

Research Article

ADVANCE-C: A Qualitative Study of Experiences Caring for Nursing Home Residents with Advanced Dementia During the COVID-19 Pandemic

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Abstract

Objectives: Assessment of Disparities and Variation for Alzheimer’s disease Nursing home Care at End of life (ADVANCE) is a multisite qualitative study of regionally diverse Nursing homes (NHs; $N = 14$) providing varied intensity of advanced dementia care. ADVANCE-C explored the experiences of NH staff and proxies during the COVID-19 pandemic.

Methods: Data collection occurred in five of the ADVANCE facilities located in Georgia ($N = 3$) and New York ($N = 2$). Semistructured qualitative interviews with NH staff ($N = 38$) and proxies of advanced dementia residents ($N = 7$) were conducted. Framework analyses explored five staff domains: care processes, decision making, organizational resources, vaccinations, and personal experience, and five proxy domains: connecting with residents, NH response, communicating with NH, decision making, and personal impact of the pandemic.

Results: Staff mentioned difficulties implementing infection control policies specifically for advanced dementia residents. Staff reported trust between the facility and proxies as critical in making decisions during the pandemic. All staff participants spoke about “coming together” to address persistent staffing shortages. Proxies described their role as an “emotional rollercoaster,” emphasizing how hard it was being separate from their loved ones. The accommodations made for NH residents were not beneficial for those with advanced dementia. The majority of proxies felt NH staff were doing their best and expressed deep appreciation for their care.

Discussion: Caring for advanced dementia residents during the COVID-19 pandemic had unique challenges for both staff and proxies. Strategies for similar future crises should strive to balance best practices to contain the virus while maintaining family connections and person-centered care.

Keywords: COVID-19, Dementia, Nursing homes

Nursing homes (NHs) have experienced devastating impacts of the COVID-19 pandemic. Although less than 0.5% of the U.S. population live in NHs, NH residents accounted for as much as 40% of COVID-19 deaths at the height of the pandemic (Grabowski & Mor, 2020). The most frail and vulnerable NH residents, such as those with advanced dementia, are at highest risk of acquiring and dying from COVID-19 (Panagiotou et al., 2021). There are more than 860,000 Americans living with dementia in NHs, comprising 61.4% of the NH population. Moreover, 36.6% of NH residents have advanced dementia characterized by severe cognitive impairment and functional disability (U.S. Centers for Medicare and Medicaid Services, 2016). These residents with advanced dementia are unable to advocate for themselves, cannot reliably communicate symptoms, and are completely dependent on staff for all their care needs (Mitchell et al., 2009). Thus they may be especially negatively affected by insufficient staffing, isolation, and deficiencies in care due to the COVID-19 pandemic, particularly when their family advocates cannot visit.

Throughout the pandemic, NHs struggled with the urgent need to make compassionate and effective management decisions, maintain communication with family, and protect the safety of residents and staff (Grabowski & Mor, 2020). Prominent national media reported widespread chaos and burden in the NH setting, highlighting overwhelming infection and death rates among NH staff and residents (Berger, 2020; De Freytas-Tamura, 2020; Engelhart, 2021). This crisis also highlighted racial disparities in NH care, with more Black residents suffering with the virus (Abrams et al., 2020; Gebeloff et al., 2020; White et al., 2020a). Little is known about the intersecting challenges of COVID-19, advanced dementia, and disparities in NH care.

The Assessment of Disparities and Variation for Alzheimer's disease Nursing home Care at End of life (ADVANCE) National Institute on Aging-funded study was a large qualitative study that sought to better understand the drivers of well-documented regional and racial disparities in intensity of care provided to Black and White NH residents with advanced dementia (Hendricksen et al., 2021; Lopez et al., 2021, 2022; Rogers et al., 2021). ADVANCE used nationwide databases to purposefully select 14 NHs within four hospital referral regions (HRRs) across the United States with varied intensity of advanced dementia care quantified by feeding tube and hospital transfer rates in this population. ADVANCE-C was a supplement grant that leveraged the unique cohort of diverse NHs and research infrastructure from ADVANCE. The aim of this study was to explore NH staff and proxies experiences caring for these residents with dementia during the pandemic across multiple domains.

