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“They just took him out of my life”: Nursing home care partner experiences in COVID-19

Nancy Kusmaul, PhD, MSW

Associate Professor, University of Maryland Baltimore County, Baltimore, MD, USA

Vivian J. Miller, PhD, MSW

Assistant Professor, Bowling Green State University, Bowling Green, OH, USA

Ji Hyang Cheon, MSW

Doctoral Student, University of Maryland Baltimore, Baltimore, MD, USA

Correspondence should be addressed to Dr. Nancy Kusmaul, University of Maryland Baltimore County, 1000 Hilltop Circle, Sherman Hall 322, Baltimore, MD 21250. nkusmaul@umbc.edu

Abstract

On March 13, 2020, the Centers for Medicare and Medicaid Services (CMS) closed nursing homes to visitors to protect nursing home residents from COVID-19 and they were closed for a year. There has been limited research on the impacts of this closure on family member/resident dyads. This study describes the impacts of visitation restrictions on residents and their family caregivers from the caregivers' perspectives. Family members and close friends "care partners" were recruited via social media and email listservs from November 2020 to February 2021. All participants completed a survey on google forms. Researchers completed semi-structured one-on-one interviews with interested participants via Web Ex. Transcripts were analyzed using rapid analysis techniques. Thirty-one family caregivers completed the survey and seventeen completed interviews. The majority of interview participants (n=11) were adult children, the remaining (n=5) were spouses (wives) and a parent whose child was in a nursing home (n=1). They reported experiencing disconnect from their residents, confusion on the part of the residents, and sadness. All family caregivers were of the opinion that their residents with dementia declined during the closure period, which was most notable when they no longer recognized their family caregivers when they were able to see each other again. All family caregiver participants expressed the opinion that they and their residents suffered irreparable harm from the prolonged separation. Providers, policy makers, and researchers must use the lessons learned from COVID-19 in future situations. Protecting residents from a deadly disease is important, but we cannot condone long term separation from family caregivers again.

Key Words: Social support, caregiving, long-term care, visitation

Family members and friends are vital caregivers for nursing home residents yet their roles were disrupted due to the COVID-19 pandemic. On March 13, 2020 the Centers for Medicare and Medicaid Services (CMS) suspended in-person indoor visits to nursing homes. In-person visitors were permitted only in compassionate care situations. Most visitors were restricted to video chats, window visits, and limited outdoor visits.

When an older adult moves to a nursing home, families and friends continue to be caregivers. They improve residents' quality of life through visiting, providing some hands-on care, and monitoring care delivered by staff (Roberts & Ishler, 2018). Family caregivers also collaborate with staff for the benefit of residents (Bramble et al., 2011). The need for long term care can drastically alter the older adult/family caregiver relationship (Gladstone et al., 2006), as daily care shifts from family members to nursing home staff (Fast et al., 2019). Nonetheless, family caregivers still play a vital role in loved ones' lives and an important role in quality of care (Price, 2015). Family involvement has long been associated with better psychosocial well-being among nursing home residents (Roberts & Ishler, 2018). Nursing home residents who receive at least monthly visits from family report higher life satisfaction, and the quality of the social environment is important to resident satisfaction and feeling 'at home' (Mitchell & Kemp, 2000; Port et al., 2005).

In a nursing home, many older adults experience loneliness (Steptoe et al., 2015). Humans have a fundamental need to belong and a lack of belonging can result in poor mental and physical health (Heinrich & Gullone, 2006; Taylor, 2020). Nursing home residents often experience functional declines and physical dependence, increased rates of depression, high levels of cognitive impairment, and other acute health problems (Schussler & Lohrmann, 2017; Stewart, 2013; Valenzuela, 2012; Van Rensbergen & Nawrot, 2010). The nursing home culture

change movement, which focuses on resident well-being and quality of life emphasizes the importance of resident/caregiver relationships (Shier et al., 2013). Caregivers' roles vary. Family members help staff know residents better and oversee care quality (Roberts & Ishler, 2018). Positive social interactions and connection between residents and family members reduce loneliness (DeWall, 2013). Family members provide hands on care for their resident such as grooming, bathing, or eating, depending on the needs and preferences of their relative (Gaugler, 2006; Roberts & Ishler, 2018). These roles were all disrupted during COVID-19 (Blinded for review).

