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Journal of Aging Studies 62 (2022) 101060

Contents lists available at ScienceDirect

Journal of Aging Studies

journal homepage: www.elsevier.com/locate/jaging

Family member roles in long term care: Lessons for the future from COVID-19

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ARTICLE INFO

Keywords:
Nursing home
Care partners
COVID-19
Visitation restrictions

ABSTRACT

This study investigates nursing home residents' and care partners' experiences during COVID-19 visitation restrictions. A nonprobability purposive sample of care partners was recruited via social media and email listservs. Care partners completed surveys ($N = 30$) and follow-up interviews ($n = 17$). Before COVID-19, care partners visited residents 3+ times per week for socialization and care. After restrictions, communication between care partners and nursing homes deteriorated. Families experienced reduced communication about residents' health statuses and little COVID-19 case information. Care partners expanded their advocacy roles, proposing policies to protect residents' rights. Care partners reported losing irreplaceable time with residents during restrictions. In future emergencies, we must balance the value of family visits with public health protection such as personal protective equipment (PPE).

Introduction

In March 2020, to protect residents living in nursing homes from COVID-19, the Centers for Medicare & Medicaid Services (CMS) instructed facilities to restrict all visitors except for "compassionate care situations", a poorly defined concept typically applied when a resident is critically ill and nearing end-of-life (Centers for Medicare and Medicaid Services, 2020a). Due to the visitation restrictions, residents and care partners were limited to distanced communication, such as phone calls, texting, video chats, email, and social media (Monin et al., 2020), and residents could not receive in-person support and assistance from care partners. We define the term 'care partner' as a family member or friend of a nursing home resident who visits and provides care. On May 18, 2020, CMS released nursing home reopening guidelines that included criteria for resuming visitation, granting discretion to state and local health departments to adjust visitation restrictions based on local conditions (Centers for Medicare and Medicaid Services, 2020b). Taking this opportunity, twelve states granted outdoor visits using CMS guidelines; the remaining 38 states created their own guidelines adapting the CMS protocols. Some state and local health departments allowed outdoor and/or window visits (Eyigor & Pekruhn, 2020), but each time an additional resident or staff member was diagnosed with COVID-19 in the facility, safety protocols were reinstated prohibiting visits for two weeks. In September 2020, as vaccines were about to be distributed, CMS announced it would allow indoor visits if nursing homes and residents met certain infection control related criteria. Since then, thousands of nursing home residents and employees have been vaccinated. As of March 2021, indoor visits are permitted unless: A) the vaccine dose rate is less than 70% or the county's COVID incidence rate is more than 10% and/or B) there are positive or quarantined cases in the nursing home (Centers for Medicare and Medicaid Services, 2020c). However, some states have continued stricter guidance. Throughout this time, these restrictions denied residents essential care and in-person connections provided by visits from family and friends.

Initially, these restrictions seemed necessary to prevent the spread of COVID-19 in nursing homes. Before we knew *how* COVID-19 spread, twenty-three people died in a King County, Washington nursing home (Van Beusekom, 2021). In the early days of the pandemic, and in accordance with the time frame of the CMS restrictions, there were significant shortages of personal protective equipment (PPE) nationally that were impacting all types of health care settings, including hospitals, first responders, and nursing homes. States were responsible for acquiring their own PPE and each state prioritized its distribution in different ways. As a result, many nursing homes lacked adequate PPE for

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https://doi.org/10.1016/j.jaging.2022.101060
Received 24 September 2021; Received in revised form 20 April 2022; Accepted 12 July 2022
Available online 15 July 2022

their staff and thus, would not have been able to provide additional PPE for visitors. Despite these very real challenges and threats to health and safety, such restrictions separated care partners and residents, and those separations continued after some of the conditions, such as the shortages of PPE, began to ease.