Method

We used a qualitative descriptive study design (Sandelowski, 2000, 2010). This study was approved by Advarra Institutional Review Board.

Facility Recruitment

The methodology of the main ADVANCE study is described elsewhere (Lopez et al., 2021). Briefly, we used the 2016–2017 Minimum Data Set aggregated to the NH level to quantify intensity of care for this population based on feeding tube and hospital transfer rates among residents with advanced dementia. High- or low-intensity HRRs were defined as above or below the national median hospital transfer and tube-feeding rates for residents with advanced dementia, respectively. High- and low-intensity facilities were defined as above or below HRR median hospital transfer and tube-feeding rates for residents with advanced dementia, respectively. From the HRRs included in ADVANCE, we selected one high-intensity HRR located in Georgia (GA) and one low-intensity HRR located in New York (NY) and aimed to recruit two high-intensity facilities and two low-intensity facilities within each HRR and the same staff and proxies who participated in ADVANCE.

Participants

We aimed to conduct semistructured interviews with staff in each facility from a range of disciplines, including directors of nursing, administrators, social workers, registered nurses (RNs), and licensed practical nurses (LPNs), certified nursing assistants (CNAs), and medical providers (physicians, physician assistants [PAs], and nurse practitioners [NPs]). Staff eligibility criteria were as follows: > 21 years, communicated in English, and cared for residents with advanced dementia for >2 months. NH administrators identified and scheduled interviews with staff at their convenience. We also aimed to recruit one Black and one White proxy from each facility, which we defined as the individual listed as the designated decision-maker for residents with advanced dementia. Administrators reached out to eligible proxies for residents with severe cognitive impairment (Cognitive Functional Scale score of four; Thomas et al., 2017) and NH stay >100 days, age > 21 years, and able to communicate in English. The research team contacted proxies who agreed to participate and arranged interviews.

Data Collection

Data collection occurred from October 2020 through March 2021 during staggered 2-week periods at each facility. The data collection team included two Masters-prepared researchers (one Black and one White race) trained in qualitative methods.

Semistructured, digitally recorded, qualitative interviews were conducted via Zoom or telephone. Verbal consent was obtained from participants, and they were given a \$25 gift card. Interview guides for staff and proxies comprised open-ended questions focused on “*a priori*” domains (see Supplemental Materials). The five staff domains were as follows: decision making; organizational resources; care processes; vaccinations; and personal impact. The five proxy domains were as follows: connecting with residents;

NH response to the crisis; communicating with NH; decision making; and personal impact of the pandemic.

Data Analysis

Recorded interviews were transcribed and checked for accuracy. Data were analyzed by four investigators with formal training in qualitative analyses including two interviewers (M. Hendricksen, H. Akunor) using framework analysis methodology (Gale et al., 2013). Transcripts were coded independently by two analysts and interrater reliability assessed using the coding comparison query in NVivo version 12 (QSR International Pty Ltd., 2018). Discrepancies were discussed until consensus was reached. Analysis consisted of open, thematic, and matrix coding (Miles & Huberman, 1994). In open coding, raw data were grouped to create large, discrete themes initially guided by our “*a priori*” domains. In thematic coding, themes were identified and refined. In matrix coding, themes were displayed on two-dimensional matrices and compared across HRRs, NHs, and proxy racial groups. Evolving themes and results were discussed with the entire research team, which

included qualitative methods and nursing home experts (R. Palan Lopez, S. L. Mitchell).

