



5 CARING FOR PEOPLE WITH DEMENTIA DURING COVID-19

Dena Shenk, Andrea Freidus, and Christin Wolf

A Life Enrichment Manager’s Perspective on the COVID-19 Pandemic and the Quality of Life of Memory Care Residents, by Logan Diard

Living a life affected by dementia can be akin to being in a prison. The answers to questions that those without dementia take for granted will never be answered. “Where am I? When am I? Who am I?” A resident with dementia will search through their functioning mental faculties to answer these questions. Often, this will result in residents turning the environment into something more befitting the reality that they feel. The senior living community or residence can be transformed into an airport, a hospital, a Department of Motor Vehicles, or a school in the mind of someone living with dementia. The common theme linking these perceived locations is waiting and a lack of control. The staff of these communities have to do their best to contend with this already perceived hostile environment and somehow flip the script for residents to create a climate of warmth and understanding. This is the best way to counteract behaviors that can crop up as by-products of the dementia diagnosis and at the same time allow caregivers the ability to perform the care needed to afford residents dignity and safety.

The paragraph above is a brief description of what memory care communities and residents across America faced on a daily basis before COVID-19. As a Life Enrichment Manager in a memory care community, I had already seen firsthand that living or working in an environment that can already be stereotyped as a prison comes with plenty of challenges and stress for all involved. As soon as the threat of COVID-19 was imposed on these communities in early 2020, the feelings of isolation and imprisonment seemingly intensified. Residents were confined to their rooms, quarantined from their own neighbors and their loved ones. Participating in community social programs and eating in community-wide dining rooms were completely suspended. Even interactions with em-

ployees were limited to only the essential, and the encounters that were had, were hidden by masks.

This left all senior living residents in isolation. None were more impacted by this isolation than residents with dementia. Their ability to understand and rationalize their environment is already affected by the disease itself. Add the COVID-19 restrictions along with the fact that most family interactions were reduced to zero on top of this and the average memory care resident was left with no idea why they had to stay in their room at all times and why they were completely unable to see their loved ones. Often, in an effort to understand this new restrictive environment, residents would assume that they had done something wrong and were being punished, or that their families and loved ones had completely abandoned them. Depression, which is already rampant in senior living, increased in severity and with little to no social interaction, residents changed their behavior to sleeping or being in a subdued state 24/7. Both depression and excessive sleep can increase the speed of disease progression of dementia.

In the memory care community where I worked, this severe isolation lasted over a year from March 2020 to April 2021. During this period, we experienced COVID-19 outbreaks twice, resulting in the deaths of ten residents. Others who were infected had long fights to regain their health, and some were not able to make a full recovery. In April 2021, restrictions were lessened after vaccinations had been administered throughout the community. The initial change was for residents to be allowed out of their rooms into the common areas together. Family members were still not allowed in at this point, but some routines of normalcy were resuming, such as eating meals in the dining rooms and small group programs.

The residents who emerged from this isolation were not the same as those who entered. As the Manager of Life Enrichment, I saw this in a variety of ways. Programs that would get large group participation were received with blank stares and the metaphorical sound of chirping crickets. Residents' appetites had greatly diminished and food-centered socials ended with the residents' plates still full. More cognitively complicated programs such as trivia or interactive, multistep crafts became nigh impossible. Even the behaviors associated with dementia shifted. Before the pandemic, exit seeking [to get off a locked unit] and sundowning behaviors¹ were elaborate and filled with fervor; now these same responses were often dampened and coming from a place of depression. The worst were the residents who emerged fully hollow, unable to accurately perceive and interpret their environment to even exhibit such behaviors. All these responses came from the same residents who would actively participate in most programs only a year earlier. As time has continued to

march on from this initial lifting of restrictions, a new sense of normalcy has settled in. Slowly, families were allowed back into the community, group programs were expanded in size, and outings outside the community were once again permitted. Still, the number of residents lost and affected by the isolation is hard to ignore. The residents who I witnessed experience the full year of isolation were permanently affected.

