>
- McMichael, T. M. , Currie, D. W. , Clark, S. , Pogojans, S. , Kay, M. , Schwartz, N. G. , ... Ferro, J. (2020). Epidemiology of covid-19 in a long-term care facility in King

- County, Washington. New England Journal of Medicine . <https://doi-org.ezp3.lib.umn.edu/10.1056/NEJMoa2005412>
- Mervosh, S. , Lu, D. , & Swales, V. (2020, April 20). See which states and cities have told residents to stay at home. New York Times . <https://www.nytimes.com/interactive/2020/us/coronavirus-stay-at-home-order.html>
- Mettler, K. , Hernandez, A. R. , Wan, W. , & Bernstein, L. (2020, March 5). Health care workers worry about coronavirus protection. The Washington Post . https://www.washingtonpost.com/health/health-care-workers-worry-about-coronavirus-protection/2020/03/05/be04d5a8-5e33-11ea-9055-5fa12981bbbf_story.html
- Minnesota Department of Health . (2020, May 2). Situation update for coronavirus disease 2019 (COVID-19) . St. Paul: Minnesota Department of Health. . <https://www.health.state.mn.us/diseases/coronavirus/situation.html>
- Port, C. L. , Zimmerman, S. , Williams, C. S. , Dobbs, D. , Preisser, J. S. , & Williams, S. W. (2005). Families filling the gap: Comparing family involvement for assisted living and nursing home residents with dementia. *The Gerontologist* , 45(suppl_1), 87-95. https://doiorg.ezp3.lib.umn.edu/10.1093/geront/45.suppl_1.87
- Snelling, S. (2012, August 6). Rosalyn carter: A pioneering caregiving advocate says more must be done . Next Avenue. <https://www.nextavenue.org/rosalynn-carter-pioneering-caregiving-advocate-says-more-must-be-done/>
- Stone, R. I. (2015). Factors affecting the future of family caregiving in the United States. In Gaugler, J. E., & Kane, R. L. (Eds.). *Family caregiving in the new normal* (pp. 57–77). Academic Press.
- Wu, Z. , & McGoogan, J. M. (2020). Characteristics of and important lessons from the coronavirus disease 2019 (COVID-19) outbreak in China: Summary of a report of 72 314 cases from the Chinese center for disease control and prevention. *JAMA* , 323(13), 1239–1242.