

THE FAMILY EXPERIENCE IN LONG-TERM CARE DURING THE COVID-19 VISITATION RESTRICTION

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BACKGROUND

Due to the COVID-19 pandemic, on March 13, 2020 the Centers for Medicare and Medicaid services closed U.S. nursing homes to all but essential vendors and staff, and other visitors were only allowed in end-of-life situations. Twenty-six states also prohibited visitors to assisted living facilities while another 21 recommended no visitations¹. These unprecedented regulatory moves required facilities, families, friends, and residents to make huge adjustments. Despite these extreme measures, COVID-19 has ravaged U.S. nursing homes and assisted living facilities, with current estimates suggesting about 25% of deaths nationwide have occurred among long-term care facility residents even considering only 16 states are reporting assisted living deaths². To gather family perspectives on the ways that long-term care communities were addressing the COVID-19 pandemic, a research team at Miami University's Scripps Gerontology Center launched an online survey on April 29, 2020.

The survey was intended to be completed by respondents who have a family member, friend, or someone else they are involved with who currently lives in a nursing home or residential care/assisted living setting. Throughout the survey, the term "your resident" was used to refer to these individuals. The survey was designed to answer the following questions:

- How are residents and families communicating with each other?
- How are families getting general information about the facility in which the resident lives?
- How and when are families getting information about the residents?
- What are families' opinions about the information they are receiving and how does this affect their overall perceptions about the facility?
- What concerns do families have?

To recruit respondents, the research team placed postings on Facebook, LinkedIn, and Twitter, and asked colleagues and others to widely share the link to the survey. As of June 19, 198 respondents with residents in long-term care had completed the survey. About 42.1% had residents in nursing homes, the remainder in assisted living. Most of the respondents were white (80.3%), female (87.2%), adult children (62.0%) of these residents. Respondents from 21 states completed the survey with the majority (52.1%) from Ohio and other midwestern states, over one-third (37.9%) from the West, and the remainder spread across nine other states. This brief report provides information about what these families had to tell us.

HOW ARE FAMILIES COMMUNICATING WITH RESIDENTS?

Prior to COVID-19 the survey respondents were very involved with the family or friends who are residents. Three in ten (31.4%) previously visited the resident several times a

week and 22.2% visited daily. Respondents also reported providing a fair amount of assistance to residents. Nearly three-quarters (73.6%) assisted with going to activities, about half (49.1%) sometimes or always assisted with grooming (e.g., hair, nails), and 44.1% sometimes or always assisted residents with eating.

We asked families how they were staying in touch with the resident since the prohibition of in-person visiting. As shown in Table 1, the most common way respondents and residents are staying in touch is by telephone. We also asked about whether the resident was able to participate in various communication options on their own, or whether the resident could participate with assistance. About half the residents (46.5%)

While media attention has focused on video calling platforms such as Zoom, Skype, and FaceTime helping families stay in touch during the pandemic, only 8.8% of respondents reported that the resident could manage these types of communication.

could manage the telephone independently and 39.2% could manage postal mail independently. While media attention has focused on video calling platforms such as Zoom, Skype, and FaceTime helping families stay in touch during the pandemic, only 8.8% of respondents reported that the resident could manage these types of communication independently. Several respondents mentioned using Amazon's Echo Show as a way to "drop in on Mom and she doesn't have to do anything." Despite having many communication options, the reality is that without assistance from busy staff, most families must rely on a traditional phone call.

More than one-half of respondents (55.8%) can see or talk to the resident through a window, but 44.2% reported they do not have a window option available. One respondent said, "I feel like window visits are not an option—they are not animals in a zoo." Another respondent expressed a different opinion.

"I wish the staff could bring her to the first floor on occasion, so we could at least wave at her through a window. I have been reluctant to request this because I'm afraid...it would be too much to ask."

Table 1. Types of Communication Options and Resident Ability

Communication options	This is not available	My resident can do this with help	My resident can do this independently
Speak to my resident by telephone	11.6%	41.9%	46.5%
Send my resident a postal mail	12.0%	48.7%	39.2%
Come to their window and see/talk to them	44.2%	35.5%	20.3%
Have a FaceTime, Skype, or other video calls with my resident	28.8%	62.4%	8.8%
Other	76.3%	15.8%	7.9%
Send my resident an e-mail	78.8%	13.8%	7.5%
Send my resident a text message	81.6%	11.0%	7.4%
Visit my resident via a special room or cubicle set up in the facility	90.7%	6.8%	2.5%

Despite having somewhat limited options due to residents' needs for assistance, some families are communicating more often. Over half (52.6%) of respondents who previously visited daily continue to communicate with the resident daily, while 37.5% of those who previously visited once a week are now contacting the residents several times a week or daily. Over a quarter (26.3%) of those who previously visited two or three times a month are now in contact with the resident several times a week. A small proportion of respondents (11.3%) are unable to stay in contact at all, due to the resident's health or physical limitation issues.