The purpose of this study was to describe the experiences of family/friend caregivers of U.S. nursing home residents during COVID-19 and to make recommendations for mitigating negative outcomes for both residents and their family caregivers.

Methods

Study Design and Participants

Relatives and close friends of nursing home residents were recruited via social media, web-based discussion groups, and listservs. To be inclusive, we used the term care partner, however majority of respondents were family members (n=31) so we use the term family caregiver in this manuscript for clarity. Participation was voluntary. Interested parties clicked on a Google Form link, completed consent, and answered survey questions. At the end of the survey, they were asked if they were willing to complete an open-ended interview and provided a phone number or email. Study procedures were approved by the Institutional Review Board of [Blinded for Review] (IRB: #449).

To participate in this study, potential participants had to: (1) be over age 18, (2) self-identify as the family member/friend 'care partner' of a U.S. nursing home resident, and (3) have

their visitation restricted since March 13, 2020. Using this nonprobability purposive sampling strategy, the researchers collected survey and interview data between December 2020 and January 2021. Thirty-one ($n=31$) family caregivers (including one person who was a partner of 30 years) completed the survey. Of those, seventeen ($n=17$) completed interviews. Interviews were conducted and recorded via Web Ex.

Data Analysis

Quantitative Data. Closed ended survey questions included the care partner's relationship to the nursing home resident, frequency of visits prior to March 13, 2020, visitation options since March 13, 2020 and perceived sense of the adequacy of the nursing home's efforts to maintain connection. Demographic questions were asked as part of the interviews. Frequencies are reported on these items in Table 1.

Qualitative Data. Interviews were transcribed verbatim. The interviews lasted between 20 and 75 minutes. Twelve interview questions were guided by the overarching aim to understand participants' nursing home experience during COVID-19. Participants were invited to add comments to help us understand their or their family members' experience. Data was analyzed using the Rapid Analysis Techniques described by Hamilton (2013). Rapid qualitative inquiry is a team based process that uses iterative data analysis to elicit the insider's perspective on a topic (Beebe, 2014). The questions of the semi-structured interview represented the first phase of the iterative process because they contained the researchers' a priori assumptions about what themes would encapsulate family members' experiences. The interviews themselves represented the family members' experiences. Each question was subsequently assigned a code. In the second phase, the research team compiled a data display allowing for the organization of participant responses (Beebe, 2014). These data displays were intended to enable the researchers

to identify “(1) patterns and themes, (2) seeing plausibility, and (3) clustering” (Beebe, 2014, p. 91). Next, two members of the research team selected two out of seventeen interviews at random, developed transcript summaries for each interview, and compared summaries for inter-rater reliability. In phase three, researchers verified their data and began the process of drawing conclusions. Lastly, in phase four, the data were condensed into the final thematic summaries.

Results

Demographic Characteristics

Most participants in this study were children of residents ($n=23$), followed by spouses ($n=5$). Nearly half (48.4%) of participants visited more than once per week prior to COVID-19. In light of the pandemic, the most used form of contact from participant to resident was the phone ($n=14$) followed by video chat ($n=6$) and window visits ($n=6$). Most participants reported that the nursing home contact support was less than adequate during COVID-19 (54.8%). Table 1 reports demographic characteristics of all family caregivers in this study ($n=31$).

We grouped the results into three themes. The first theme was descriptive, and contains the experience as described by the family members. The other two themes capture the impacts of the experience on residents and on their caregivers.

