



COVID-19 Experiences of Relatives of Nursing Home Residents

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Abstract

Nursing home residents comprise a disproportionate share of coronavirus-related deaths in the United States. Additionally, lockdown restrictions disrupted residents' relationships with their family members to an unknown extent. This study explored family members' perceived family role and interactions with nursing home residents and staff during the COVID-19 pandemic. Using a qualitative descriptive approach, 10 family members were interviewed using a semi-structured guide. Interviews were audio-recorded and transcribed verbatim, and data were analyzed using Braun and Clarke's Reflexive Thematic analysis. Themes and subthemes indicated that family members accounted for residents' care in new ways, found existing relationships becoming amplified under stress, maintained connections through creative alternatives, and also felt powerless to provide care, despite their knowledge and experience. Family members increasingly relied on staff to meet residents' care needs and provide updates, and often desired to provide assistance and companionship beyond what policy permitted, representing a major opportunity for improving experiences.

Keywords

family member, family caregiver, nursing home resident, COVID-19, pandemic

Introduction

At the beginning of the COVID-19 (Coronavirus disease 2019) pandemic in March of 2020, nursing homes enacted visiting restrictions and other measures to limit the spread of this communicable disease (American Geriatrics Society, 2020). Although positive cases of COVID-19 among residents of nursing homes have accounted for 5% of the total cases in the United States, they represent a disproportionate 31% of deaths attributable to the disease (Kaiser Family Foundation, 2021). While policies that prioritize the physical well-being of older adults have been necessary to protect their health and safety, they may have inadvertent negative impacts as well. Closing nursing homes to visitors separates residents from their families and friends. Isolation, quarantine, and wearing of personal protective equipment (PPE) that obscures facial expressions and muffles speech further limits human interaction of all kinds. Psychological, emotional, and spiritual well-being of residents in nursing homes may also be impacted by social distancing, which could result in loneliness, depression, and stigma associated with the negative stereotype of vulnerability to disease (Monahan et al., 2020).

Given the far-reaching effects of the COVID-19 pandemic, it is important to examine the experiences of different

perspectives of those involved in nursing homes. Due to its uniqueness and recency, the impact of the pandemic on family members of residents in nursing homes is not entirely known. Separation from loved ones and the uncertainty of crisis could cause anger, loneliness, fear, anxiety, or other feelings or reactions. Family members of residents of nursing homes are often omitted from research discussions, but in many cases have provided care for residents prior to their transition to the facility, and may still maintain expectations for being able to provide care and personal contact. After previous large-scale crises such as natural disasters, family members described balancing concern for their own safety as well as the safety of the resident (Christensen & Castañeda, 2014), and noticed increased confusion and disorientation in residents with Alzheimer's when their normal living routines were drastically altered (Gibson et al., 2018). Family members' own experiences have been affected by the ongoing

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Table 1. Interview Guide.

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1. Can you tell me what your relationship is to the resident? How long has your family member lived in the facility?
 2. When did you first hear of the coronavirus and who did you hear it from?
 3. What feelings and thoughts did you experience when you first heard of the virus? How did you deal with those feelings and thoughts?
 4. How often did you visit your family member prior to COVID? How about now?
 5. What was your reaction when you heard about visitor restrictions? What did you do to deal with the situation?
 6. Are there any other family members involved in caring for your family member in the nursing home?
 7. What was your experience in interacting with the nursing home staff and your family member when COVID started? Has anything changed since then?
 8. Have you noticed any changes in the care your family member has received in the nursing home?
 9. What is your concern now? What do you think the COVID situation will be like in the future? What are your plans right now to deal with the situation?
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pandemic itself, including their work and home lives, as well as by policies directed toward residents of nursing homes. Therefore, the purpose of this study was to understand family members' experiences with regard to their perceived family role and interactions with residents and nursing home staff during the COVID-19 pandemic.

Methods

Given the complete lack of research evidence related to the specific study purpose at the time the study was designed and data were collected, a qualitative descriptive approach was chosen to provide an initial description of nursing home residents' family members' experiences during the beginning of the COVID-19 pandemic (Sandelowski, 2010). Convenience sampling was used to recruit family members from two nursing homes in New York State. Eligibility criteria included (1) being 18 years old or older, (2) being a family member of a nursing home resident during the COVID-19 pandemic, and (3) being able to communicate in English. Recruitment flyers were displayed and distributed in those two nursing homes, and family members were informed by staff about the study. Potential participants contacted the research staff regarding the study via emails or phone calls and eligible family members were then scheduled a time for an interview. A semi-structured interview guide was developed based partially on the existing literature (Gibson et al., 2018; Heppenstall et al., 2013) (Table 1) and used to conduct individual interviews via Zoom or phone. During the interview, participants were asked about their experience of being a family member of a person who resides in a nursing home in terms of their experiences in making connection with their loved one in the nursing home and their perceived interaction with and quality of care provided by nursing home staff during the COVID-19 pandemic. The interviews lasted about 30 to 50 minutes. Interviews were audio-recorded and transcribed verbatim, and transcriptions were cross-checked for accuracy by a second researcher. The study was approved by the University Institutional Review Board. Informed consent was obtained for those who were eligible to participate in the study before the interview started. Participants were not compensated for interviews. Interview data were rich in detail, and analysis