Care partners are integral in nursing home admission, concerned with whether a resident will enter a nursing home and which nursing home they choose. After residents enter nursing homes, family and friends continue serving as care partners (Gladstone, Dupuis, & Wexler, 2006). Care partners may feel a combination of relief and guilt about admitting loved ones to a nursing home (Cronfalk, Ternestedt, & Norberg, 2017), and care partners often feel a responsibility to continue to take care of residents (Bern-Klug & Forbes-Thompson, 2008). Care partners visit regularly and provide care, such as helping to eat or doing personal care tasks (Cronfalk et al., 2017; Williams, Zimmerman, & Williams, 2012). Care partners also help residents maintain family relationships by bringing residents home for family events, providing socialization and connection in the nursing home, and monitoring whether residents are properly cared for (Cronfalk et al., 2017), enabling residents to achieve a better quality of life. Moreover, care partners represent residents with cognitive impairment, making care decisions and managing care options related to end-of-life (Caron, Griffith, & Arcand, 2005; Gonella, Basso, De Marinis, Campagna, & Di Giulio, 2019).

Care partners' regular visits are positively linked to residents' health and quality of life (Mitchell & Kemp, 2000). Good relationships between staff and family can promote family involvement and positively affect residents' health. When care partners provide dietary assistance, for example, residents' protein and energy intake increases (Wu et al., 2020), and illness in residents with high family involvement is more readily detected (Port, 2006). In addition, staff and family can together reduce deteriorations of the resident's behavioral, cognitive, and functional status by promoting family involvement in the resident's interventions and activities (Jablonski, Reed, & Maas, 2005). In addition, the more often the care partner communicates with the staff, the higher the quality of life of the resident as perceived by the care partner (Roberts & Ishler, 2018). Collaboration between care partners and staff can positively affect residents' lives.

Care partners may feel overwhelmed by regular visits to the residents because of their own family life (Cronfalk et al., 2017), particularly if they are visiting because they are concerned about the quality of the care being provided. Care partners make fewer visits to residents if they have transportation problems, bad relationships with staff, and/or lack family to share the duty (Port, 2004). The length and frequency of visits is directly correlated with the distance a care partner lives from the nursing home; the closer they live to the nursing home, the more frequently and longer they visit (Yamamoto-Mitani, Aneshensel, & Levy-Storms, 2002). In addition, care partner visits may be inhibited by their own health problems or those of other family members, feelings of discomfort with the nursing home setting, work commitments, or financial problems (Miller, 2018).

Methods

Study design and participants

This study used a mixed-methods design to collect data from nursing home resident care partners about their experiences with visitation during COVID-19. All study methods were approved by the IRB at the University of Maryland Baltimore County (IRB #: 449). Care partners of nursing home residents (e.g., friends, family members) were recruited via professional networking groups and social media (i.e., Twitter, LinkedIn). We used the term care partners in our recruitment to be inclusive of non-relative significant others of nursing home residents. Participation in this study was voluntary. Interested parties clicked on a Google Form link, completed consent, and answered survey questions. See Appendix B for included survey questions. At the conclusion of the survey, participants were asked if they were willing to complete an open-ended interview and consented to the qualitative follow-up by providing their phone number or email address. See Appendix A for the interview guide. To participate in the study, individuals had to: (1) be 18+ years old, (2) self-identify as a 'care partner' of a U.S. nursing home resident, and (3) have visitation restricted as a result of COVID-19, specifically since March 13, 2020.

Through a nonprobability purposive sampling strategy, researchers collected quantitative (survey) data between December 1, 2020 and February 1, 2021 and qualitative (interview) data between December 8, 2020 and February 9, 2021. A total of thirty ($N = 30$) family caregivers completed the quantitative (survey) portion of this study, and of those, seventeen family members ($n = 17$) completed the qualitative (interview) portion of this study. The survey asked participants basic questions including relationship to resident, visitation pattern prior to COVID-19, primary means of communication with resident during COVID-19, and perceived adequacy of communication during COVID-19. No scales were used, as the primary purpose of the survey was to screen participants for the interview and obtain basic information about their loved one in a nursing home and experiences of visitation.