The Experience

Participants self-identified, so although we advertised for nursing home care partners, several participants had residents in memory care units, assisted living, or continuing care retirement communities. Despite that, all participants had visits disrupted by the March 13, 2020 CMS order. All participants received communication from the community via email or phone that visits would be shutting down. Nearly all ($n= 13$) of the participants visited daily or almost daily prior to the restrictions. Some who visited just before the restrictions heard from staff and

made one last visit to bring clothing, cut hair, or take their resident on an outing. Many believed at the time the lockdown would be for two weeks.

Once the nursing homes locked down, participant experiences diverged. Some received regular emails from the nursing homes about conditions, though most described those communications as broad or vague. It was difficult for caregivers to figure out where the COVID cases were in the building in relation to their residents. Several found it nearly impossible to obtain specific information on their resident once illness caused staff shortages.

In summer 2020, some geographical areas loosened restrictions. Many participants had outdoor or window visits with their residents. However, in some cases the resident's cognitive or health status limited their utility. One wife said because her husband was blind, a video or window visit was no different to him than a phone call. They were better for her because she could see what was happening with him. One family says they maintained their connection to their mother because they installed a Facebook portal in her room just before lockdown. It allowed them to see her condition, and its ease of use meant staff were willing to assist her with it.

Effects on Resident

Family caregiver participants universally reported visitation restrictions had profound negative physical and/or cognitive impacts on their resident. While participants acknowledged residents with dementia would have declined over the ten months, almost all felt these declines were accelerated by the restrictions. Participants said residents lost weight due to decreased appetite or their lack of presence to assist with meals. Many residents also experienced mobility declines due to room restrictions to reduce COVID spread. Finally, participants reported increased loneliness and depressed mood in their residents. Family caregivers felt the acute loss

of remaining time in their resident's life. One daughter said, "My mom's not going to make it another year... This last year was precious that I will never be able to recoup with her." Similarly, a wife said, "I've lost the potentially good time I might have with him."

Effects on Family caregiver

Prior to lockdown, many family caregiver participants were visiting their resident several times a week. The lockdown interrupted their support networks and connections to their residents. One said, "I felt like they just took him out of my life because there was personal touch and contact is communication with people, especially one with Alzheimer's." Family caregivers described feeling "sad", "guilty", "terrible", "frustrated", and "frightened/worried" by the lack of access to the resident and information about their condition. Another said, "As a family caregiver it was scary. It's scary having someone in a nursing home, especially scary when you can't be there to see what's going on." About half of our respondents found caregiver support groups which became important to their social networks. Family caregivers who did not access such support and/or lacked social support from family members and friends reported more sadness and fear than those who had these.

Discussion

This study confirmed that family caregivers experienced disruptions to their connections with their nursing home residents that were detrimental to both residents and family caregivers. Nursing home policies and practices such as adequate staffing, staff assistance with virtual or other visits, and good communication appeared to lessen but did not eliminate family caregiver distress. It is important to support to residents and their family caregivers to preserve the well-being of both parties. Many family caregivers feel their role becomes ambiguous after the person

for whom they have been caring moves into long-term care (Fast et al., 2019; Friedemann et al., 1997). The COVID-19 visitation restrictions added to feelings of ambiguity and helplessness.

Research suggests that it is especially vital to keep family caregivers involved in the care of residents with dementia because they provide historical background, make care decisions, provide personal and social care, and are advocates (Tornatore & Grant, 2002; Yamamoto-Mitani et al., 2002). Our family caregiver participants felt particularly disconnected from residents with dementia, and found it challenging to advocate for their family members' needs while remote.

Limitations

As a qualitative study intended to describe experiences, we did not seek a representative sample. This left some groups underrepresented, and perhaps their experiences of disrupted visitation was different. Specifically, our recruitment methods excluded individuals who do not use social media, listservs, or web-based discussion groups. Additionally, since our sample turned out to be all frequent visitors, our recruitment methods failed to attract participants who visited family members less frequently. Future studies should consider frequency of visits as a factor if seeking a representative sample.

