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To cite this article: Edem Hado & Lynn Friss Feinberg (2020) Amid the COVID-19 Pandemic, Meaningful Communication between Family Caregivers and Residents of Long-Term Care Facilities is Imperative, Journal of Aging & Social Policy, 32:4-5, 410-415, DOI: [10.1080/08959420.2020.1765684](https://doi.org/10.1080/08959420.2020.1765684)

To link to this article: <https://doi.org/10.1080/08959420.2020.1765684>



Published online: 22 May 2020.



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Amid the COVID-19 Pandemic, Meaningful Communication between Family Caregivers and Residents of Long-Term Care Facilities is Imperative

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ABSTRACT

Older adults residing in long-term care facilities are especially vulnerable for severe illness or death from COVID-19. To contain the transmission of the virus in long-term care facilities, federal health officials have issued strict visitation guidelines, restricting most visits between residents and all visitors, including family members. Yet, many older adults rely on family care for social support and to maintain their health, well-being, and safety in long-term care facilities, and therefore need to stay connected to their families. The federal government, state and local leaders, and long-term care facilities should take further actions to enable the relationship between residents of long-term care facilities and families during the COVID-19 pandemic.

ARTICLE HISTORY

Received 16 April 2020

Accepted 30 April 2020

KEYWORDS

Long-term care; nursing homes; COVID-19; family; family caregivers

In describing the COVID-19 pandemic, Andrew Cuomo, Governor of New York, said the “coronavirus in a nursing home can be like fire through dry grass” (Harris et al., 2020). In the United States, more than 2 million Americans reside in long-term care facilities like nursing homes and assisted living residences (Kaiser Family Foundation, 2017; Ungar & Hancock, 2020). Nearly half (48%) of nursing home residents are living with Alzheimer’s or other dementias, and among older adults in residential care settings, including assisted living facilities, 42% have some form of dementia (Alzheimer’s Association, 2020).

Family and other unpaid caregivers – including relatives, partners, friends, and neighbors – are the most important source of emotional and practical support for older adults with chronic, disabling, or serious health conditions (National Academies of Sciences, Engineering and Medicine, 2016; Reinhard et al., 2019). This perspective thus highlights the reliance of long-term care facilities on family support and the importance of the family caregiver role with the COVID-19 pandemic. It argues that family caregivers can serve as crucial and trusted partners in the nation’s strategy to curb the spread of the COVID-19 virus, and help the people they care for to cope with the stress

and anxiety of this unprecedented situation (Centers for Disease Control and Prevention, 2020). Proactive solutions for maintaining the family caregiver role during the COVID-19 pandemic are proposed.

Residents of long-term care facilities rely on family support

Across the nation, family caregivers are often the critical factor that enables older adults and people with disabilities who need long-term services and supports (LTSS) – also known as long-term care – to live at home and in the community (Hado & Komisar, 2019). As an older adult's care coordinator and primary advocate, family caregivers oftentimes become the “eyes and ears” for the concerns and safety of the care recipient with complex care needs, including when their care recipient resides in a long-term care facility like a nursing home or assisted living facility. They help navigate the health and LTSS systems, facilitating communication with providers and discussing issues that require shared decision making (Sarkar & Bates, 2014; Wolff, 2012). They also commonly serve as surrogate decision-makers when the care recipient loses the capacity to make important decisions (National Academies of Sciences, Engineering and Medicine, 2016). Because of their crucial support role, family caregivers are in a unique position to better understand, articulate and support the emotional, social, and health needs of the care recipient (Reinhard et al., 2019). Across all ethnic groups, family care is the most preferred and trusted source of assistance for individuals who need help with activities of daily living (Whitlatch & Feinberg, 2007).

Family caregiver role grows with COVID-19

As the COVID-19 virus spreads across the country, residents of long-term care facilities are among the populations hardest hit by virus-related deaths (Barnett & Grabowski, 2020). To slow the spread of COVID-19 to vulnerable older adults in long-term care facilities, the federal Centers for Medicare & Medicaid Services (CMS), which regulates most skilled nursing homes, has issued strict guidelines on visitation to nursing homes (Centers for Medicare & Medicaid Services, 2020a). Most assisted living facilities, although not regulated by the federal government, are also limiting or halting visitors to their facilities.

Even if physical visits are not possible, the guidelines should not inhibit relationships and connections between residents and their family members and close friends, which are crucial to one's well-being – both physical and emotional. Family caregivers of nursing home residents, and those living in assisted living facilities, should monitor the health, well-being, and safety of their family members in long-term care facilities as closely as possible.