Now that the dust has settled, it is hard to determine whether the right things were done during that initial year of isolation and fear. However, I am not writing this to point fingers in the rearview. An incident such as this is unprecedented, and only so much can be done when passing through and beyond the event horizon. Now that we are on the other side, so to speak, the important task is to learn what worked and what did not in order to be better prepared for future pandemics. When trying to do so, I do my best to remain aware of two points. First, that the severity of COVID-19 to this population was not overexaggerated and that it was a serious threat requiring a serious response. Second, the response at times was just as bad if not worse than the disease itself. To many residents, their quality of life directly hinged upon the ability to spend time with loved ones. Many memory care residents' quality of life focused on not only that key interaction between them and their loved ones but also interactions among their neighbors and the employees seeking to care for them. With these relationships severed completely, the average dementia resident was left with nothing. The residents who were able to endure survived, but from my perspective, something was lost in the process. This is why I am happy to be a part of this written work; it aims to take a realistic look at the pandemic as a whole. No sides shall be taken. Experiences can be presented as just that—a unique human perspective from which we might learn how to better respond to detrimental circumstances in the future. My hope for future pandemic-level events is that we can seek to preserve that environment where residents are able to exercise their self-identity, be able to retain their dignity, and have control of their surroundings to the best of their abilities, all while retaining their safety from harmful threats such as both isolation and viruses akin to COVID-19.

Reflections on the COVID Experience from a Physician's Assistant, by Robyn Wolkofsky

"Helpless" does not adequately describe the feeling of watching the climbing number of nursing home deaths dominate the news cycle, and hearing literal cries of caregivers through the phone during the early days of the COVID pandemic. We quickly realized our patients in long-term

care were the most vulnerable. It seemed that once the virus breached the facility doors, these units became an incubator of disease, COVID relentlessly claiming lives in its wake. For months, essential information needed to control the pandemic was unknown: the mode of transmission, how to prevent spread, treatment protocols, and how to procure adequate PPE. For the first time in my career, there was no evidence-based journal, article, or website to reference for answers, options, and treatment plans.

I felt pangs of guilt and anxiety, mixed with gratefulness and determination, working from home trying to care for my patients and their caregivers, while colleagues risked their health and that of their families working on the front lines in hospitals and emergency rooms. Those of us in health care were looked to as experts to decipher conflicting information that was being disseminated regarding testing, quarantines, vaccines, masks, and office policies. At the same time, there was a growing mistrust of healthcare professionals and agencies in the national news and social media. The contentious political climate deeply affected the responses of caregivers and family members to our recommendations.

My medical practice went virtual overnight. Video appointments were often with caregivers, as it was nearly impossible for long-term care staff to access the technology required for these calls with patients. After speaking with a family caregiver, I would call the facility nursing staff to obtain an update on the patient, reconcile medications and give orders, followed by another call to family to convey what I had learned about their loved one, which was often more than they had heard for weeks. This cycle of phone calls with families and facilities was an admittedly mediocre, inefficient, but necessary substitute for physical exams and patient interviews. I counseled and reassured caregivers despite having imperfect information of the situation happening behind the facility walls.

Connection and engagement, keys to staving off decline, and enhancing quality of life for people living with neurodegenerative diseases such as dementia, were stolen from them during the pandemic. Regular physical therapy, critical to prevent falls and skin breakdown, had to be discontinued. Residents were isolated in their rooms. People in declining health before the pandemic often died alone after days of severe illness and isolation.

People with cognitive challenges are exquisitely perceptive, as if their heightened awareness overcompensates for loss of reasoning and understanding of their environment. Behavioral, non-pharmacologic approaches by well-trained caregivers have been shown to reduce the need for medication to treat behavioral and psychiatric symptoms. However, during the pandemic, reports from memory care facility staff of patient agitation and depression were rampant. Masked faces took the place of

warm, encouraging smiles that had previously soothed anxious residents. Gone were the structured activities led by recreation therapists, the humor of familiar, caring staff, and the comforting touch of a caregiver's hand.

Thankfully, we have since returned to some sense of normalcy with in-person appointments, where good handwashing, masks, and friendly hugs are welcomed. Repeatedly, caregivers communicate not only their loved ones' decline but their own exhaustion throughout the pandemic. Caregivers are now several years older, with increasing health issues of their own, in part due to the stress and isolation, along with forgoing health screenings to avoid potential COVID exposure.