HOW ARE FAMILIES GETTING INFORMATION ABOUT THE FACILITY?

We asked families if and how they are getting general information about what is happening in the resident's facility. Nearly three-quarters (73.0%) of respondents indicated they are receiving general information from the facility about how things are going, while the other quarter (27.0%) reported that they do not receive any general facility information. About one-quarter (27.8%) indicated that they are getting new information compared to what they received before visiting restrictions were put in place, and that general information comes more frequently (24.2%). Two-thirds (63.1%)

think the information they are getting is the right amount—everything they want to know. But the others say the information they receive is too little.

To determine how families are getting general information, respondents were presented with several communication sources and asked to select all the sources from which they receive general facility information (see Table 2). Almost one-third (31.8%) reported that they receive mass e-mails from the facility, followed by letters or notices through postal mail (12.6%) and a family newsletter from the facility (12.1%). Phone calls were a common “other” strategy reported by respondents. Phone calls were described as generally direct to family members but several mentioned automated phone “robocalls” that came every day from the executive director or other staff.

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Table 2. Sources of General Facility Information

Source	%
Other	34.3
Mass e-mails from the facility	31.8
Letters or notices through postal mail	12.6
Family newsletter from the facility	12.1
Posts on the facility’s website	9.6
Posts on the facility’s social media (Facebook, Twitter, Instagram, etc.)	8.6

About one-quarter (25.8%) of respondents reported receiving general facility information from more than one source, but four in ten (41.9%) reported that they received general information through **only** one source. In general, those that receive information from more than one source think they get the right amount of information (61.7%), while about the same proportion of those who received information from only one source thought it was the right amount (65.4%). In open-ended responses, some respondents suggested closed Facebook groups for families and group text messages as good ways to let families know what is happening.

HOW AND WHEN ARE FAMILIES GETTING INFORMATION ABOUT RESIDENTS?

Families were asked to report how the facility communicated with them about family or friends who are residents and the frequency of that communication. Most respondents

reported they receive information about the resident by telephone, with about 67% of those families indicating this only happens when there is an issue. Respondents also reported receiving information about the resident via e-mail and postal mail. Regardless of the strategy used by facilities to communicate information about residents to their families, it most often occurs to address an issue rather than providing regular check-ins (see Table 3).

Table 3. Types and Frequency of Communication about Residents					
	Rarely or never	Only when there's an issue	Once or twice a week	3 to 6 times per week	Daily
Text message (SMS)	84.9%	9.2%	3.3%	2.0%	0.7%
Other	73.5%	11.8%	11.8%	-	2.9%
Postal mail	68.9%	29.1%	2.0%	-	-
E-mail	57.3%	31.8%	8.3%	1.3%	1.3%
Telephone call	21.1%	66.9%	9.7%	2.3%	-

When asked what type of resident information is typically shared with them, respondents most frequently reported *resident's health status* (68.4%), *concerns or issues about the resident's life* (65.2%), and *anything that has changed in the resident's life* (53.5%).

92.0% of respondents who hear a story or anecdote about the resident feel they are getting the right amount of information.

Families were then asked to share whether the information they received about the life or care of their family member or friend is *too little* or *the right amount—everything I want to know*. Half (50.6%) of respondents said they are getting the right amount of information about the resident. When we examined families' perceptions of the information they receive by type of information (see Table 4), we found that 92.0% of respondents who hear a story or anecdote about the resident feel they are getting the right amount of

information. We also found that 87.8% of respondents who hear about how the resident is spending their time, and 81.4% of respondents who hear about the resident's mood, think they are getting the right amount of information. Thus, the more specific details of the resident's daily life the families are given, the more likely families are to perceive they are getting the right amount of information.

Table 4. Types of Resident Information and Family Perception about Communication		
	Too Little	The right amount
A story or anecdote about my resident	8.0%	92.0%
How my resident has been spending time/activities for the residents	12.2%	87.8%
My resident's mood	18.6%	81.4%
Anything that has changed for my resident	26.5%	73.5%
My resident's health status	34.0%	66.0%
Any concerns or issues about my resident	35.6%	64.4%

WHAT PERCEPTIONS DO FAMILIES HAVE ABOUT FACILITIES?