Despite the unique challenges that protecting vulnerable older adults from the coronavirus presents, the current surge in COVID-19-related deaths in long-term care facilities makes meaningful human and family connections all the more important. Residents and family members should be able to communicate and visit virtually, especially during times of stress – such as this one. The health impacts of social isolation are real and very serious (National Academies of Sciences, Engineering and Medicine, 2020; Tan, 2020).

Proactive solutions to meet the challenge

Enabling the relationship between the family and residents of long-term care facilities is especially challenging at this time, and necessitates action in multiple areas, including strengthening communication channels, activating family councils, and mobilizing gerontological social work students. At the same time, family caregivers must look out for their own safety and health.

Strengthening nursing home-family caregiver communication channels

In the updated guidelines, CMS is encouraging nursing homes to keep residents' loved ones informed about their care. CMS should strengthen this measure by requiring nursing homes to do so. It is vitally important to ensure timely communication with family caregivers, especially in light of the recent CMS recommendations on transferring or discharging residents between facilities based on COVID-19 status (Centers for Medicare & Medicaid Services, 2020b). Long-term care facilities should, to the fullest extent possible, inform family of any requirements and procedures for placement in alternative facilities. One way that facilities can achieve this is by assigning staff members as primary contacts for families (e.g., the designated family caregiver or representative) to facilitate regular communications with staff by telephone, e-mail or video. Facilities should also promote ways for family caregivers to stay in touch with residents – through, for example, regular phone calls and “virtual visitation” (e.g., Face Time, Skype, Zoom). This should include facilitating conversations with residents and their family caregivers about treatment options and putting advance care plans in place (Lynn, 2020).

State and local leaders can also play an important role. They should encourage specific communication workarounds for residents and families as they put in place visitation limitations. These might include processes for staff to facilitate phone calls, making video-enabled devices available to facilities, and requiring more frequent facility communication with families. A state's long-term care ombudsman may be able to help facilitate this effort (The National Consumer Voice for Quality Long-Term Care, 2016).

Activating family councils

Federal regulations give family caregivers of nursing home residents the right to be part of a family council and meet together on-site in the nursing home to advocate for residents and partner with staff to improve quality of care (The National Consumer Voice for Quality Long-Term Care, 2020). During the COVID-19 pandemic, facilities should facilitate alternative means of communication for family councils (using e-mail, Skype, or “phone trees”) to exchange information and for family members to support one another and stay informed.

Mobilizing students and trainees

Because family visits are an essential method for monitoring quality of care, and because workforce shortages also pose key challenges for long-term care facilities now and in the foreseeable future (Gardner et al., 2020), a range of strategies will be needed by facilities to ensure that regular communication is provided to the family caregivers of residents. One potential strategy is to mobilize students and trainees such as gerontological social work students – also known as geriatric social work – to assist staff in long-term care facilities to maintain communication and provide social support. These students are trained in skills to promote active listening, communication, empathy, and critical thinking, among others. These and other students and trainees in the health professions could be assigned to call family caregivers of residents on a regular basis to keep them apprised of their family member’s situation and infection control procedures in the facilities, and to lend support to these caregiving families.

Although beyond the scope of this article, other steps are urgently needed now to reduce the risks to older adults in long-term care facilities posed by the adverse consequences of COVID-19 for staff. These steps include universal testing of residents and staff, ensuring personal protective equipment for staff and residents, and providing paid sick leave as an employment benefit (Gardner et al., 2020; Glynn, 2020; Harris et al., 2020).

Family caregivers must maintain personal safety and take care of their health

During COVID-19, it is also critical that family caregivers manage their *own* health, stress, and well-being. It is especially important to address the feeling of helplessness and heightened anxiety about a care recipient living in a long-term care facility that is restricting the access of residents’ families and friends to protect them from the spread of this disease. Joining online caregiver support groups can help foster the sharing of information, advice and encouragement.

Conclusion

The health, well-being, and safety of residents of long-term care facilities remains a top concern for families across the country, particularly during the COVID-19 pandemic. For many vulnerable older adults residing in nursing homes or assisted living facilities, family and friend involvement and connectivity are crucial factors that enable them to reside in a facility setting. Accordingly, the federal government, states, and long-term care facilities should ensure continuous and meaningful family engagement, communication, and inclusion in all settings of care, particularly in long-term care facilities.

Key Points

- Older adults in long-term care facilities are at greater risk for severe illness or death from COVID-19.
- Family caregivers are the most trusted allies and care coordinators for residents of long-term care facilities.
- Recent federal guidelines restricts family visitation in nursing homes, leading to greater isolation among residents.
- Lack of physical visitation should not inhibit ongoing family communication and engagement especially during the COVID-19 crisis.
- Federal government, state and local leaders, and long-term care facilities can take specific actions to enable meaningful communication between residents of long-term care facilities and families.

Disclosure statement

This article is based on a blog published by the AARP Public Policy Institute on April 7, 2020. No potential conflict of interest was reported by the authors.