The first and second authors, both social work faculty members experienced in qualitative research, conducted the interviews using a semi-structured guide they developed jointly and based on the research question. The interview expanded on the survey questions asking about things such as: (1) typical communication from the nursing home prior to March 13, 2020, (2) how the nursing home communicated visitation policy changes, (3) how the resident was impacted by the visitation policy changes, and (4) how the care partner was impacted by the visitation policy changes. Each question was open-ended with probes used as needed to explore their experiences. Interviews were conducted virtually, using WebEx, and recorded.

Data analysis

The interview software generated a preliminary transcript. A graduate research assistant listened to the audio files, reviewed the transcripts for accuracy, and made corrections where necessary. Seventeen transcripts were corrected and uploaded into NVivo for analysis. The interviews lasted between 22 and 76 min (M = 35 min). The 315 total pages of qualitative data was studied using a conventional content analysis approach as described by Hsieh and Shannon (2005). First, words, phrases, and paragraphs were organized according to the interview schedule. Second, each interview was coded using an "open, prospective approach guided by the study's research questions" (Towsley, Beck, Dudley, & Pepper, 2011, p. 213). The first author conducted the initial analysis. Third, the research team engaged in peer debriefing to identify unintended biases influencing analysis (Padgett, Mathew, & Conte, 1998). Through peer debriefing, researchers reached consensus on codes and themes (Creswell, 2007).

A content analysis approach is appropriate for this study, as little literature to date explores these specific research questions and our research questions are inductive. Moreover, credibility was enhanced within the analysis process through peer-debriefing (Creswell & Miller, 2000). All themes were reviewed and discussed with all authors, including how specific quotes fit into various themes. Results include direct quotes from interview participants with their respective anonymous identification to note differentiation between respondents. The main findings are described in detail below, followed by recommendations to improve person-centered nursing home care during future public health emergencies.

Results

Demographic characteristics

Survey respondents

There were $N = 30$ respondents to the electronic survey, and of those,

$n = 17$ completed interviews. The majority of survey respondents were children of nursing home residents ($n = 23$) and spouses of nursing home residents ($n = 5$). Respondents could indicate more than one relationship on the survey; additional responses included child, friend, and other. Half of the participants (50%) visited the nursing home more than once per week prior to the pandemic. Once the COVID-19 visitation restrictions were put into place, care partners most often used the phone ($n = 14$), video chat ($n = 6$), and window visits (n = 6) to contact their resident. Over half of the survey respondents reported that communication with the nursing home was less than adequate during the COVID-19 pandemic ($n = 16$ or 53.33%). Of note, while we did not ask the gender of survey respondents, all interview respondents were female, identifying as wives, daughters, and a mother. See Tables 1 and 2 for a detailed information about survey responses.

Interview participants

Of the respondents who completed the interview, most were daughters of the residents ($n = 11$), followed by wives ($n = 5$). The remaining participant was a mother of an adult child with a disability who lived in a care home. While we report her demographics as a survey and interview participant, the mother's data was removed for qualitative analysis since this study focuses on older adults. Interview participants' ages ranged from 51 to 71 years old (M = 63, SD = 6.13), and residents' ages ranged from 28 to 99 years old (M = 82, SD = 16.52; M = 85, SD = 8.53 without the son). All interviewees reported visiting their resident at least once per week, with seven interviewees visiting seven times per week ($n = 7$). Approximately 82.3% of interviewees reported that their loved ones ($n = 14$) experienced Alzheimer's disease or related dementias. Table 3 contains detailed information on interview respondents, including their state of residence. We recruited for care partners of nursing home residents, but participants were allowed to self-identify. As a result, several participants reported about their experiences with residents in dementia care units or assisted living facilities that did not meet the CMS definition of a nursing home or skilled nursing facility. We include them in the data analysis because their roles prior to the pandemic were identical to the roles reported by nursing home care partners, and they reported being impacted by the same regulatory changes.

The interviews with the 16 ($n = 16$) family members of older adults revealed three overarching themes: *Reduced direct involvement of nursing home care partners with residents due to COVID-19; One-way communication from nursing homes before, during, and after COVID-19*; and *The future of care partners in long-term care.* (See Table 4)

Table 1
Demographic characteristics of all care partners ($N = 30$).