Conclusion/Implications

While the COVID-19 pandemic and its negative impacts on nursing homes is unprecedented in modern care, these findings suggest the policy response to the pandemic also caused harm to residents and families. Providers, policy makers, and researchers must use the lessons learned from this pandemic in future situations. Protecting residents from deadly diseases is important, but long-term separation from family caregivers causes irreparable harm too.

Specifically, nursing home disaster planning conducted by leadership (administrators, directors of nursing, etc) must include adequate personal protective equipment (PPE) for both staff and family visitors. During COVID-19 shortages of PPE meant that not only was there not sufficient PPE for staff but that the limited quantities that existed could not be shared with family visitors who were seen as non-essential. Other policy measures include reservations and time restrictions on visits, ventilated areas, COVID-19 testing, and vaccine requirements for residents and/or visitors. Some of these were implemented in different states and countries as time went on, but there does not seem to be any clear plan that was more accepted than any other (Hemmings et al., 2021). However, the overall implication from the adverse effects of visitor restrictions are that reasonable and prudent measures should be taken to balance the risks of visitation with the psychosocial benefits of family support.

References

Author.

Beebe, J. (2014). *Rapid Qualitative Inquiry A Field Guide to Team-Based Assessment. Second Edition.* Rowman & Littlefield.

Bramble, M., Moyle, W., & Shum, D. (2011). A quasi-experimental design trial exploring the effect of a partnership intervention on family and staff well-being in long-term dementia care. *Aging & Mental Health, 15*(8), 995–1007.

<https://doi.org/10.1080/13607863.2011.583625>

DeWall, C. N. (2013). *The oxford handbook of social exclusion.* New York, NY: Oxford University Press.

- Fast, C. T., Houlihan, D., & Buchanan, J. A. (2019). Developing the Family Involvement Questionnaire-Long-Term Care: A Measure of Familial Involvement in the Lives of Residents at Long-Term Care Facilities. *The Gerontologist*, 59(2), e52–e65.
- Friedemann, M. L., Montgomery, R. J., Maiberger, B., & Smith, A. A. (1997). Family involvement in the nursing home: Family-oriented practices and staff-family relationships. *Research in Nursing & Health*, 20(6), 527–537.
[https://doi.org/10.1002/\(sici\)1098-240x\(199712\)20:6<527::aid-nur7>3.0.co;2-o](https://doi.org/10.1002/(sici)1098-240x(199712)20:6<527::aid-nur7>3.0.co;2-o)
- Gaugler, J. E. (2006). Family involvement and resident psychosocial status in long-term care. *Clinical Gerontologist*, 29(4), 79–98. https://doi.org/10.1300/j018v29n04_06
- Gladstone, J. W., Dupuis, S. L., & Wexler, E. (2006). Changes in family involvement following a relative's move to a long-term care facility. *Canadian Journal on Aging*, 25(1), 93–106.
<https://doi.org/10.1353/cja.2006.0022>
- Hamilton, A. (2013). *Qualitative methods in rapid turn-around health services research*. U.S. Department of Veterans Affairs, HSR&D National Cyberseminar Series: Spotlight on Women's Health.
https://www.hsr.d.research.va.gov/for_researchers/cyber_seminars/archives/
- Heinrich, L.M. & Gullone, E. (2006). The clinical significance of loneliness: A literature review. *Clinical Psychology Review*, 26(6), 695–718.
- Hemmings, N., Salas, J.B., Chern, S.J., Comas-Herrera, A., Roget, G.D., Ettelt, S., Fenech, M-A., Ferri, C.P., Boas, P.J.F.V., Hödl, M., Jacobs, R., Kerse, N., Kruse, F., Lauter, S., Leichsenring, K., Lorenz-Dant, K., Low, L-F., Lum, T., Marczak, J....Yu, J. (2021, August 5). Current situation in relation to “visiting” in care homes and outings for residents. *LTCcovid international overviews of long-term care policies and practices in*