Results

Of the eight facilities in the two HRRs, five facilities agreed to participate; two high-intensity facilities (NY1 and GA1), and three low-intensity facilities (NY2, GA2, GA3). Characteristics of staff and proxy participants are shown in Tables 1 and 2. Staff interviews averaged 37 min (range, 20–56 min). Of the participating staff ($N = 38$), 11 identified as Black, 22 were White, and were from the following disciplines: administrators ($N = 5$), directors of nursing ($N = 5$), social workers ($N = 5$), nurses (RN/LPN) ($N = 10$), CNAs ($N = 7$), prescribing providers (physician/PA/NP; $N = 4$), and other ($N = 2$, activities director, resident care coordinator). Proxy interviews averaged 27 minutes (range, 18–41 min). Of the participating proxies’ ($N = 7$), 42.8% identified as Black, 57.1% were White, and included spouses ($N = 2$), adult children ($N = 3$), and other relationships ($N = 2$).

Table 1. Characteristics of Facilities and Nursing Home Staff Participants in ADVANCE-C

	Facility				
	GA1 $N = 8$	GA2 $N = 8$	GA3 $N = 8$	NY1 $N = 8$	NY2 $N = 6$
Facility characteristics					
Bed size ^a	Small	Small	Medium	Large	Medium
Advanced dementia residents tube-fed, %	12.6	0.0	4.1	5.3	0.0
Number of hospital transfers among advanced dementia residents per person-year	1.2	0.1	0.6	0.4	0.2
Staff characteristics					
Mean age, years (SD)	45.9 (12.4)	48.4 (10.9)	48.0 (6.9)	48.1 (9.9)	44.8 (12.8)
Sex, N					
Male	1	2	1	1	0
Female	7	6	7	7	6
Race, N					
Black	1	6	2	1	1
White	7	2	5	6	2
Other ^b	0	0	1	1	3
Occupation, N					
Administrator	1	1	1	1	1
Director of nursing	1	1	1	1	1
Nurse (RN/LPN)	2	2	2	2	2
Certified nursing assistant	1	2	2	1	1
Social worker	0	1	1	1	1
Prescribing provider	2	1	1	1	0
Other ^c	1	0	0	1	0
Mean years working in long-term care	17.4	24.2	12.8	18.6	14.3

Notes: GA = Georgia; NY = New York; LPN = licensed practical nurse; RN = registered nurse; SD = standard deviation.

^aBed size categories are based on the distribution of sample: small = 85–125 beds; medium = 126–200 beds; and large > 200 beds.

^bOther race includes Asian and Hispanic ethnicity.

^cOther occupation includes one resident care coordinator and one activities director.

Table 2. Characteristics of Proxy Participants in ADVANCE-C

	Facility				
	GA1 N = 2	GA2 N = 1	GA3 N = 2	NY1 N = 2	NY2 N = 0
Proxy characteristic					
Mean age, years (SD)	77.0 (0)	79.0 (0)	65.0 (12.7)	66.5 (3.5)	—
Sex, N					
Male	1	0	0	0	—
Female	1	1	2	2	—
Race, N					
Black	1	0	1	1	—
White	1	1	1	1	—
Relationship to resident, N					
Partner/spouse	1	1	0	0	—
Adult child	0	0	1	2	—
Niece/cousin	1	0	1	0	—

Notes: GA, Georgia; NY, New York; SD = standard deviation.

Although ADVANCE-C aimed to explore differences in staff findings by HRR and facility intensity, and proxy findings between Black and White proxies, matrix analyses did not show discernible patterns or differences along these parameters. Thus, results are described for staff and proxies in all facilities without reference to HRR or NH intensity of care or proxy race.

Staff Experiences

Decision making: “The family has to be able to trust us”

Because residents with advanced dementia cannot communicate for themselves, staff frequently referred to the importance of having a connection with proxies when making decisions related to hospital transfers, advance directives, and care planning. Staff also recognized the importance of having the proxies’ trust. This was especially relevant in discussions around advance directives and care planning. All facilities readdressed care plans and advance directives during the pandemic. Some facilities had processes in place to readdress advance care plans regularly, others implemented processes specifically for the pandemic. Visitors were not allowed into the facilities, so proxies had to rely on and trust the staff reports of the residents’ with advanced dementia status and video calls with the resident to make decisions. As an administrator (NY2) said:

And so it’s a whole lot more communication between because if the family come in and able to see their loved one it is much easier to portray the picture, um, advanced dementia, as well as the decline in the progression of the disease process. Versus now it’s basically through the little Zoom visit ... the family has to be able to have that trust in us that we speak on the, uh, what is best for the resident on behalf of the resident.