Characteristic	n	%
Relationship with the resident (Multiple responses)		
Parent	23	60.5
Spouse	5	13.2
Child	4	10.5
Friend	2	5.3
Visitation pattern 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
Contact method during COVID lockdown		
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

Table 2
Electronic survey summary (N = 30).

Relationship to the resident (multiple responses)	Visitation pattern prior to March 13, 2020	Adequacy of nursing home support to connect with resident since March 13, 2020	Interview complete
Parent	More than once a month	Adequate	No
Parent	More than once a week	Less than adequate	No
Parent	More than once a week	Adequate	Yes
Spouse, friend	Daily	Less than adequate	Yes
Child	More than once a week	Adequate	Yes
Parent	More than once a week	Adequate	Yes
Spouse	Daily	More than adequate	Yes
Spouse	More than once a week	Adequate	Yes
Parent	Daily	Less than adequate	Yes
Parent	Daily	Less than adequate	Yes
Parent	Weekly	Less than adequate	Yes
Parent	More than once a week	Adequate	No
Partner	Daily	Adequate	No
Parent	More than once a week	Less than adequate	Yes
Parent	Daily	Less than adequate	No
Parent	Daily	Adequate	No
Parent	More than once a week	Less than adequate	No
Parent	Weekly	Less than adequate	Yes
Spouse, Sister	Daily	Less than adequate	Yes
Parent	More than once a week	More than adequate	No
Parent	More than once a week	Adequate	No
Parent	Daily	More than adequate	Yes
Parent, friend	Daily	Less than adequate	Yes
Spouse	Daily	Adequate	Yes
Child	Daily	Adequate	Yes
Parent	More than once a week	Less than adequate	No
Parent, grandparent	More than once a week	Less than adequate	No
Parent	More than once a week	Less than adequate	No
Parent	More than once a week	Less than adequate	No
Parent	More than once a week	Less than adequate	No

Reduced direct involvement of nursing home care partners with residents due to COVID-19

Although nearly half of the individuals who participated in the interviews worked full time before visitation restrictions, fourteen of the seventeen participants visited nursing home residents at least three times per week, with seven reporting visiting daily. Several adult children shared responsibility with their siblings, such that even if they did not visit every day, the resident received a daily visit from one of the children. During these visits, family members reported providing hands on assistance with feeding, advocacy on behalf of their residents, and companionship, such as a wife who described sitting and holding hands with her husband as they watched TV together.

After the restrictions, family members connected only by phone call or video chat for the first few months of the visitation regulations, rendering previous roles, particularly hands-on roles, limited or impossible. In addition to the loss of hands-on roles, the majority of care partners experienced challenges in continuing the roles they still could perform. They wanted to call every day to provide advocacy and companionship, for example, but the number of contacts was

Table 3
Interview-related data and demographic characteristics of care partners and residents ($n = 17$).

Interview date (M/D/Y)	Interview length (minutes)	Care partner age (yrs)	Resident's relationship with care partner	Visitation pattern (times per week)	Resident age (yrs)	Resident health issue	State of residence (postal code)
12/08/2020	76	51	Mother	4–5	87	Alzheimer's	MA
12/16/2020	26	65	Mother	3–4	87	Fell/Broken hip/Dementia	VA
12/21/2020	50	74	Husband	2	76	Traumatic Brain Injury/Alzheimer's	IL
12/21/2020	23	66	Husband	7	76	Alzheimer's	VA
12/23/2020	22	64	Father	3–4	91	Alzheimer's	VA
12/29/2020	35	58	Mother	5	85	Alzheimer's	MA
12/29/2020	67	65	Husband	7	N/A	Post-polio syndrome/Chronic obstructive pulmonary disease/ Congestive heart failure	CA
01/15/2021	35	59	Mother	1 *	87	Stroke/Dementia	TX
01/15/2021	40	63	Mother	7	80	Dementia	WV
01/19/2021	40	60	Father	N/A**	93	Vascular dementia	CT
01/19/2021	31	55	Son[a]	3-4	28	Intellectually disabled	TX
01/20/2021	60	62	Mother	6–7	99	Dementia	CA
01/21/2021	23	67	Husband	7	71	Alzheimer's	CT
01/22/2021	36	68	Mother	2 ***	91	Stroke/Vascular dementia	CT
01/22/2021	23	70	Husband	7	81	Alzheimer's	IL
01/28/2021	35	56	Father	7	76	Dementia/Schizophrenia	CT
02/09/2021	52	71	Mother	3–4	99	Parkinson's	NY

