2 CHALLENGES IN PROVIDING CARE IN RESIDENTIAL LONG-TERM CARE COMMUNITIES

"It Spread Like Wildfire"

Fire Through Dry Grass at the Coler Rehabilitation and Nursing Center, New York City, by Dena Shenk, with Andres "Jay" Molina, Alexis Neophytides, Vincent Pierce, and Peter Yearwood

On a cold, sunny afternoon in September 2021, I walked past the Coler Rehabilitation and Nursing Center on the north end of Roosevelt Island in New York City. I was curious because of the vigil I'd attended virtually and the communications I'd been receiving from OPEN DOORS and Nursing Home Lives Matter, advocacy and artists' groups operating from within Coler. I was lucky to come across a small group of men in wheelchairs who I recognized from these projects. A conversation, sharing of contact information, and a couple of group photographs formed the basis for the following introduction to the injustices that occurred on Roosevelt Island, and the work being done by this community of Reality Poets, filmmakers, advocates, visual artists, musicians, sons, brothers, and fathers who live at Coler Nursing Center.

Early in the COVID-19 pandemic, the city of New York opened a hospital for COVID-positive patients within Coler. These long-term residents fought back against this invasion of their home, and the following examples in this chapter demonstrate this important, ongoing work and growing movement.

Introduction by Vincent Pierce, Director of OPEN DOORS, and founder of Nursing Home Lives Matter

OPEN DOORS is an organization known for disability justice, gun violence prevention, leadership of Black and brown people who use wheelchairs and art that sends positive messages and dope vibes. In July 2020 I launched #NursingHomeLivesMatter in response to the dehumanization

and confinement of Coler Rehabilitation and Nursing Care Center's primarily Black and brown residents during the pandemic. We were fighting for our lives—COVID patients were brought into our home, no safety precautions were followed, and bodies piled up in two refrigerated trucks parked outside. Then as the lockdown dragged on for more than a year, we were fighting to see our families or just get beyond the iron gate and yellow tape that corralled us in like convicts or animals at the zoo. Now we're fighting for a *bigger* cause. We realize that nursing home residents and workers all over the country suffered the same way we did and have been dealing with the same problems we have, long before anyone heard of coronavirus. #NursingHomeLivesMatter works for a healthcare system that protects and cares for all those in long-term care, whether for thirty years or a few months, and for those who care for us. We are introducing a new vision for a nursing home that really is a *home*. Not a prison-like institution that prioritizes revenues over people. Our lives matter!

Taking a Stand by Peter Yearwood

March 2020. My world and everyone else living on this planet came to a complete stop. There was something in the air that was killing people by the thousands and sickening thousands more. That "something" was COVID-19, a novel virus that health professionals and scientists claim they knew nothing about. I say this because they knew how deadly and contagious this virus was. When the virus was detected in my city (New York), the entire city went on lockdown. People were told to stay indoors and not leave their homes unless absolutely necessary. For me and thousands like me that live in long-term care facilities, this was like a death sentence, because so many in these institutions have underlying illnesses that this virus seems to thrive on; if we contracted this virus, so many of us would be at risk of dying. The dangers we faced were twofold: first there was the virus, and then there were the people who were supposed to be keeping us safe. They had no idea of what to do in a situation like this; they were using textbook guidelines for something that was not playing by the rules, and this was evident through their response to this highly contagious, deadly virus.

I was tested positive three days after my unit went under quarantine, and the reason for this is that they were quarantining the sick and the healthy in the same space. We all shared the same bathroom, same dayroom, and were cared for by staff that never changed their PPE. From one patient to another, this is evidence of the administration lying about having sufficient PPE, or they were not following protocol. I saw and have pictures of a staff member discarding their PPE in the dayroom garbage receptacle that patients use regularly.

As a resident of Coler long-term care on Roosevelt Island, I feel the people in power truly failed us by not taking actions that could have saved many lives. A very close friend and supporter of OPEN DOORS made a video of all the people we knew wishing us well and asking us to stay strong, and upon seeing that, one of our members broke down and cried because he, like many of us, thought no one cared. Our voices were not being heard, and they (the administration) were nonexistent. I never saw anyone from the administration for weeks—or for the duration of the first wave, for that matter.