Another nurse practitioner (GA3) further described the challenges around Zoom visits and the importance of the proxy trusting the staff reports of the resident’s status while having to make decisions about care for someone with advanced dementia like this:

... you know ... you just, uh, give them what you see ... you have that sense of trust because you’ve been dealing with them for a while. And so they trust your observation, they do trust the staff as well. So it makes a huge difference ... you know, and they do have the Zoom calls so they can see, you know... [but] she was sleeping the whole time, I could barely get her to wake up, she was rattling during the call. Um, and then they’d make the decisions based on that ... and they make the decision on, you know, on whether to transfer the patient or not.

Organizational resources: “We all came together”

The major organizational resource available to staff was their ability to pull together as a team. All facilities reported experiencing grave staffing shortages throughout the pandemic, due to staff quitting out of concerns for their safety or their family’s safety, unemployment offering higher reimbursement, or staff needing to quarantine during facility outbreaks, “there’s times where we had over 56 staff members out at one time” (NY1).

Despite these shortages, all staff participants discussed how their team took an “all hands on deck” approach, utilizing nonclinical staff to assist with care, such as administrators and social workers assisting residents with advanced dementia with feedings and providing direct care when needed. Many described how this brought their team closer together. For example, one social worker (NY2) mentioned:

... you had directors and management and administration that were, you know, going to the floors and ... working weekends and helping with feeding when we had staff out with COVID ... I think it really brought everyone closer together.

Another administrator (GA1) described:

I really feel like that we have come together as a team ... we've gotta do whatever we've gotta do to keep these residents safe.

Care processes: "You have to become even more family"

Staff reported difficulties with adaptations in care that did not benefit and were even detrimental for residents with advanced dementia. For example, all facilities reported using video calls, phone calls, window visits, and scheduled, socially distant outdoor visits to maintain connections between residents and families. However, staff noted that although these interactions were sometimes helpful for families, they were largely ineffective for residents. Residents with advanced dementia were unable to hear their families due to social distancing, recognize their faces due to masks, or receive their physical touch; a common way for families to communicate affection for these residents who cannot understand their surroundings. One NP described (GA2):

We had a number of family members that ... stopped scheduling the calls just because there was no connection there ... they basically were looking at a picture of their loved one ... So we did have a number of family members that had just decided ... that it was doing more ... emotional harm to them personally than it was good for the resident.

Staff also reported SARS-CoV-2 testing as especially challenging for residents with advanced dementia. Because these residents could not understand what was happening to them during nasopharyngeal swabs, it was very difficult for staff to test for the virus. Many residents with advanced dementia had to be restrained, and others were too combative to test them regularly. The residents' suffering and anguish was emotionally distressing for staff. One social worker (GA2) described:

... for this person to scream bloody murder, you're sticking something in their nose and they're confused, you know, that really hurt me to the point that I was emotional.

Many staff talked about the significant impact of isolation on residents with advanced dementia. Staff reported that residents lacked the normal social cues to eat during meal times, which contributed to significant weight loss. They also perceived more rapid cognitive decline than usual. One administrator (NY2) mentioned that antipsychotic

use increased trying to manage worsened behaviors among their residents with dementia.

... we were doing really doing great on the use of anti-psychotics, that definitely went up ... people definitely got more medication and more depressed during the pandemic.

While caring for residents with dementia, staff also reported difficulty connecting with residents while having to wear masks, because residents could no longer see their faces/smiles. As this NP (NY1) described:

... wearing a mask and a shield going into a room, I can't interact like I would or make someone feel comfortable with my smiles ... You know, you feel a barrier just because there is a barrier.

Due to these particular challenges for residents with advanced dementia, staff reported needing to "become even more family" or a type of surrogate family member. Many staff felt it was even more important throughout the pandemic to spend more time with residents with advanced dementia because families were unable to visit. A nurse (GA2) said:

At that time, you got to be a family member. Not only a caregiver, but you got to be a family member. Because their family members couldn't be there.