Note. * Only one time because the admission was right before COVID, ** The resident was admitted on 13th March 2020, *** The care partner visited two times a week, but hired personal CNA to take care of the resident every day.
[a] This participant was removed for analysis due to son's age.

significantly limited for residents who needed help from staff because they were unable to operate the phone independently. In some cases, video chat was limited to once a week because staffing shortages, exacerbated by the pandemic due to the increased care needs of residents and the reduced numbers of staff due to their own illnesses, drastically decreased the amount of time available to spend with residents. In one case, no contact with the resident happened for at least a month. Another family member shared their continued attempts to remain in contact:

> I do call every day. And very shortly into this, I think, maybe one week into it or even less, they made iPads available for every unit in nursing and in the assisted living - they already had iPads for the independent living folks - but they made those available - one per unit at that point - so families could get in touch that way and see their loved ones (Wife, age 66, Virginia).

When nursing home residents had severe cognitive impairment, communication via telephone or video chat was difficult. These residents did not understand what the COVID-19 outbreak was or why their care partners could not visit them. Another family member shared:

> I would say, a couple of weeks passed, we started doing the Skype visits once a week for, like, a half an hour. Which is difficult, and we can talk about that - for someone at her level of Alzheimer's. Because…she can't engage with it (Daughter, age 51, Massachusetts).

Eventually, most nursing homes allowed window visits. A window visit was a visit in which a resident and their family could see each other through a window, with the resident inside the building and the family member(s) outside the building. Procedures and frequency for window visits varied greatly. While in one case a care partner was not allowed to have window visits until an ombudsman intervened, there was also a care partner who had daily window visits. In general, care partners described having window visits between once a week and once a month.

One-way communication from nursing homes before, during, and after COVID-19

Seven out of 16 participants ($n = 7$) reported that communication with the nursing home was more frequent before COVID-19 than after COVID-19, and/or that communication was lacking even before the pandemic. Family members also described that they were more proactive in communicating with nursing homes before COVID-19 than after; visiting participants could have direct conversations with staff when needed, sharing and receiving information that improved resident care. Once visitation restrictions began, family members reported receiving only one-way notifications, not two-way communication with nursing homes. One family member shared, "I get very little communication by email. The only time I get emails is when, oh, we're going to be open for window visits, or we're going to be open for inside visits, or the hairdresser's coming. That's about it" (Daughter, age 60, Connecticut).

Not only did the nursing homes that our respondents' family members were in fail to share information unless the residents had health problems, but some nursing homes did not disclose COVID-19 cases that occurred in the facility. One family member shared:

> We never receive a call from them unless there is a medical problem. … If it's just, they're having a hard time dressing her, bathing her, whatever, we don't get a call. We don't know. So, communication - this has been an ongoing issue with our family [during COVID]. (Daughter, age 58, Massachusetts).

Such communication would have allowed family members to help address concerns, but the lack of communication prevented such collaboration.

When communication was lacking, participants questioned the transparency of the nursing home's communication, not convinced that they were hearing the whole story, which reduced trust. In addition, there was no sharing of new information at the care plan meeting unless requested, and care team members who participated in the meeting did not seem to be communicating amongst themselves. Families felt care plan meetings were treated by facility staff as merely a mandatory event required by regulations and that they were ineffective.

Fourteen of our 16 interview respondents ($n = 14$) had family members with some form of dementia. While this did not have an impact on the communication respondents received from the nursing home, it did impact the residents' ability to contact them directly and perhaps might have contributed to the overall feeling of disconnection during this time. This suggests that it is that much more important for nursing homes who serve people with dementia to communicate with family members.

Table 4
Key theme, subtheme, and example quotes.