concurrent with the initial eight interviews indicated that the sample held sufficient information power to elucidate the aim of the study (Malterud et al., 2016). The final two interviews were conducted to include additional participants with familial relationships to nursing home residents that had not yet been represented in the sample. The researchers did not member-check interview data due to the evolving nature of the pandemic and resulting shifts in policies and perspectives.

Interview data were analyzed using Braun and Clarke's Reflexive Thematic analysis (Braun & Clarke, 2006). Four researchers independently analyzed the interview data and then met to discuss initial codes. Based on conceptual similarities, initial codes were clustered into potential themes which were further combined or refined by the research team. This refinement process continued until 100% consensus agreement was reached among the research team regarding the meaning of the coded data for the entire data set and the adequate representation of themes. Memos were written by all research team members throughout all stages of the analysis to enhance the rigor of the study through reflexivity.

Results

Ten family members, including spouses, adult children, and other relatives of residents in nursing homes were interviewed, including two men and eight women (see Table 2). Four major themes, including "accounting for resident's care," "family involvement in caregiving situation," "maintaining connections with residents," and "powerlessness to provide care for resident" were identified describing family members' experiences. Three subthemes within "maintaining connections with resident" were "finding alternative ways to communicate," "finding alternative ways to visit," and "finding alternatives for goods/services for resident."

Accounting for Resident's Care

Family members often had a history of caring for residents at home prior to their transition to the nursing home, and as a result, were accustomed to being directly involved in their

Table 2. Sample Characteristics.

Family member identification number (FM#)	Gender of family member	Resident's relationship to family member	Gender of nursing home resident
FM#1	Female	Other ^a	Male
FM#2	Male	Parent	Female
FM#3	Female	Parent	Female
FM#4	Female	Parent	Female
FM#5	Female	Parent	Female
FM#6	Female	Parent	Female
FM#7	Female	Parent	Female
FM#8	Female	Other ^a	Male
FM#9	Female	Other ^a	Female
FM#10	Male	Other ^a	Female

^a"Other" relationships include aunts/uncles, cousins, siblings, and spouses/partners, and are aggregated to protect the anonymity of the nursing homes residents and their family members.

care. Family members still desired to ensure residents' needs for care were being met, and in the absence of in-person visits, relied heavily on reports from staff for information about residents' condition.

Although family members generally felt that updates from staff were appropriate, they frequently commented on the lack of firsthand information regarding their loved one residing in the nursing home. One family member stated,

It's kind of hard that my hands are tied right now that I have to take care of her from my chair in the living room and call on the telephone and just talk to the people and use their eyesight as to what they're seeing because I have to use my hearing to know what's going on with her, 'cause I can't put eyes on her. (Family #5)

Similarly, when asked if there had been any changes in the resident's care, family member #3 aptly said, "I wouldn't be able to notice," and went on to describe how she used to observe care directly, but now pieced together a picture based on summary information from staff, inferences from phone encounters, and conversations with the resident.

Family Involvement in Caregiving Situation

Existing relationships between participants in this study and other family members of residents were amplified under the stress of COVID. Collaborative relationships between family members contributed positively to the residents' and family members' experience of the situation, while prior conflict between family members was a source of added burden during this time.

Several participants described multiple family members pitching in to help. Family member #3 explained:

My father did get her [the resident] a phone because I'm one of seven [children]. [. . .] We're kind of all over; at least we're on the East Coast, but she really feels comforting [sic] that she

talks to us because we all just randomly call her and we do the same with my dad. So we do have that cohesiveness with the family.

In contrast, some participants perceived dysfunctional family dynamics that were exacerbated by pandemic-related restrictions. Previous perceptions of bearing the majority or the entirety of the responsibility for a resident's care because others do not contribute appeared to be particularly impactful, as family member #2 stated regarding his adult siblings:

There are other people in my [family]. [. . .] they have no clue what's going on because they never got involved with father and mother [. . .] if you really want to do something and get involved, then you would do it, these are your parents, you know, it's called sacrifice. And I used to tell them, "there's no team here. There's no team," you know, "step up to the plate," you know, "let's be a team." Nobody showed up [. . .] if they wanted to see their mother; they, they'd make an effort.