A director of nursing (GA1) described:

We've had to step up more and be more of a family to these residents ... but because literally their family can't come here, we I think have all taken it personal to love 'em even more, care for 'em even more, show 'em the family love more.

Staff also discussed how government guidelines negatively affected their care processes. One LPN (GA1) said keeping up with the changing guidelines "was a full-time job." Others felt the guidelines were important to keeping the virus from spreading. Some staff reported extreme frustration with the restrictiveness of government guidelines. As one CNA (GA3) expressed:

They've made us imprison them, take away all their rights, put them in their room, not let them have any interaction with others except for the person that they're in the room with. For months, for almost a whole year now.

Vaccinations: "It was chaotic"

At the time of data collection, vaccines were not available in two facilities (NY2, GA3). In the others (NY1, GA1, GA2), many staff reported discomfort at being among the first group to be vaccinated. Almost all administrative and leadership teams were vaccinated, but many staff reported initial reluctance about getting a vaccine. As one social

worker (NY1) stated, “People wanna see ... the rest of us go through it first and see how it went ... we are seeing more people want it now.” Facilities partnered with pharmacies, but administrators reported the first vaccine rounds were “chaotic,” “rushed,” and “unorganized.” One administrator (GA2) described disappointment with how delayed vaccines coincided with a facility outbreak of COVID-19:

You know, how many lives could have been saved ... had the [vaccine] came to us sooner as promised, or at least initially promised ... the response plan from the federal and the state level [was] so uncoordinated.

Personal impact: “I bear an enormous burden”

All staff discussed the difficulty of caring for residents through the pandemic. They described the emotional toll of caring for dying residents with dementia, the burden of shifts lasting 12 hr or longer, and symptoms of burnout. As one CNA (GA3) described:

... months and months of it. And just watching the decline ... and people die. It just weighs on you ... some days I'll leave here and ... just cry on the way home. I feel terrible about it. I bear an enormous burden and a sense of guilt over it ... because, you know, I can't do anything about it.”

Staff in the Georgia facilities reported faith as a source of comfort to help deal or cope with the stress. In one NH (GA3), a CNA said “I pray, I ask God to give me strength to make it through the day,” while the social worker described having “daily conversations with God about, about [the stress of caring for residents], and how it is.”

Although many staff did not express concerns for their personal safety, others expressed concerns about bringing COVID-19 home to their loved ones, especially to vulnerable family members (medically ill, elderly, and very young). An LPN (GA1) said, “I didn't feel safe going home [after work] and then I didn't feel safe coming back here because I have children and grandchildren.”

Proxy Experiences

Connection with resident: “We'll be there as soon as they'll let us”

Proxies reported NHs trying various ways to maintain connections with residents, including video calls, outdoor visits, and very limited, socially distant indoor visits. Although some proxies reported that these visits were helpful, many said not being able to see residents in person was extremely difficult, and that they were waiting for visitor restrictions to be lifted. Some proxies mentioned that time was limited with their loved ones because they were at the end of their lives, making the lack of visiting especially difficult. One proxy (NY1) described:

I have to tell her that, “We'll be there as soon as they'll let us come in”... It's very hard, you know, she doesn't understand. And it's harder, I guess, because I know she doesn't have that much more time, that she'll know us, and we wasted a year because of COVID.

NH response: “They did the very best they could”

In general, most proxies overwhelmingly felt NHs did the best they could under the circumstances and empathized with NH staff. One proxy (GA1) described concerns for not only their loved one, but for the health and well-being of staff:

... they've done an excellent job, because they've only had one outbreak of COVID. [Resident] did not have COVID ... it's hard for me not being able to go, but I understand the situation they're in and I know how contagious this is.

However, proxies in one NH (GA3) described how mistrust of the facility staff, combined with the inability of the resident with advanced dementia to advocate for themselves, contributed to worry about whether their loved one was receiving the best care possible.

... are they sincerely caring for her, are they jerking her around, and just because she can't communicate ... some of the ... people are in the wrong calling, if that makes any sense. I think you got to have that in your heart and you mind, to be a good caregiver.