Key theme	Subtheme	Quotes
Care Partner Roles Prior to COVID-19 and How They Changed	N/A	I do call every day. And very shortly into this, I think, maybe one week into it or even less, they made iPads available for every unit in nursing and in the assisted living - they already had iPads for the independent living folks - but they made those available - one per unit at that point - so families could get in touch that way and see their loved ones. (P08: Wife, age 66, Virginia)
		I would say, a couple of weeks passed, we started doing the Skype visits once a week for, like, a half an hour. Which is difficult, and we can talk about that - for someone at her level of Alzheimer's. Because…she can't engage with it. (P02: Daughter, age 51, Massachusetts)
Communication- before, during, and after (and its impacts on care partner roles)	N/A	"I get very little communication by email. The only time I get emails is when, oh, we're going to be open for window visits, or we're going to be open for inside visits, or the hairdresser's coming. That's about it." (P10: Daughter, age 60, Connecticut)
		We never receive a call from them unless there is a medical problem. … If it's just, they're having a hard time dressing her, bathing her, whatever, we don't get a call. We don't know. So, communication - this has been an ongoing issue with our family. (P01: Daughter, age 58, Massachusetts)
The Future of Care Partners in Long-term Care	Resident Advocacy	I'm on another - a group where we're just pushing for essential caregivers to be allowed in to help. And it's - to me, it's a win/win for everybody, because it's not only helping the patient, it's helping the nursing home. I mean, there is one nurse that when I leave at night, she'll say to me, thank you so much for helping. You know, because that's one less person they have to feed. It's someone else that they can help, instead of taking the time for my husband. (P12: Wife, age 67, Connecticut)
	Policy Advocacy	"I did my best to channel my anger into advocacy and information and research and kind of letting the world know what was going on because I think there's so much ageism in our American society in particular that people didn't really care." (P11: Daughter, 62, California)
	Essential Caregiver	The biggest thing I think would be they needed to let family in at least one, at least one family member per resident could have suited up in PPE. Just like the other staff that went in and out, in and out, in and out. You know, nobody is more motivated to keep a loved one safe than their loved one. I am certain without a shadow of doubt that family members would have been even more careful about staying within a bubble themselves so that they did not jeopardize their loved one. You know, I personally was willing to give up everything to be able to see my mom in terms of not seeing my grandchildren. You know, I was willing to do whatever it took to help my mom get through this. I knew the rest of us would see each other on the other side. (P11: Daughter, age 62, California)

The future of care partners in long-term care

Resident advocacy

Once COVID-19 arrived, families reduced their direct care roles but expanded their roles as activists and advocates. One family member described this role change stating:

> I'm on another - a group where we're just pushing for essential caregivers to be allowed in to help. And it's - to me, it's a win/win for everybody, because it's not only helping the patient, it's helping the nursing home. I mean, there is one nurse that, when I leave at night, she'll say to me, "Thank you so much for helping." You know, because that's one less person they have to feed. It's someone else that they can help, instead of taking the time for my husband. (Wife, age 67, Connecticut).

They advocated to be allowed to see their loved ones and to be able to help staff. Many participants understood that in order to see residents, policy would need to change.

Policy advocacy

Several family members actively gathered information to better understand what happened since COVID-19 and engaged in advocacy activities to promote the interests of residents. For example, they participated in rallies with other families and wrote to elected officials, publicizing the situation of residents and proposing policies to promote residents' rights. In addition, some participants shared they collected information, researched nursing homes online, educated others, or corrected misconceptions. Through these activities, these individuals transformed beyond caring for their own residents into advocates championing for all nursing home residents. One family member shared:

> I became like this very vocal online commenter for the nursing home stories, like advocating for what should be done. What was being done that they were missing. And finding that I was able to shape stories …So, I found it as way to have a voice, and there are other nursing home families there. And to sort of try to make this better by advocating the on the ground view, which I felt I had between myself and my friends, and just being in the nursing home for so much, I mean, it's a lot of time I've spent there, so I had a sense of you know, what was not being done and what the party lines with the CDC and what wasn't working. That was this very strange outcome of all of this. I had never commented online. (Daughter, age 51, Massachusetts).