Maintaining Connections With Residents

COVID-19 completely altered the ways in which family members maintained contact with residents. Family members searched for solutions that worked in their specific situations, and tried different ways and means to keep in touch with residents as the pandemic progressed and restrictions changed.

Finding alternative ways to communicate. Phone calls and videoconferencing software were commonly used by family members to communicate with residents. Phone use was a relatively acceptable communication tool, being both familiar and accessible. Family members described that nursing home staff sometimes assisted residents with using the technology required for communication, especially when it was new to or difficult for the resident. Family member #6 explained:

We Skyped a little bit, but she really didn't—she talked to the person that was with her [staff] more than she would talk to us as a family. I think a lot of that was because she couldn't hear. [. . .] She asked me to get her a cell phone, so I did [. . .]. The only problem was because I couldn't go in and show her how to use it [. . .]. What I do now, they will call me on her cell phone and I talk to her in her room. [. . .] Other than going to the window and using the cell phone, that's about the only communication I have with her now.

Finding alternative ways to visit. Window visits enabled family members to see residents in person while maintaining infection prevention precautions by remaining outside of the building or in another physically separated space. Residents whose rooms were on the ground floor were able to meet with relatives without leaving their rooms, while those who lived elsewhere needed to meet with relatives in other areas with outward-facing windows. Although not ideal, window visits provided a makeshift form of face-to-face contact. Family member #2 said:

I was doing Skype with her [the resident], but it was very, very difficult for her. She didn't really grasp what was going on and window visits are still difficult but she sees me and she knows who I am.

Finding alternatives for goods/services for residents. After facility administrators allowed relatives to drop off food and personal items such as clothing for residents, relatives took the opportunity to bring special or favorite foods, especially during the holidays. Family member #6 stated:

One of the nurses said to me that she's [the resident's] really not eating [. . .] she said "you could bring her some food." So, I came home and I whipped it up and took it right back for her lunch [. . .] she called me [. . .] and she says, "oh, she's eating whatever you sent in," so I says, "now it's something I can do again for her." So, I feel better.

Some family members, such as Family member #4, noted instances where staff could go "above and beyond" to fill service gaps, saying "there's a couple of people that work there [the nursing home] [. . .] that have actually taken their own time, on their own, to do my mom's hair and other residents' hair, and [. . .] the recreational staff have done the residents' nails." However, several family members explained that their efforts to find alternative services were ongoing or that needs were not fully met. Family member #3 described:

My mom had a partial denture and it broke. [. . .] she saw [. . .] a dentist there [. . .] and then there was no dentist coming in and I had gathered the one they had retired. So my mother's dentures that she was fitted for and my father was told that they were done were, like, somewhere in limbo. [. . .] But my father has, like, numerous times reached out and, you know, the staff is like, "we don't know what to tell you. We don't have a dentist. We don't know where to go with this."

Powerlessness to Provide Care for Resident

Prior to the COVID pandemic, some family members indicated that they would visit their resident family member every day, often multiple times a day for several hours at a time. Essentially, visiting family members believed they were an asset, providing additional assistance to nursing home staff in caring for their loved one. This frequent presence enabled an ongoing physical and emotional closeness between family and resident. Family felt engaged in, and well informed about resident care. They could observe for themselves the day-to-day progress of loved ones.

When COVID shut down all nursing home visitation, that daily, direct closeness and interaction between family and residents was completely lost. Family voiced feeling powerless to provide any care for loved ones. They could not interact in the same way with each other as they had before the pandemic lockdown. Some family members with personal or professional experience providing care expressed a willingness to assist the already overextended staff, but felt helpless that they were not permitted in the nursing home at all. Family member #5 stated, "It was frustrating because [. . .] we couldn't even come and be helpers, or volunteer. [. . .] Even if we had to be tested, just like the staff, that we could have been an extra pair of hands to help them out."

Feelings of powerlessness to provide care extended beyond the desire to simply complete tasks. For example, Family member #3 explained:

I think the thing that bothers the most is that we felt that even though they were taking care of my mother's physical needs and things like that, they weren't thinking—we didn't see where they were focusing at all on the emotional needs of like my mom and the other [residents].

Furthermore, for some family members prior to the lockdown, physical care was a way of interacting with residents with cognitive decline. In the absence of being able to help with activities of daily living, Family member #8 stated that the visiting restrictions "went on long enough that [the resident] doesn't have any idea who I am, and I tried to visit, but he just doesn't recognize me."