Communication—or its lack—has an impact on family perceptions about the facility where their family member or friend receives care. We asked families whether they would recommend the facility to a family member or friend who needed care, and whether they had peace of mind about the care their family member or friend was getting when they weren't there. We thought that one important influence on these family perspectives might be whether the facility had COVID-19 cases. And indeed, our results found differences among respondents based on whether or not there were COVID-19 cases in the resident's facility, and whether the respondents were unsure if there were COVID-19 cases.

As shown in Table 5, the respondents who did not know if COVID-19 was present in the resident's facility had the poorest perceptions of the facility—even compared to respondents who have residents in facilities with COVID-19 cases. One respondent commented, "They are not communicating to residents or family members the extent of the COVID illnesses. I've learned through the Ohio website that there are [many] residents and staff with the illness."

The respondents who did not know if COVID-19 was present in the resident's facility had the poorest perceptions of the facility.

Table 5. Family Perceptions by COVID-19 Cases in the Facility

COVID-19 cases	Would Recommend		Peace of mind	
	Yes	No	Yes	No
Yes	75.8%	24.2%	71.5%	28.5%
No	88.4%	11.6%	84.1%	15.9%
Don't know	53.6%	46.4%	50.0%	50.0%

Note. "Yes" combines responses *Yes, definitely* and *Yes, probably*; "No" combines *No, probably not*, and *No, definitely not*.

Part of the families' dissatisfaction may be traced to doubts about the facility's honest communication. When families were asked how confident they were that the facility would inform them if cases of COVID-19 were found, six in ten (60.8%) of those who said there were no cases in the resident's facility were *very confident* they would be informed, compared to less than one-quarter (23.3%) of those who did not know whether COVID-19 was present in the facility. As one respondent said, "It is horrible that I can NOT trust the place she lives in." Another reported, "Facility wanted to know if I wanted my parent to be informed about the person who tested positive. Real concern about paternalism and reluctance to be transparent."

WHAT CONCERNS DO FAMILIES HAVE?

Families were asked what concerned them most about not being able to visit in person. Respondents were asked to choose up to three concerns from a list of eight and could also add their own concerns in an open response. The most commonly selected concern was *Resident will feel lonely or isolated* (63.1%) followed by *Resident will pass away and I can't be with them* (32.8%) and *The care and other things that I used to do won't happen* (31.8%).

Several respondents noticed declines among the resident since visiting restrictions have been in place, with depression, anxiety, increasing confusion, and a lack of exercise and physical activity among their concerns.

Three in ten (30.8%) worried *My resident will not understand why I'm not there* and some worried (16.2%) worried *My resident will become ill with COVID-19*. In open responses, several respondents noticed declines among the resident since visiting restrictions have been in place, with depression, anxiety, increasing confusion, and a lack of exercise and physical activity among their concerns. "She has been in her room for 45 days with little exercise which is important for her to walk daily." Another mentioned, "My resident's health has seriously declined since he has been so isolated."

Aligned with having multiple concerns, four in ten (40.6%) respondents had considered a move out of the resident's current facility. Slightly less than half (44.4%) of respondents with residents in facilities where COVID-19 cases are present and six in ten (60.7%) who do not know if COVID-19 is present had considered a move. When asked about what factors prevented them from suggesting a move, about half the respondents (54.8%) indicated that they do not have the skills and/or resources to care for the resident at home. About one-third (31.5%) indicated that changing facilities was unlikely to change the situation, and 27.4% reported that the resident would not be able to return to the same facility once the COVID-19 crisis is over. About one-quarter of respondents (23.3%) worried that they will infect the resident with COVID-19 if they bring them home. Several also mentioned that the move itself would be upsetting and disorienting for the resident.

WHAT ARE THE IMPLICATIONS OF OUR FINDINGS?

Most respondents had positive perceptions about the facility. However, their perceptions varied depending on the situations related to their communication with the facility and their family member residing in the facility. Specifically, the families with the lowest perceptions of the facility were those who did not know whether there were COVID-19 cases. These respondents indicated that they are not getting new or frequent information, and are likely basing their perceptions on a lack of communication from the facility. The respondents with the highest perceptions of the facility are those who, in addition to hearing about changes and concerns, also hear anecdotes about their family member residing in the facility or are informed how the resident is spending their time or participating in activities.