Another described their advocacy role as a solution to their anger about the situation, saying: "I did my best to channel my anger into advocacy and information and research and kind of letting the world

know what was going on because I think there's so much ageism in our American society in particular that people didn't really care." (Daughter, 62, California).

Essential caregiver

One policy families promoted was essential caregiver legislation. Essential caregiver policies permit each resident to have one caregiver designated to visit to assist the resident even if visitation is restricted by public health emergencies such as COVID-19. Our participants believed essential caregiver legislation would prevent what happened during COVID-19 from happening in the future. Family members believed that visitation restrictions contributed to the deterioration of residents' physical and mental health. They felt essential caregiver legislation was critically important to allow them to continue their involvement with family in long-term care:

> The biggest thing I think would be they needed to let family in at least one, at least one family member per resident could have suited up in PPE. Just like the other staff that went in and out, in and out, in and out. You know, nobody is more motivated to keep a loved one safe than their loved one. I am certain without a shadow of doubt that family members would have been even more careful about staying within a bubble themselves so that they did not jeopardize their loved one. You know, I personally was willing to give up everything to be able to see my mom in terms of not seeing my grandchildren. You know, I was willing to do whatever it took to help my mom get through this. I knew the rest of us would see each other on the other side. (Daughter, age 62, California).

Seventeen states[2] attempted to pass essential caregiver legislation (Leading Age, n.d.); New York State (S614B, 2021), North Dakota (SB 2145, 2021), Washington State (HB 1218, 2021), and Texas (SB 25, 2021) enacted Essential Caregiver laws in 2021. This family member described:

> I was asked to sit on the governor's workgroup …I worked with many different stakeholders, me being the only one who was not affiliated with an association or a facility, or an elected official. I had no letters after my name that they recognized… We gave a list of policy suggestions to the state of Connecticut who was just opened back up. And two of the subcommittees suggested essential caregiver status. One of the short-term goals that came out of the Mathematica report. There were 22 recommendations. Some were long-term. Some were short term, and one of the short-term goals, SR5 was to establish an essential caregiver program. It has been, I feel like…Every person I talked to face-to-face. It's an excellent idea. (Daughter, 68, Connecticut).

Discussion

COVID-19 visitation restrictions taught important lessons about the role of families in nursing home care and future considerations. Undoubtedly, family members fill gaps in staffing by providing individualized Activities of Daily Living (ADL) care for residents (Centers for Medicare and Medicaid Services, 2016). Ongoing staff shortages mean that the provision of this care by family members will continue to improve quality of life and quality of care for residents. In addition to this essential care, our study found that family members provide important social connections that cannot be replaced by paid staff, such as holding hands, reminiscing about shared memories, and providing connection to children and grandchildren.

Communication between nursing homes and care partners is essential for quality care (The Consumer Voice for Quality Long-Term Care, 2017). Open, transparent communication reduces misunderstandings and promotes trust and collaboration between care partners and staff. Trusting relationships between staff and families are critical for good care and lead to better outcomes for residents. Not only should facilities communicate about general conditions, such as during COVID-19, but updates should be specific and tailored to each resident. This is supported by earlier literature showing that personalized relationships between nursing homes and care partners allows for sensitive and individualized care of residents, including the incorporation of their preferences into daily care routines (Chen, Sabir, Zimmerman, Suitor, & Pillemer, 2007).

The roles that families provide cannot be replaced by paid staff because no employees have the depth and longevity of relationships that care partners have with residents. Care partners are essential, and the future of long-term care needs to maintain access for them during public health emergencies and recognize their roles at all times. Several states have proposed essential caregiver legislation. This type of legislation should be approached cautiously to avoid harm. It must ensure current residents' rights by allowing them to choose when, where, and how to have visitors. Such legislation must ensure the resident, or in the case of a resident with cognitive impairment, their decision-maker, maintains control over identifying their designated essential caregiver. As such, policy stipulations must not be overly prescriptive as to who can be an essential caregiver. Policies that limit caregivers to family members discriminate against those who would prefer to have friends or who lack relations. Whether essential caregiver legislation is passed or not, incorporating care partners into care planning routines is our best chance for improving care and for preventing the stress and isolation of COVID-19 to happen again.