Discussion

This study found drastic changes in the interactions between family members and residents of nursing homes during the COVID-19 pandemic. Family members frequently noted a shift to almost total reliance on staff to meet residents' care needs and share information and updates. Although a previous study found while family members of nursing home residents during the COVID-19 pandemic expressed needs for more information, particularly context-specific details regarding safety measures and options for interaction (Wammes et al., 2020), findings from this study suggested family members' greater concern was for residents' overall

care and well-being, which they found difficult to assess from a distance.

Family members who participated in this study described their experiences with their other relatives (in addition to the resident) as part of a greater context of care. These social networks influenced family members' interactions with residents, serving as a source of support when existing relationships were positive, and as an added stressor when there was tension or disagreement. No previous research has uncovered how the family relationship changed and impacted their interaction with nursing home residents during COVID-19. Previous literature regarding natural disasters described family caregivers' reactions to and management of acute situations or short-term events (Christensen & Castañeda, 2014; Gibson et al., 2018), while COVID-19 has presented a sustained period of crisis and restrictions. While family members adjusted habits and expectations after the immediate disruption of the lockdown, they still experienced continued stress and uncertainty, perhaps allowing time for prior family conflict to resurface. The longitudinal impact of COVID-19 on family dynamics and relationship is a relevant consideration for future research.

Family members of residents who were capable of adapting to visiting restrictions described creative solutions to maintaining relationships in the absence of physical togetherness. Smartphone-based videoconferencing has been shown to decrease feelings of loneliness in nursing home residents (Tsai et al., 2020), presenting an opportunity to communicate when lockdown restrictions occur. Similarly, more frequent telephone calls have been associated with less negative emotions in nursing home residents during the pandemic (Monin et al., 2020). However, family members of residents with impairments or illnesses that made communication challenging expressed frustration with managing technology. Additionally, except in cases where residents were able to accommodate alternative measures for maintaining relationships on their own, they had to rely on nursing home staff to help with these tasks, many of whom were also facing issues such as PPE shortages, inadequate staffing, and burn-out (White et al., 2021).

While family members in this study described working together with nursing home staff to meet residents' needs, family members also regretted not being permitted to assist with the kinds of tasks that were within their knowledge and ability. Beyond a desire to receive an update on care, family members wanted to actively participate in residents' lives. Some family members of nursing home residents in Finland similarly felt that although communication with residents was possible, not being able to provide care created distance in their relationships that they could not overcome (Paananen et al., 2021). In contrast, when policies in Canada allowed designated family members to visit by appointment to perform specific care tasks for nursing home residents, some family members found the process to be too prescriptive and preferred to be able to visit primarily to provide emotional or

psychological support (Dupuis-Blanchard et al., 2021). These differing perspectives may suggest that family members consider their relationships with nursing home residents to be holistic, encompassing different aspects of care to degrees that vary according to their personal preferences.

Policies in place at the time of data collection for this study did not allow in-person visits to nursing homes, but family members expressed being willing to maintain infection prevention precautions and follow necessary rules to be physically present with residents. Reopening nursing homes to outside visitors was met with good infection prevention compliance and positive experiences in the Netherlands (Verbeek et al., 2020), suggesting that family members' consideration for safety as well as personal interest was likely genuine. As the COVID-19 pandemic continues and resolves, and as infection prevention precautions are considered in the future, nursing homes should strive to implement visiting policies that balance needs for mitigating risks and providing support and contact to residents, particularly by integrating family members as essential components of networks of care teams (Stall et al., 2020).

In terms of limitations of this study, conducting interviews by phone meant that facial expressions or body language could not be obtained or interpreted. In addition, as only family members of residents who were living in nursing homes at the time of the interview were eligible to participate, the sample did not include family members who may have found alternative living arrangements for residents, or family members of residents who died. Although it was not the primary focus of this study, the study team was not able to interview family members of residents who were at the end of life. Because the study sample was recruited from two nursing homes in close geographic proximity, family members willing to participate may have had somewhat homogeneous experiences, perceptions, and expectations, and these findings may not be representative of family members of residents in areas where COVID-19 disease transmission was either higher or lower, or where policies, rules, and regulations were different.

Importantly, these findings contribute a better understanding of the impact of COVID-19 on family members' experiences and relationships with nursing home residents. Family members are an underutilized resource in the holistic care of residents, and policies should support safe, feasible visits, which will benefit everyone involved. Future research should also develop interventions to assist family members to cope with their emotional stress and improve their experiences. Additionally, lasting effects of the pandemic on family members and residents should be explored as restrictions are lifted.

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