It was the most terrifying experience of my life, but there was light in all the darkness through something called Commun-unity, or common unity, when everyone comes together to fight a common enemy—which is just what happened on this tiny rock we call home. I have read and seen stories like this on TV but have never experienced such love and support from people who were for the most part total strangers to me. It was through their support that I was able to stay strong and survived this deadly virus. Most of these people stepped up and came to our aid with things like PPE—thousands of the N-95 masks, gowns, hand sanitizers—which we distributed to the staff and patients. These supporters also added their voices to influence the powers that could actually do something because we realized that this administration were puppets. The people at the top pulled the strings and they danced; they were not advocating for our safety.

I have lived in this country for more than a half a century and always felt I did not have the right to speak up about wrongs that I was experiencing because I am an immigrant. It wasn't until during the pandemic that I decided to break my silence and fight against a machine that was putting so many lives at risk. It was like, what can you do to me now? I am fighting for my life and the lives of many others. I remembered visiting Four Freedoms Park pre-pandemic and reading the four fundamental freedoms people all over the world should have, so I decided I had nothing to fear but fear itself. Never again will I be silent about a wrong being done to me or my people.

Through Dry Grass (reality poem) by Vincent Pierce

Fire through dry grass is what I experienced
but this grass was never green
Or did it ever smell like that fresh cut grass on a summer morning
the fire was never visible
but O did it spread like a wildfire

You see the grass was never your actual grass
and the fire was never your actual fire

the grass was human beings
and the fire was what we know today as COVID-19

It all started mid-February
with rumors of a virus so contagious that you can contract it
from the closest stranger
I didn't believe it
but at the same time I can hear the late Rev Minnie Bell Powell
my grandma saying
god is coming boy you better get right with him

By late February it hit my home harder than Mike Tyson in his prime in the first round

Body after body ambulance after ambulance
Is what I witnessed

Scared to close my eyes at night to wake up gasping for air

'Til one morning the fever and the shakes hit me
Nurse give me a Tylenol I have a toothache
Knowing that wasn't what it was
But knowing I had to tell my mind that's what it is
Just so I could shake it off
Mind over matter

My favorite OG Roy Watson wouldn't have ever thought he would wake up gasping for air
Not even being able to grab his phone and dial 911
But through this poem I honor you Roy
And the other 500,000 COVID has taken away

Years later the grass is still burning without a firefighter in sight
And the man who made such a invisible weapon of mass destruction is sitting back saying mission accomplished
Fire through dry grass. . .

Introduction to *Fire Through Dry Grass* the documentary of life within Coler during the pandemic lockdown

Fire Through Dry Grass uncovers in real time the devastation experienced by residents of a NYC nursing home during the coronavirus pandemic. Codirectors Alexis Neophytides and Andres "Jay" Molina take viewers inside Coler, on Roosevelt Island, where Jay lives with his fellow Reality Poets, a group of mostly gun violence survivors.

Wearing snapback caps and Air Jordans, Jay and the other Reality Poets don't look like typical nursing home residents. They used to travel

around the city sharing their art and hard-earned wisdom with youth. Now, using GoPros clamped to their wheelchairs, they document their harrowing experiences of being on lockdown. COVID-positive patients are moved into their bedrooms; nurses fashion PPE out of garbage bags; refrigerated trailer morgues hum outside residents' windows—all the while public officials deny the suffering and dying behind Coler's brick walls.

The Reality Poets' rhymes flow throughout the film, underscoring their feelings that their home is now as dangerous as the streets they once ran and—as summer turns to fall turns to winter—that they're prisoners without a release date. Instead of history repeating itself on this tiny island with a dark history of institutional neglect and abandonment, *Fire Through Dry Grass* shows these disabled Black and brown artists refusing to be abused, confined, and erased[1].

Introduction

Life Care Center Nursing Home in Kirkland, Washington, was originally identified as the epicenter of the US COVID-19 pandemic and received significant negative media attention (Watkins et al. 2020).[2] Data have shown that the older population, especially those in congregate living communities, were being hit hard by this pandemic that wreaked havoc throughout the country (Gardner, States, and Bagley 2020). In July 2020, we began interviewing workers in residential long-term care communities, including nursing homes, assisted living communities, continuing care retirement communities (CCRCs), family care homes, and memory care for persons living with dementia.

COVID-19 has made visible long-standing problems in residential long-term care that advocates tie to widespread ageism in the US. These include, but are not limited to, problems of quality care associated with underappreciated and underpaid staff, the commodification of care that lacks dignity for those being served, and increased feelings of helplessness and depression among residents who struggle to find meaning in a model of institutionalized care that is disenfranchising (Cateau 2021; Kane 2001; Polivka 2020a, 2020b; Rosen et al. 2011).