Aligned with having multiple concerns, four in ten (40.6%) respondents had considered a move out of the resident's current facility.

Despite the huge toll that COVID-19 has taken on nursing homes and assisted living facilities, staff in the majority of facilities are spending time communicating with families in a variety of ways and providing assistance for communication between residents and families. However, where families don't know the status of COVID-19 in the facility, or don't have confidence in facility communications, their perceptions of the facility are lower. Even if no positive COVID-19 cases have been found, facilities can build the confidence of families by telling them what is being done to prevent cases and reassuring them that the resident and the family will both be told if staff or residents test positive. In some cases, families mentioned getting their facility information from the resident rather than the facility. While that is useful, facility communications directly to families ensure a clear and consistent message.

Regular communication of general facility information—from at least one source if not more—helped respondents feel they received the right amount of information. Mass e-mails, a daily robocall with facility updates, and regular telephone calls were mentioned as effective strategies. Those who rarely received phone calls were least likely to think they were receiving the right amount of communication. As one respondent said “I would like weekly measures on the facility and measures to control the virus, as well as problems with those measures.”

Communications from the facility about the resident were also important, with families feeling they were getting the right information when they received quality of life information such as the ways the resident was spending time, or what their mood had been like.

Respondents had numerous concerns, some of which can be addressed. Worries about the resident passing away alone can be allayed by reminding families that visitors are allowed in end-of-life situations and explaining the facility’s policy in that regard. Families’ worries about loneliness and isolation may be lessened if facility reports about the resident include anecdotes or stories about an event or something in the resident’s day, as well as information about how they are spending their time. Training direct care staff to regularly send texts or record case notes such as “Mrs. Smith loved the blueberry pie at lunch.” or “Mr. Jones learned to play solitaire on the tablet today.” can go a long way towards reassuring families that things are going as well as can be expected.

Many respondents expressed confidence and appreciation for the resident’s facility and staff in this difficult time. One respondent said, “All is well. I’m so happy that my Mom is in her facility at this time. She is getting the care she needs in as safe an environment as she could be in.” Another said, “I was extremely glad when they closed the nursing home so quickly to avoid the virus....They have done a great job keeping her and everyone else in the building safe, happy, healthy and entertained.”

Others mentioned a desire for assistance from the “busy and overworked” staff. Several wished for a minute of kindness or caring, even knowing that staff might not have it to give.

“If they would just take some extra moments with the patient to make sure they are comfortable, to chat, to just give them some TLC....get her situated in her Lazy Boy with the things she needs (glasses, water, remote) and put on a channel she would like, that would make a fundamental difference.”

Some respondents expressed concerns that the solution of isolation may be worse than the threat of COVID-19. “An elderly person....cannot be held prisoner like this. I understand the need to keep the residents safe, but at what cost?”

As we write this report, assisted living facilities have begun to reopen to visitors and states are allowing outside visits by a single visitor to nursing home residents. As policy makers and facilities try to determine the right balance between safety and socialization, it is clear from these findings that targeted and timely communication with involved family members and friends should be a key management strategy. Policies that have required nursing homes to communicate about COVID-19 cases are a step in the right direction and should include assisted living settings as well. However, we know little about the guidance that has been provided to long-term care staff to help them determine—and execute—appropriate communication strategies. Likewise, we recommend further research to understand the perspectives of long-term care residents and staff and the challenges they have faced during this pandemic. We are in uncharted territory and it will take knowledge, trust, and cooperation to realize the best possible outcomes for residents, families, and staff in our long-term care settings.

ENDNOTES

¹ True, S., Ochieng, N., Cubanski, J., Wyatt, K., & Neuman, T. (June 16, 2020). *Under the radar: States vary in regulating and reporting COVID-19 in assisted living facilities*. Kaiser Family Foundation. Retrieved from <https://www.kff.org/coronavirus-covid-19/issue-brief/under-the-radar-states-vary-in-regulating-and-reporting-covid-19-in-assisted-living-facilities/>

² Kamp, J., & Mathews, A. W. (2020, June, 16). As nursing home deaths top 50,000, states ease lockdowns. *Wall Street Journal*. Retrieved from <https://www.wsj.com/articles/coronavirus-deaths-in-u-s-nursing-long-term-care-facilities-top-50-000-11592306919?shareToken=stca82fb18421a4db38687223a8325883c>