As the world emerges into a new normal, many patients and caregivers are still fearful and isolated. Some adult day care and senior programs remain closed or abbreviated, limiting opportunities for caregiver respite and patient engagement. Adult children caregivers are under pressure like never before. School closings, job loss, work from home, loss of in-person supports and outlets to manage stress, while continuing to care for and worry about everyone around them, are extraordinary challenges they continue to face.

I believe we have work to do, and lessons have been learned, including the following:

1. The healthcare industry can adapt quickly. Telehealth was promptly covered by insurance and promises to continue to increase health-care access long after COVID.
2. Connection is critical for our patients and the lack of it is devastating.
3. Health and wellness of congregate living staff and that of their residents is interconnected.
4. Design of congregate living facilities should focus on limiting the spread of communicable disease, expanding outdoor spaces, fresh air, and natural light.
5. Support, financial compensation, and respite care for family caregivers would allow families to remain at home together, improving care for many patients while reducing the burden on long-term care communities and government programs.

Innumerable physical and psychological effects of the COVID pandemic will emerge over the coming years. As a healthcare provider, a mother, and a daughter of a parent living with a high-risk health condition, I believe we need to use the knowledge gained from this unprecedented, collective trauma to fuel our work in creating improved health and quality of life for people living with dementia in need of long-term care.