Communication: “They always let us know”

The majority of proxies were very satisfied with availability and frequency of communications with frontline and administrative staff. One proxy said, “I talk to them every day. And they share with me, you know, everything ... my communication with them could not be any better” (GA1). Proxies reported receiving phone calls, emails, and video meetings that included updates on their resident's condition as well as facility COVID updates. One proxy (NY1) described how phone calls from NH staff made them feel like they knew what was happening during the time they were not allowed to visit the facility.

I think they've done a good job of, is just keeping me abreast of what is going on with her. Um, you know, all of the times she was tested for COVID. They would call and say, you know, “She tested negative.”...I don't know, they just seem to check in often—so that, while I can't see her, I know what's going on.

Decision making: “They know our wishes”

Almost all proxies reported not having to make decisions around hospital transfers, care planning, or resuscitation because the resident's and proxy preferences were already

known and documented. A proxy in the south (GA3) described how having their resident's preferences on file from admission made them feel more confident about having to make a decision around hospitalization should the decision arise: "[resident's hospitalization preferences] is in their file. They've got all of it. They know our wishes."

One proxy (NY1) did hospitalize their loved one and described the decision as traumatic because the resident could not understand what was happening or advocate for herself:

They sent her to the hospital and because she can't read, she can't write, she doesn't understand, and they're asking her questions, it was very, very traumatic ... and the doctor ... was trying to ask her questions because he wanted to give her an MRI, and she can't answer them. So it was very traumatic.

Personal impact: "It's been a rollercoaster"

All proxies described feeling stressed and very emotional, "emotionally ... it's been a rollercoaster" throughout the pandemic. Without the ability to see their loved ones whenever they chose and the toll of being separated from their family support systems, proxies described video calls with the residents as heartbreaking:

I do video calls and everything, but ... if I sit here and say it wasn't difficult, even with me having the best experience, it's still ... difficult and I appreciate you calling because I don't think I've expressed how I felt about this. (NY1)

Another proxy (GA2) described the stress of worrying about their family member getting COVID-19, and not being able to connect with them:

... it's been a real real hard go of it, because, you know, I worry about how she's doing and if she would get it [COVID-19] ... And um, not being able to see her, touch her, you know, just converse with her closely. It's been extremely hard.

Discussion

This unique qualitative study sheds light on the experience of caring for residents with advanced dementia during the COVID-19 pandemic. Our findings highlight (a) the importance of developing dementia-specific policies and procedures for future crises, (b) the critical nature of communication to both quality of care and the experiences of family of NH residents with advanced dementia, and (c) the detrimental effect of social isolation on both residents and proxies. NH staff experienced ubiquitous challenges providing care for this vulnerable population regardless of region and facility intensity. Staff reported common adaptations made for residents during the pandemic,

such as window visits and video calls, were not effective in maintaining connections for residents with advanced dementia. However, technology played a critical role in maintaining frequent communication, via phone calls, video calls, and emails, for the decision makers of NH residents with advanced dementia. Proxies of residents with advanced dementia indicated that although facilities were doing their best to try and to maintain personal connection, they felt especially isolated from their loved ones throughout the pandemic. Staff and proxies stressed that the separation and isolation of NH residents with advanced dementia from their families due to infection control guidelines was detrimental to not only the health of residents, but the well-being of the proxy. Both staff and proxies emphasized that mutual trust was critical for making decisions regarding residents' care during the pandemic.

This report extends prior literature regarding NH staff experiences during the pandemic by providing a deeper understanding focused on the impact of caring for residents with advanced dementia. Similar to previous research, staff reported concerns of bringing the virus home to their families, and a deep sense of empathy and concern for residents in their care (White et al., 2020b, 2021; Panagiotou et al., 2021). However, staff encountered substantial challenges specific to advanced dementia such as testing these residents for the virus, keeping their masks on, and keeping them isolated in their rooms. The ability of residents with advanced dementia to comprehend precautions precluded successful implementation of infection control protocols. Most staff reported that isolating residents with dementia was particularly challenging and had unforeseen outcomes. Consistent with national media reports (Healy et al., 2020; Wan, 2020), NH staff perceived more rapid decline in cognitive status and weight loss among residents with dementia due to the lack of social interaction. Taken together, the staff experience underscored the need for dementia-specific considerations for future NH emergency preparedness plans.