- relation to Covid-19, Issue 2*. Retrieved from <https://ltccovid.org/2021/08/05/current-situation-in-relation-to-visiting-in-care-homes-and-outings-for-residents-ltccovid-international-overviews-of-long-term-care-policies-and-practices-in-relation-to-covid-19/>
- Miles, M. B., Huberman, A. M., & Saldana, J. (2019). *Qualitative Data Analysis: A Sourcebook* (4th ed). SAGE.
- Mitchell, J. M., & Kemp, B. J. (2000). Quality of life in assisted living homes: a multidimensional analysis. *The Journals of Gerontology: Series B*, 55(2), P117–P127. <https://doi.org/10.1093/geronb/55.2.p117>
- 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(SpecIssue1), 87–95. https://doi.org/10.1093/geront/45.suppl_1.87
- Price, B. (2015). Approaches to counter loneliness and social isolation. *Social Welfare & Social Work*, 27(7), 31-39.
- Roberts, A. R., & Ishler, K. J. (2018). Family involvement in the nursing home and perceived resident quality of life. *The Gerontologist*, 58(6), 1033–1043. <https://doi.org/10.1093/geront/gnx108>
- Schussler, S. & Lohrmann, C. (2017). *Dementia in nursing homes*. Springer Verlag.
- Shier, G., Ginsburg, M., Howell, J., Volland, P., & Golden, R. (2013). Strong social support services, such as transportation and help for caregivers, can lead to lower health care use and costs. *Health Affairs*, 32(3), 544-551.
- Steptoe, A., Deaton, A., & Stone, A. A. (2015). Psychological wellbeing, health, and ageing. *Lancet*, 385(9968), 610-648.

Stewart, R. (2013). Reducing depression in nursing homes: So little, so late. *Lancet*, 381(9885), 2227.

Tornatore, J. B., & Grant, L. A. (2002). Burden among family caregivers of persons with Alzheimer's disease in nursing homes. *The Gerontologist*, 42(4), 497–506.
<https://doi.org/10.1093/geront/42.4.497>

Taylor, H. O. (2020). Social isolation's influence on loneliness among older adults. *Clinical Social Work Journal*, 48, 140-151. <https://doi.org/10.1007/s10615-019-00737-9>

Valenzuela, T. (2012). Efficacy of progressive resistance training interventions in older adults in nursing homes: A systematic review. *Journal of the American Medical Directors Association*, 13(5), 418-428.

Van Rensbergen, G. & Nawrot, T. (2010). Medical conditions of nursing home admissions. *BMC Geriatrics*, 10(46). <https://doi.org/10.1186/1471-2318-10-46>

Yamamoto-Mitani, N., Aneshensel, C. S., & Levy-Storms, L. (2002). Patterns of family visiting with institutionalized elders: The case of dementia. *The Journals of Gerontology: Series B*, 57(4), S234-S246.

Table 1

Demographic Characteristics of all family caregivers (n=31)

Characteristic	n	%
Relationship with the resident*		
Parent	23	60.5
Spouse	5	13.2
Child	4	10.5
Friend	2	5.3
Other (Grandparent, Partner, Sister, Colleague)	4	10.5
Pattern of visit before COVID		
Daily	12	38.7
More than once a week	15	48.4
Weekly	2	6.5
More than once a month	1	3.2
Less than once a month	1	3.2
Contact method		
Phone	14	45.2
Video chat	6	19.4
Window visit	6	19.4
In-person indoor visit	2	6.5
In-person outdoor visit	2	6.5
Other	1	3.2
Nursing home contact support		
More than adequate	3	9.7
Adequate	11	35.5
Less than adequate	17	54.8

*Note: Relationships sum to more than 31 because respondents could include any or all of the nursing home residents they supported.