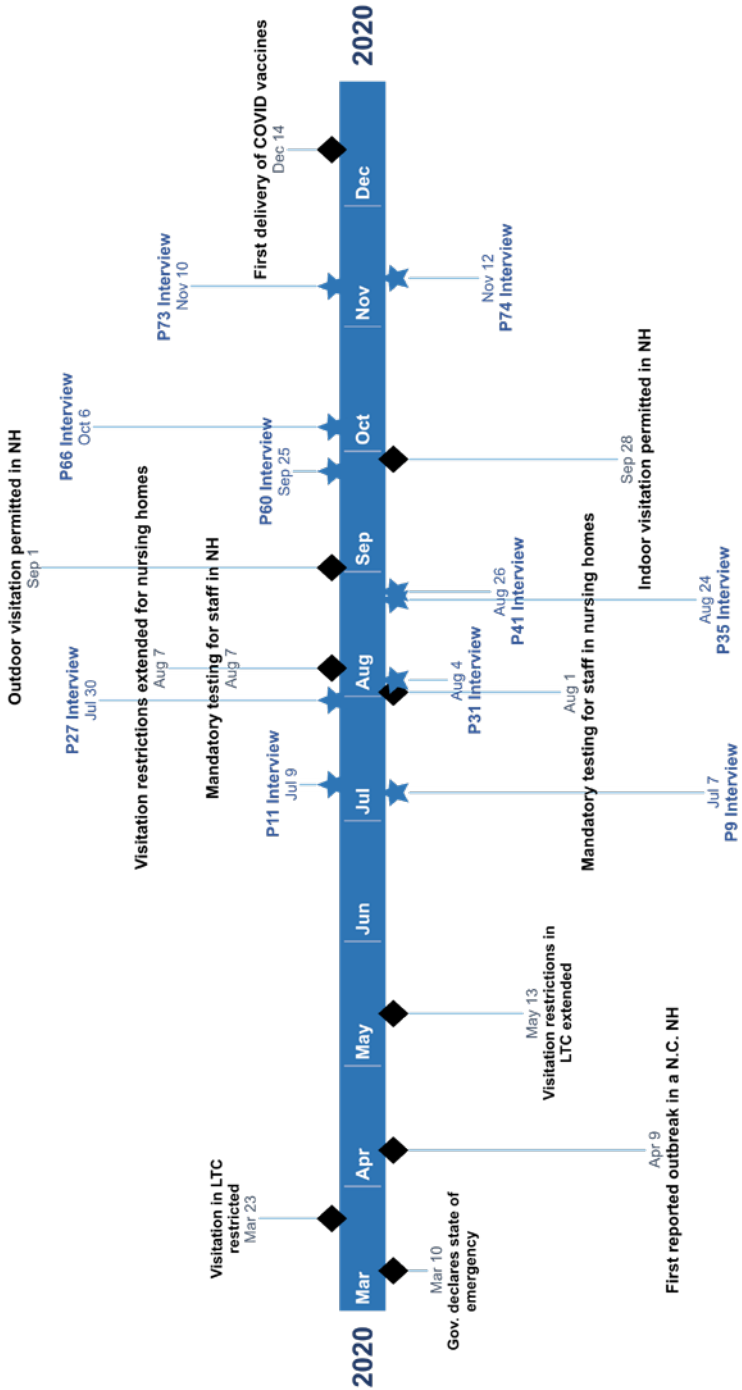


Figure 5.1. Timeline of Interviews Quoted in Chapter 5.

COVID-19 PRESENTS UNIQUE CHALLENGES FOR those caring for persons living with dementia in all residential environments from their own homes to nursing homes to assisted living and special care units for persons living with dementia.² Memory impairment makes it difficult for a person living with dementia to comply with safety measures such as frequent handwashing, mask wearing, social distancing, and quarantine procedures known to reduce infection and transmission of COVID-19. In this chapter, we capture the experiences of workers including administrators and managers, social workers, activities professionals, nurses, home health workers, and CNAs who demonstrated high levels of resiliency in their efforts to improvise and pivot programming, infection control measures, and communication that would be effective for persons living with dementia. We also present challenges identified in providing care during the pandemic, including communication with residents and clients, safety issues, engagement and social isolation, and access to technology, which were heightened when combined with memory impairment and various levels of cognitive decline.

Background

Dementia is typically a chronic and progressive syndrome characterized by loss of cognitive function caused by deterioration of healthy neurons in the brain (National Institute on Aging [NIA] 2017; WHO 2020). The most common cause of dementia in older adults is Alzheimer's disease (NIA 2017). Other causes of dementia stem from Lewy body dementia, vascular dementia, and frontotemporal disorders resulting from atrophy of lobes in this area of the brain, and mixed dementias (NIA 2017). While symptoms may vary according to the type and stage of dementia, it is generally expected to contribute to difficulties with memory, visual perceptions, communication, attention, and behavior (NIA 2017; WHO 2020). Risk factors include age, ethnicity, prior heart conditions, and brain trauma, with age playing the largest role (CDC 2021). Diagnosis is confirmed via cognitive and neurological tests aimed to detect attention, problem solving, and memory issues, analysis of blood samples, physical exams, review of medical history, psychological tests aimed to rule out other disorders, brain scans such as CT or MRI, or a specific combination of these (CDC 2021; NIA 2017). Facing the cognitive decline associated with a diagnosis of dementia, older adults living with later stages of dementia often lose the ability to manage themselves, resulting in dependence on others (NIA 2017). Widespread stigma and exclusion are attached to dementia as a category of abnormal aging (Libert and Higgs 2022). Many professionals, caregivers, people living with dementia, and activists dislike the term "dementia" and

continue to seek a more descriptive term, such as “deeply forgetful people” (Post 2022).

Deinstitutionalization in the 1960s and 1970s created a large influx of older adults living with dementia into nursing homes and away from psychiatric hospitals (McLean 2007). Initially lacking in regulation, abuse was commonplace in these care homes, however, with the passage of the Omnibus Reconciliation Act of 1986, comprehensive nursing home reform and regulation began (McLean 2007). The advent of special care units in the 1970s and 1980s to support the needs of persons living with dementia created the belief that special care would be given for these conditions, but lucrative funding opportunities were often the primary motivation in the creation of such units (McLean 2007). This created a persistent tension of meeting bureaucratic goals while providing quality care to residents. Focusing on the need to make a profit, care is often routinized, and conflict ensues between residents who do not feel they are genuinely at “home” and caregiving staff who, despite their best intentions and efforts, often lack the time and energy needed to provide the quality care their residents seek and deserve.

These factors contribute to care that is “task oriented” and focused on tending to basic physical needs, rather than caring for the whole person (McLean 2007). Once an awareness of the needs of persons living with dementia were brought to light, the impetus for change was born and outdated models of care would no longer suffice. With an emphasis on personal agency and quality of life, rather than symptom management and quantity of life, person-centered care became the care model of choice for persons living with dementia and remains so today.