Sadruddin, Feroz, and Inhorn (2020, 17) call out ubiquitous ageist ideology in relation to COVID, explaining: "When aging is viewed primarily as an undesirable process of physical and mental decline, accompanied by increasing levels of burdensome care, then the elderly are seen as disposable, unworthy of our protection. This seems to be the defining rhetoric in the United States at present." The morbidity and mortality numbers in the US demonstrate the particular vulnerability of older Americans in congregate

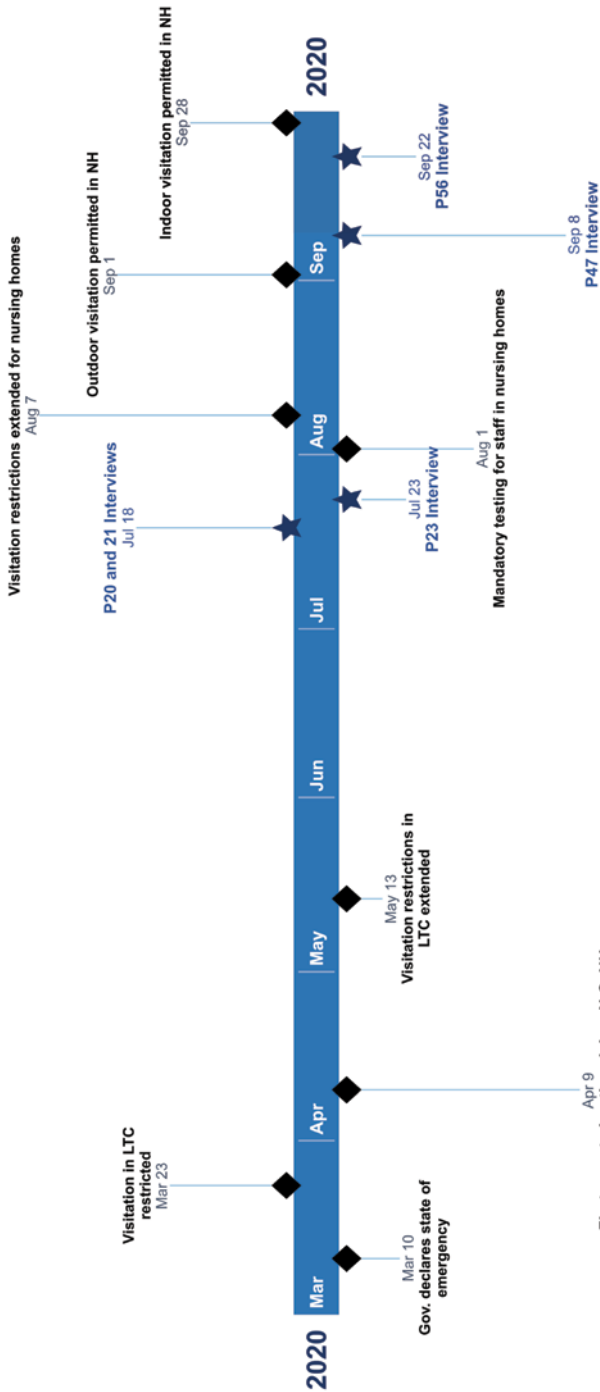

Figure 2.1. Timeline of Interviews Quoted in Chapter 2.

care (Gardner, States, and Bagley 2020), and some discourse suggested a justification to "sacrifice" older Americans to ensure a modicum of economic stability. In most states, approximately one-third to one-half of all COVID-related deaths were attributed to residents and staff of residential long-term care communities. In North Carolina, the average weekly number of COVID deaths related to residential long-term care communities in early June 2020 hovered higher, at around 60 percent (North Carolina Department of Health and Human Services 2020). We are not aware of other research on how residential long-term care staff, providers, advocates, ombudsmen, and surveyors[3] were adapting to these unprecedented circumstances, with high rates of infection and death during the early stages of this complex health emergency.

Residential long-term care providers are not traditionally considered "frontline" healthcare workers during complex health emergencies. This is largely because the population they serve, primarily older adults, and the congregate residences within which they work, have not been particularly affected during previous pandemics such as Ebola, SARS, or MERS. The coronavirus pandemic is unique in how it has hit these sites and their residents especially hard. Residential long-term care communities are neither designed nor equipped to treat people with serious COVID-19 (Gardner, States, and Bagley 2020).