Limitations

There are a few limitations worth noting. First, recruitment methods via social media excluded friends and family members who do not use those types of communication, which might disadvantage some older spousal care partners, those from less financially advantaged backgrounds, or those from more rural/less developed regions. Second, our recruitment methods led to an interview sample that was entirely female. Their roles varied, including daughters, wives, and a mother, as did their ages, but they were all female, which is unusual even as the disproportionate amount of care work remains gendered. Third, this study lacks the perspective of residents whose preferences should be the first priority in all person-centered nursing home care. Fourth, the sample included here are a mix of dementia and non-dementia care dyads, which could present differing perspectives and varying experiences, particularly as they focus on communication. Lastly, the care partners who participated in this study were from different states, which suggests differing COVID-19 policies and procedures impacted individual experiences.

Conclusions and implications

Family care partners are essential for quality of life and quality of care for nursing home residents. During the COVID-19 pandemic, and its visitation restrictions, the families in this study reported that they and their loved ones experienced preventable harm and that they lost irreplaceable time together. The right to visitation is *primary* yet it was quickly and comprehensively dismissed in the interest of public health. We cannot change what happened during the COVID-19 pandemic, but in future emergencies, we must ensure an adequate supply of PPE for staff, so there is available protection to allow a reasonable amount of family visitation, and other procedures, such as essential caregiver legislation, that will solidify these valuable visits into public health protections. We must do this work now so that families and residents are

[2] Arizona, Delaware, Florida, Illinois, Indiana, Michigan, Minnesota, Missouri, Nebraska, New Jersey, Oklahoma, Oregon, Rhode Island, South Dakota, Tennessee, Texas, and Washington.

never again in a situation that denies them contact, time, and support.

Declaration of Competing Interest

The authors have no funding to report.
The authors have no conflicts of interest to report.

Acknowledgements

The authors wish to acknowledge the family members that courageously shared their stories with us.

Appendix A. Qualitative interview questions

No	Interview questions
1	Can you tell me about your pattern of visits to the facility prior to March 13th of 2020?
2	What's a typical communication from the facility look like, prior to March 13th, 2020?
3	How the nursing home communicated changes to you about the visitation policy?
4	How has the facility communicated with you about conditions in the facility?
5	How have the facility communicated with you regarding the health of the resident?
6	Has the resident been sick with COVID?
7	Have there been any cases of COVID-19 in your resident's nursing home?
8	What did your communication with the resident look like?
9	What social supports has your family been receiving?
10	How had your resident been impacted by the change in visitation policy?
11	How have you been impacted by the change in visitation policy?
12	Did stopping the visitors make the resident safer from COVID?

Appendix B. Electronic survey questions

No	Survey questions	Response options
1	What is your relationship to the person or persons you have in the nursing home? [Choose all that apply] Are they your:	1 – Parent 2 – Spouse 3 – Child 4 – Friend 5 - Other
2	If you answered other to the above question, please fill in your relationship to the nursing home resident.	Open-ended
3	What was your pattern of visitation prior to March 13, 2020? (How often did you visit the nursing home resident?) If you checked more than one nursing home resident, answer for the one you visited most frequently.	1 - Daily 2 - More than once a week 3 - weekly 4 - More than once a month 5 - Less than once a month
4	What is the MOST FREQUENT way you have connected with your nursing home resident since March 13, 2020?	1 - Phone 2 - Facetime/Video chat 3 - Window visit 4 - In-person indoor visit 5 - In-person outdoor visit 6 - Other
5	If you answered other to the above question, please fill in how you have connected with your nursing home resident.	Open-ended
6	Has the nursing home provided adequate ways for you to connect with your resident since March 13, 2020?	1 - More than adequate 2 - Adequate 3 - Less than adequate
7	Would you be willing to participate in a virtual (phone call or video) interview describing your experiences?	1 - No 2 - Yes
8	What is the best way for the researcher to reach you?	1 - Email 2 - Phone

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