Person-centered care derives from the theory of patient-centered care, which is based on the claim that care should be focused on the needs of the patient rather than the provider or institution offering care. The difference in the name is significant as the term “patient” connotes an individual needing treatment for sickness, and “person” is more accurate when discussing persons living with dementia as residents of long-term care or receiving long-term support and services in the community. Per Maslow (2013), identifying this concept as “person centered” is critical to understanding the benefits of this approach for caregivers tending to medical and nonmedical care needs. Many of the daily needs of persons living with dementia require attention that does not fall under the category of medical care. Recognizing the special challenges present in providing person-centered care for those living with dementia, Kitwood refined these concepts, and his model is widely accepted and practiced in the United States under the more precise label of “person-centered dementia care” (Kitwood 1997).

With the advent of regulatory advances at the federal level, person-centered care is no longer just a desired outcome, but one actually mandated with measurable guidelines (Maslow 2013). While these guidelines attempt to provide some consistency to the application of person-centered care, varied conceptualizations and interpretations exist, and it is difficult to regulate implementation. Crandall et al. (2007) view personhood, knowing the person, maximizing choice and autonomy, quality care, and provision of a supportive environment as the primary components of person-centered care. Kitwood and Brooker present the core tenets of person-centered care as valuing people with dementia and their caregivers and treating them as individuals, viewing the world through the lens of

Table 5.1. Participants Who Care for People Living with Dementia

Participant #	Position	Credentials	Experience	Age
9	Administrator, corporate nursing home	BA Healthcare Mgmt. & Nursing Home Administrator License (2015)	2 months (in current position)	28
11	Activities Program Coordinator, corporate memory care assisted living	BA Physical Health Education	11 years	52
27	Administrator/Owner, adult care homes	BS, MBA, and Assisted Living Administrator License	18 years	56
31	Executive Director, corporate assisted living	Associate Degree	10 plus years	42
35	Physician Assistant, memory health provider	Physician Assistant	6.5 years	46
41	Activities Coordinator, assisted living	CNA, some college	16 years	48
60	Administrator/Co-Owner, family care home, memory care	BS Engineering and Licensed Nursing Home Administrator	3.5 years	62
66	Executive Director, adult day health care	BA Psychology, MA Gerontology	20 years	49
73	Owner/Agency Director (nonmedical home care)	BA Psychology	9 years	60
74	Manager, Life Enrichment, corporate memory care assisted living	BS Science, CNA	2 years	27

the person living with dementia, and recognizing the value of relationships for all persons, including those with dementia (Brooker and Latham 2015; Kitwood and Brooker 2019). It is easy to see the difficulties in comprehending and translating these components into concrete actions for caregivers to apply in their daily routines. Maslow (2013) argues that practice-based knowledge is accessible through the core concepts of person-centered care while acknowledging the need for governmental and nongovernmental programs and initiatives to address the gaps in knowledge and practice. Considering the unique care needs of persons living with dementia, we will discuss our findings regarding the requirements and challenges facing staff in their efforts to meet those needs during the COVID-19 pandemic.

Findings

Safety Issues and Infection Control

Keeping residents and clients safe required extra work by caregivers because memory impairment made it difficult for persons living with dementia to comply with safety measures such as frequent handwashing, mask wearing, social distancing, and quarantine procedures known to reduce infection and transmission of COVID-19. The owner of a special care community for persons living with dementia expressed the view of many of our participants succinctly: “In terms of COVID, there are a number of items which changed. It’s become a much more strenuous place to be, because assisted living could. . . Not assisted living, everybody feels it. But in assisted living, it’s even more so because of the obligation you have not to expose people who are the most vulnerable” (P60). As one activity professional in a memory care community summarized: “It has affected so much about how we operate in our community. Hasn’t been easy, hasn’t been easy” (P11).