Contemporary Challenges Providing Residential Long-Term Care Pre-COVID-19

In the US, residential long-term care is provided in nursing homes, CCRCs, assisted living communities and smaller family care homes. Nursing homes, often called skilled nursing homes, are regulated by federal guidelines. Assisted living communities are overseen at the state level, and regulations and terminology vary from state to state. In North Carolina, they are licensed as adult care homes and include family care homes, licensed to house up to six residents. These do not include unlicensed and poorly regulated facilities (Lepore et al. 2019). Special care for persons living with dementia is provided in dementia units within nursing homes or assisted living communities, as well as free-standing memory care assisted living communities. CCRCs are communities with a range of levels of care available on a single campus. All these congregate living communities are often referred to as facilities, but we use the terms "communities" or "homes" to de-emphasize the medical model and focus on these as homes. Long-term care is also provided through community-based programs and in-home services, but they are beyond the scope of this chapter.

A number of large corporations have come to dominate the long-term care industry in the US, and there are major concerns related to the quality of care in these institutions. One of the pervasive challenges involves issues related to staffing. Issues that staff, who are often minority women, face are not new. They are exacerbated by the pandemic including high job turnover, low wages, and meager benefits (Harahan 2010; Rosen et al. 2011), limited job satisfaction (Dill, Morgan, and Marshall 2013; Karantzas et al. 2012; Rosen et al. 2011), emotional and mental burnout (Karantzas et al. 2012), lack of institutional and societal support for the work they do (Jakobsen and Sorlie 2010), and limited autonomy (Shenk 2009). COVID-19 made even more apparent many of the failings that characterize congregate care for older Americans as it presented unprecedented challenges to the staff of residential long-term care communities. These staff are tasked with the difficult job of ensuring their own well-being and safety, the well-being and safety of residents, and the maintenance of a robust response when and if this or a similar virus reemerges.

Due to the nature of the medical emergency and the differential mortality of older adults, the focus was predominantly on protection rather than quality of life. While long-term care communities were locked down, ombudsmen, family members, and other visitors were prohibited from entering. Concerns for safety were deemed more important than allowing the visits of family, some of whom otherwise visited regularly and assisted with feeding and other care. Residents were forced to stay in their rooms instead of congregating for meals, engaging in social activities, and visiting with family and friends. Only building staff were allowed inside buildings. Controlling an active COVID outbreak can take months, and during that time residents were restricted to their rooms with no group activities or communal dining.

While provisions were made for "compassionate care" visits, this was originally interpreted narrowly as visits to residents at the end of life; that is, someone who was actively "transitioning," which is the term commonly used by these healthcare service providers when someone is dying. Other types of compassionate care situations were identified in a CMS memo on 17 September 2020 to include a resident grieving after a friend or family member recently passed away, experiencing weight loss or dehydration, experiencing emotional distress, seldomly speaking, or crying more frequently. Through a person-centered approach, long-term care communities were instructed to work with residents, families, caregivers, resident representatives, and the ombudsman program to identify the need for compassionate care visits.

In this chapter, we focus on data collected as part of Phase 2 of the research, which includes narratives of thirty-one participants working in a

variety of residential long-term care environments during the pandemic in central North Carolina. (These findings are discussed in chapter 8, in comparison to research in a Swiss nursing home.) Early in the pandemic, the highest rates of COVID-19 mortality were associated with residential long-term care including nursing homes, assisted living, memory care units, adult family care homes, and CCRCs. Our samples included staff at fifteen different communities, including three skilled nursing homes, four assisted living communities, four memory care units, two adult care homes, and two CCRCs. This included one chaplain, one marketing professional, four CNAs, two med techs, six activities professionals, five nurses, one nurse practitioner, seven administrators, two dining staff, and two housekeepers.

When residential long-term care communities were locked down in mid-March, residents were forced to stay in their rooms instead of congregating for meals, engaging in group activities, or visiting with family and friends. Only residential long-term care staff were allowed inside buildings and staff were no longer allowed to work in more than one job to control the spread of COVID. (This will be discussed again in chapter 6.) Social isolation was a concern, and visitation protocols evolved in attempts to meet the needs of residents (see chapter 4). Knowledge about COVID-19 changed quickly, and residential long-term care homes struggled to provide effective care while initially prioritizing the physical safety of residents. One interviewee explained:

> [COVID-19] just went through the whole building. . . . One day we went from one person that had been sent to the hospital coming back positive, and as soon as that happened, it was like everybody that she was around had it within a matter of a day, two days. (P21)

This is an excerpt from an interview with a direct care worker who volunteered to work on a COVID-19 unit in a nursing home in central North Carolina, where an early outbreak led to the death of over twenty residents in just under two and a half months. The participant acknowledged vacillating between feelings of anger, frustration, helplessness, fatigue, and deep-seated grief. She mourned over residents she knew and loved and had watched "suffocate" to death. She felt helpless, unheard, and angered that her experiences were not being used to prevent mortality.