The majority of proxies expressed satisfaction with NH communication, and the critical role communication played instilling their trust in staff. Contrary to media reports of families kept in the dark about their loved one's status in NHs during the pandemic (Shih Bion, 2020), our findings indicate proxies felt that NHs continually updated them on resident's status and any facility changes. The unique needs of proxies of NH residents with advanced dementia should be noted, understanding that these residents have limited life expectancy, proxies consistently reported distress regarding missing out on their loved ones remaining days, adding to the emotional burden they carried through the pandemic.

Limitations of the study merit comment. We used best methodological practices (triangulation, double-coding, team consensus) to mitigate biases found in qualitative analyses. Nevertheless, these findings are limited to participating NHs and individuals who consented to be

interviewed, but do include the experiences of diverse NHs, staff, and proxies. Moreover, we may not have captured prevalent racial differences in experiences between Black and White proxies due to the small number of participants. Lastly, due to restrictions we were unable to conduct any physical observations in participating facilities, therefore our findings rely solely on staff reports of experiences in the NHs.

This study provided a unique opportunity to understand experiences of NH staff and proxies of residents with advanced dementia during the COVID-19 pandemic in facilities in different regions of the United States with differing intensity of care. Staff consistently described the heavy emotional burden of caring for residents with advanced dementia and underscored the importance of considering the psychological consequences of the trauma they experienced throughout the pandemic. Overall, the findings suggest staff and proxies felt that facilities were doing the best they could with the resources available to them with an all hands-on-deck approach to providing care, especially for residents with advanced dementia. While hospital staff and other frontline healthcare workers were touted as heroes, NH staff were often vilified in the media (De Freytas-Tamura, 2020; Rabin, 2021; White et al., 2021).

In the wake of the pandemic, 2,405 staff and 153,445 NH residents have died from COVID-19 to date (U.S. Centers for Medicare and Medicaid Services, 2022). The pandemic shone a harsh light on critical flaws in the U.S. NH system and further exacerbated long-standing inequities of its most vulnerable residents, particularly those with advanced dementia. The pandemic also renewed calls for widespread system transformation and heightened focus on emergency preparedness for future public health emergencies (e.g., pandemic influenza, bioterrorism) and natural disasters (e.g., floods, hurricanes, earthquakes, wildfires). This report emphasizes the need for dementia-specific strategies to improve NH preparedness for future crises (National Academies of Sciences, Engineering, and Medicine, 2022). It further underscores the need for increased support for NH staff from policy-makers and clinicians; a demand that will surely continue following the pandemic (Grabowski & Mor, 2020). Challenges NH staff and proxies faced throughout the COVID-19 pandemic exacerbated the burden and stress they experience and are likely to contribute to continued staff shortages and increased rates of caregiver burnout in the future. It is critical that dementia-specific strategies strive to balance best practices to mitigate future crises while maintaining family connections and person-centered care for this vulnerable population.

Supplementary Material

Supplementary data are available at *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences* online.

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Author Contributions

M. Hendricksen participated in all aspects of the study including conducting interviews, data analysis and interpretation, and drafting the manuscript. S. L. Mitchell designed the study, obtained funding, and contributed to the interpretation of findings and critical revision of the manuscript. R. P. Lopez designed the study, obtained funding, supervised data analysis, and contributed to interpretation of findings and critical revision of the manuscript. A. Roach contributed to data analysis and interpretation of findings. A. H. Rogers contributed to data analysis and interpretation of findings. H. Akunor conducted interviews and contributed to data analysis and interpretation of findings. E. P. McCarthy contributed to development of interview guides, supervised data collection, and contributed to interpretation of findings and critical revision of the manuscript.

Conflict of Interest

None declared.

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