Staff were navigating wearing masks and often shields along with full protective equipment while also encouraging residents to wear masks and social distance. An activities director in another memory care unit shared many of the residents’ reaction and oftentimes confusion as they had trouble processing the sudden emergence of PPE. He began by reenacting a resident’s response to PPE:

“What you got on your face? Take that thing off of your face. Why are you wearing that thing on your face?” Just constantly! They’ve gotten used to it for now. That was initially when it happened. . . . I don’t hear it anymore. It’s definitely tough to communicate with some of the ones that are hard of hearing, ’cause a big part of how they communicate is they watch the lips

move. And then with this. . . . They literally have no idea what you're saying. (P74)

Those with cognitive impairments generally didn't understand or comply with infection control guidelines making it challenging to enforce restrictions. As one participant described:

This, being memory care, certainly we cannot ask that our residents stay in their rooms. They're gonna come out and they wanna see what's going on. We may have residents that wander, you know that. So we've had to kind of change how we deliver our programs. We program in place where that resident is, that's where we are. We make sure that we are social distancing ourselves from the residents, which in itself is a challenge. (P11)

As the owner of one special care community explained: "Staff wears masks 100 percent, . . . I have cameras installed, I'm checking, but I don't need to check anymore because it's become second nature for everybody. For residents, they don't wear masks, obviously" (P60).

It should also be noted that added surveillance of caregivers created the potential for an additional layer of stress on the workforce. Care for persons living with dementia is enhanced by consistency and connection and those elements were difficult to sustain when caregivers' faces were covered and maintaining safe distance was required. It was often difficult for residents and clients to recognize and hear the caregivers, making caregiving even more challenging.

Communication

As we've discussed, communication among staff with residents, clients, and their families has been a key concern for caregivers throughout the pandemic. The rapid changes in understanding about the disease, policies, and guidelines have been difficult for caregivers, and caring for people with cognitive impairment has offered additional challenges in regard to helping them understand masking, the need to isolate, changes in visitation, and use of technology. They can't always recognize staff wearing masks or understand why they themselves need to wear them, or why they need to be isolated. As one home care owner shared:

"We had clients that didn't understand that they couldn't go out. It's like, "When can we go out for lunch?" And I'm like, "Well, let's make sure it's safe to do that. There are no restaurants open." . . . But yeah, we listen to that conversation over and over, that's real for a lot of our dementia clients, and it's multiple times a day." (P73)

Similarly, persons living with dementia weren't able to understand why their family wasn't visiting, and weren't able to recognize visitors through masks, the window, telephone, or virtual apps. For example, caregivers described their reactions when visitors waited outside the resident's window without the person living with dementia recognizing their spouse, for example. The use of technology was less effective for people living with cognitive impairment which is unfortunate, because they were the most vulnerable to the effects of isolation. As one nursing home administrator explained: "These window visits are so sad almost, sometimes you can't orient them to who it is, and it's just really, really, really hard and they can't hear. That's a huge thing, even with the phone or baby monitor, they still can't hear, and they just get confused" (P9).

This sadness implies an additional layer of emotional trauma the caregivers were feeling as they continued to provide care. As one activities coordinator in a special care community for persons living with dementia described when asked about the emotion showing on their face during our interview:

It was really difficult when we first started doing the window visits and the Zoom visits—just, just seeing the fear in the family members' faces, and just wanting to be there to touch them, because I think that they felt like if they could hug them, if they could touch them, that everything would be okay, or at least they knew that they were okay. It was hard, yeah. (P11)

Interfacing with technology was often disorienting for the person living with dementia, whether communicating with family or having a telehealth visit. As one nurse practitioner in a medical practice for persons living with dementia explained:

It really just depends on a few things, one's cognitive ability. Sometimes they're pretty advanced [cognitive decline], especially if we're talking about memory care, and then coordination of technology and access and ability to communicate on their own, they would need a personal staff member to do so. And we try to kind of also gauge who would be distressed by it versus who would be comforted by it. Sometimes they're just confused enough where it's [virtual technology] not real productive for them, and it might be more upsetting and confusing to have a voice coming through an iPad or something at them. It's not working for everybody. (P35)

The caregivers experienced sadness, stress, and anxiety regarding effective provision of care while addressing the confusion and stress of residents and clients. The caregivers had to make decisions about how to meet the needs of individual persons living with dementia as their caregiving responsibilities were expanded.