References

- Alzheimer's Association. (2020). 2020 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 16(3), 391+. <https://doi.org/10.102/alz.12068>
- Barnett, M. L., & Grabowski, D. C. (2020, March 24). Nursing homes are ground zero for COVID-19 pandemic. *JAMA Health Forum*. <https://jamanetwork.com/channels/health-forum/fullarticle/2763666>
- Centers for Disease Control and Prevention. (2020). *Groups at higher risk for severe illness*. <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/groups-at-higher-risk.html>
- Centers for Medicare & Medicaid Services. (2020a). *CMS.gov: Guidance for infection control and prevention of coronavirus disease 2019 (COVID-19) in nursing homes (Revised)*. Department of Health and Human Services. Retrieved April 13, 2020, from <https://www.cms.gov/files/document/3-13-2020-nursing-home-guidance-covid-19.pdf>

- Centers for Medicare & Medicaid Services. (2020b). *CMS.gov: 2019 novel coronavirus (COVID-19) long-term care facility transfer scenarios*. Department of Health and Human Services. Retrieved April 14, 2020, from <https://www.cms.gov/files/document/qso-20-25-nh.pdf>
- Gardner, W., States, D., & Bagley, N. (2020). The coronavirus and the risks to the elderly in long-term care. *Journal of Aging & Social Policy*, 1–6. <https://doi.org/10.1080/08959420.2020.1750543>
- Glynn, S. J. (2020). *Congress must extend paid leave protections to all workers in next Coronavirus response bill*. Center for American Progress. <https://www.americanprogress.org/issues/women/news/2020/03/24/482196/congress-must-extend-paid-leave-protections-workers-next-coronavirus-response-bill/>
- Hado, E., & Komisar, H. (2019). *Long-term services and supports*. AARP Public Policy Institute. <https://www.aarp.org/content/dam/aarp/ppi/2019/08/long-term-services-and-supports>
- Harris, A. J., Leland, J., & Tully, T. (2020, April 11). Nearly 2,000 dead as Coronavirus ravages nursing homes in N.Y. region. *The New York Times*. <https://www.nytimes.com/2020/04/11/nyregion/nursing-homes-deaths-coronavirus.html>
- Kaiser Family Foundation. (2017). *Total number of residents in certified nursing facilities: 2017*. <https://www.kff.org/other/state-indicator/number-of-nursing-facility-residents/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>
- Lynn, J. (2020). Getting ahead of COVID-19 issues: Dying from respiratory failure out of the hospital. *Health Affairs*. <https://www.healthaffairs.org/doi/10.1377/hblog20200330.141866/full/>
- National Academies of Sciences, Engineering, and Medicine. (2016). *Families caring for an aging America*. National Academies Press. <https://nam.edu/families-caring-for-an-aging-america/>
- National Academies of Sciences, Engineering, and Medicine. (2020). *Social Isolation and loneliness in older adults: Opportunities for the health care system*. National Academies Press. <https://www.nap.edu/read/25663/chapter/1#ii>
- Reinhard, S. C., Feinberg, L. F., Houser, A., Choula, R., & Evans, M. (2019). *Valuing the invaluable: 2019 update*. AARP Public Policy Institute. <https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html>
- Sarkar, U., & Bates, D. W. (2014). Care partners and online patient portals. *Journal of the American Medical Association*, 311(4), 357–358. <https://doi.org/10.1001/jama.2013.285825>
- Tan, E. (2020, March 16). How to fight social isolation of coronavirus. AARP. <https://www.aarp.org/health/conditions-treatments/info-2020/coronavirus-social-isolation-loneliness.html>
- The National Consumer Voice for Quality Long-Term Care. (2016). *Long-term care ombudsman program: What you must know*. <https://ltcombudsman.org/uploads/files/library/long-term-care-ombudsman-program-what-you-must-know.pdf>
- The National Consumer Voice for Quality Long-Term Care. (2020). *Covid-19 and nursing homes: What residents and family need to know*. <https://theconsumervoice.org/uploads/files/general/covid-19-consumer-fact-sheet.pdf>
- Ungar, L., & Hancock, J. (2020, April 9). COVID-19 crisis threatens beleaguered assisted living industry. *Kaiser Health News*. <https://khn.org/news/covid-19-crisis-threatens-beleaguered-assisted-living-industry/>
- Whitlatch, C. J., & Feinberg, L. F. (2007). Family care and decision making. In C. Cox (Ed.), *Dementia and social work practice: Research and interventions*(pp. 129–147). Springer.
- Wolff, J. (2012). Family matters in health care delivery. *Journal of the American Medical Association*, 308(15), 1529–1530. <https://doi.org/10.1001/jama.2012.13366>