Communication has been crucial as practices pivoted in response to changing infection rates and guidelines. This includes communication with families of residents and clients, among staff themselves, and with residents and clients. In residential long-term care, it was generally activities staff or CNAs who handled the extra tasks of connecting calls and arranging and monitoring controlled visits while caring for residents who were experiencing emotional and physical responses to the effects of the COVID experience. Many of the caregivers we talked with who provide care to persons living with dementia in their home or community-based program were involved directly in calling clients and their family members to assure their basic needs were being met. In spite of these efforts, the caregivers shared their emotional reactions to seeing the decline of many clients, since many day health programs and senior centers were closed for at least a few months and persons living with dementia were isolated at home.

Engagement and Social Isolation

Our data reveal that residents of residential long-term care communities, especially those with cognitive impairments and dementia, are experiencing both mental and physical decline related to their isolation. A research participant who works in a memory care unit stated definitively, “100 percent of our residents have declined,” noting that one resident who weighed only 170 pounds to begin with had lost thirty pounds over the course of six months. Another participant stated: “We underestimate how quickly isolation does its damage.” They went on to explain: “Dementia cases progress the fastest when in isolation. When they’re not being challenged. When they’re not being engaged. When they don’t have the ability to choose.”

Activities, and more broadly social engagement, are crucial to the required routine that caregivers help create for people with cognitive impairments. Activities staff are most often expected to provide much of this routine, and this was even more difficult than usual during the pandemic. For example, as one activities provider in assisted living described, she improvised her engagement with each of the residents while they were unable to meet in groups. They provided things like puzzles, crosswords, or a daily bingo sheet to the higher functioning residents to work on in their rooms. For those with cognitive impairment, they went and spent time with them.

Another activities coordinator in a special care community for persons living with dementia expressed the difficulties in seeing the residents’ reactions to window visits while family were not allowed to come inside:

And it’s been really challenging and hard for the staff. And my department is the department that is managing that, of course, with the care, with the help

of nursing. It's been difficult on us emotionally to see those kinds of emotions expressed and to know that. . . Just to hug. . . They wanna be hugged. (P11)

One care provider in an adult day health program that reopened in June 2020 reported: "We learned how to take our phone during the Zoom call and put it on a big-screen TV in the living room so that it could be like they were visiting. . . . It was a time when you had to be very creative, you have to tap into your creative side" (P66).

Providing engagement and avoiding isolation for residents and clients with dementia restricted to their rooms or homes was incredibly challenging both for caregivers in residential long-term care and for those providing care for those living at home in the community. The challenge escalated due to the ongoing nature of the pandemic. One community medical provider shared that some patients were so confused that they really needed people to pull them out of their rooms but that was difficult on staff during the pandemic. They explained:

Staff aren't available to do that right now, there's just. . . There are so many other obligations. . . . I think the lack of socialization and interaction lets a lot of people become much more agitated, disoriented, confused in their rooms all day. . . . It's heartbreaking. Yeah, it is. After [family members] go to the windows and see and call me saying, "I see they're declining, I can see they're losing weight." (P35)

A day care provider explained the challenge of communicating effectively and meeting the needs of both family caregivers and the clients: "Now, from our [family] caregivers' perspective, we want them to know what we're doing. We want to put the emphasis on: 'We're keeping your loved one separated from others, but yeah, they're still getting social interaction,' but from our participants' perspective, we want them to feel normal and at home here" (P66).

These providers repeatedly described the physical and emotional decline they've seen in the residents, clients, and patients with cognitive impairments they care for and the emotional weight that puts on them as caregivers. One adult day care provider that had closed for a few months from March to June 2020 summarized how they felt about the impact they saw on clients of being quarantined and kept at home for the three months they were initially closed:

Seeing our participants decline, that's probably been the hardest part, because I feel like if we had remained open and they had continued coming, we would have seen very low declines. That truly has been heartbreaking. Thinking about sixteen of our participants passing away is heartbreaking.

That's just unusual, and so many of those deaths could have been delayed or prevented. One of our participants had gallbladder issues and needed gallbladder surgery, a simple procedure. She would have done well, she was mobile, she was active, but the hospital delayed the procedure and she ended up passing away. So things like that have been frustrating and sad and heart-breaking. It's just hard to describe. (P66)

Many workers described the negative impact of COVID on those they care for and the emotional stress they felt as they dealt with providing care while also handling their own personal challenges.

Staffing and Personal Challenges

Adequate staffing is key to providing effective care for persons living with dementia in the best of times. As the owner of several small assisted living special care communities described:

The biggest issue in this business, it's finding right caregivers. And right caregivers are not the person who moves the fastest, it's the person who have the biggest heart. And selecting and finding these people is a process, ongoing. And eventually after two and a half years, it took me, where I have a team where I have comfortable feeling that residents are being taken care of. And it's not only obligations, it's just they have right heart in the right place. (P27)

Already overworked providers of care for persons living with dementia had to deal with additional personal stress and anxiety brought on by the pandemic. Rules changed and both residential care and in-home providers were limited to working in one community or assisting fewer clients. This is financially challenging because they often have to work multiple jobs to ensure a living wage. In addition, many had children and other family members at home who they had to support and protect. As one adult day care provider explained:

It's really affected them [their coworkers] because of what they see happening to our participants and our caregivers, but also because of what's going on in their personal lives and resources. Some have children at home trying to do online school, and their whole routine and schedule has been upset, so that's been hard. So we've tried to work together to support each other and try to be flexible about each person's personal needs, but it's probably affected some of my coworkers, a little bit more than it has me because of what they have going on in their personal life. (P66)

Caregivers in all of these environments have also had to deal with their own needs and challenging personal situations, including some who had

COVID themselves, while continuing to provide safe and effective care for persons living with dementia. Home and community-based care providers also felt the impact on family caregivers who now had their loved ones at home 24/7 and needed additional support.

Discussion

All of these changes clearly added to the workload and challenges faced by caregivers providing long-term support and services both in residential long-term care and home and community-based settings. They were all forced to improvise in order to provide adequate care for their clients and residents with cognitive impairments during the pandemic. This included practicing effective infection control and caring for residents who caught COVID. Simultaneously, they had to protect themselves and their families from COVID. Some caregivers reported extreme stress and even PTSD from their experiences.

We have drawn from these narratives to demonstrate how caregivers of persons living with dementia pivoted and took on additional responsibilities including physical, emotional, and technical support labor. For example, they replaced some of the direct and relational care that families usually provide including assistance with eating. They also had to update relatives of the status of the loved ones they could not visit as well as help implement virtual window or outdoor visits. These essential workers were generally not compensated or were minimally compensated for this extra work in the form of bonuses, raises, or paid leave. Additionally, while some felt supported by their administrators and managers, they did not report access to professional emotional or mental health support despite reports of trauma, anxiety, and sadness. Efforts at providing the person-centered care that is essential to assuring adequate quality of life for persons living with dementia were often stymied due to limited time and increased responsibilities. The structural impediments, including but not limited to inadequate pay, limited benefits, and the lack of a career trajectory, need to be addressed to ensure the maintenance of a healthy, committed workforce that can safely care for persons living with dementia. Overall, the experiences of the global pandemic reported on here have demonstrated the importance of these essential workers and the inadequacy of and fractures in the long-term care system, particularly for persons living with dementia in the United States.

Andrea Freidus is the graduate director of the MA/MPH program at UNC Charlotte. She is an applied medical anthropologist whose most research interest is about the impact of COVID-19 on congregate and community-based care for older Americans in the Charlotte region.

Dena Shenk is emerita professor of anthropology at UNC Charlotte. She is author of *Someone to Lend a Helping Hand: Women Growing Old in Rural Society* (1998) and has published numerous articles and book chapters about aging, people living with dementia, and their formal caregivers in the United States, Denmark, and Peru.

Christin Wolf is an applied medical anthropologist dedicated to utilizing personal narratives to provide practical solutions to public health issues for the purpose of increasing health equity in her community. A resident of Charlotte, North Carolina, her faculty-led research has focused on food insecurity on college campuses and most recently the impact of COVID-19 on congregate and community-based care for older Americans in her region.

Notes

1. The term “sundowning” refers to a state of confusion occurring in the late afternoon and spanning into the night. Sundowning can cause a variety of behaviors, such as confusion, anxiety, aggression, or ignoring directions, and can also lead to pacing or wandering.
2. Adapted from Shenk, Freidus, and Wolf (2022).