We have developed this case study in an attempt to make the voices, trauma, and anger of these workers heard. We foreground the narratives of a group of workers who are often ignored, undervalued, and without voice. The site of this case study is a corporately owned nursing home in central North Carolina. Six staff members volunteered to work on the COVID unit: one LPN, one RN, three certified nurse assistants (CNAs), and

a housekeeper. We interviewed four of these staff members from the COVID unit (one nurse, two CNAs, and a housekeeper), and the nursing home administrator. Through initial and ongoing data analysis, we noted the emotional nature of the interviews. Based on our inductive approach, we turned to affect theory to analyze the narratives of these five participants and to maximize the analytical value of their feelings and sensory experiences about providing care through a COVID-19 outbreak. Please note that the photographs presented in this chapter are not from the case study site but were made available by Attic Angel Assisted Living and Memory Care.

Drawing from interviewees' expressed affective experiences, we demonstrate how affect and emotion circulate to structure the experiences and perceptions of residential long-term care workers, through their engagement with each other, as well as with residents, families, administration, policy, and the virus itself. We report on the emotional experiences of direct care workers as they emerged from their narratives of caring for older adults in long-term care during the COVID-19 pandemic. Four affect categories emerged from our data analysis: fear/anxiety, sadness/grief, anger/

Illustration 2.1. Staff appreciation signs made by volunteers (PowerPoint slide 99). Photo credit: Attic Angel Assisted Living and Memory Care. (The photos presented in this chapter are not from the case study site but were made available by Attic Angel Assisted Living and Memory Care.)

frustration, and trauma/stress. We report on them separately to illuminate how these feelings are expressed and structure the experiences of these direct care workers.

Circulation and Affect

As we began to analyze the narrative interviews with these workers in residential long-term care, we were struck by the high level of emotion and turned to affect theory. A wide range of scholars have convincingly demonstrated that affect structures how humans interpret, understand, and make sense of their lives (Ahmed 2004a, 2004b; Griffiths and Scarantino 2008; Skoggard and Waterson 2015; Slaby, Mühlhoff, and Wüschner 2017). However, due to the fluid and dynamic nature of affect, it remains difficult to document and analyze affective engagements, or to understand and make social scientific claims about subjective, emotive experiences (Ahmed 2004b). With regard to these methodological challenges, Ahmed suggests a narrative approach, arguing one can "read" the affective in texts (2004b, 27) as we do here.

Affect theory has become increasingly popular as a way to make room for ethnographic scholarship that values the emotions, feelings, and subjectivity inherent in the lived experiences of individuals and communities and are foundational to how they understand and interpret their own and others' lives (Martin 2013; Skoggard and Waterson 2015; Stewart 2007). Affect is being used here as a framework that focuses on an examination of an individual's visceral, emotive experiences within the material world (Lyon 1995). Affective analysis is often understood as that which is individually felt but simultaneously informed by social context (Stewart 2007). Following Skoggard and Waterson (2015), we are not convinced of the need to distinguish between affect and emotion. Emotion, in our view, is not as individualized as some scholars would suggest. We draw on Ahmed (2004a) to demonstrate that emotions do not exist in a vacuum as they are always already structured by the social context within which someone is born and lives, and by the interactions that occur within their lives. In other words, while we can speak of emotions as they are individually felt or embodied, emotions are induced, shaped, and molded by the social context and the material world, past and present. Since emotions and affect are more similar than they are different, we use these terms interchangeably. Our emphasis here is on the way emotions are structured by the social, and by circulating between bodies and objects (including policy). In our analysis, we document participants' emotions as individually felt and expressed, but assess them in terms of how they are constructed

in response to and also impact the sociopolitical landscape. Documenting these affective responses allows for a critical review of long-standing structural inequities, ageism, and inadequate policy and programming in long-term care.

Findings

We have organized our findings according to the codes that emerged from our analysis, while recognizing that emotions are rarely discrete categories. They often overlap with some participants expressing anger, fear, and frustration simultaneously. We do not suggest that the categories we have identified as emerging from this analysis are straightforward. Instead, we draw on the range of expressed emotions to illustrate the broader affective experience of working on a COVID-19 unit in a congregate care community with substantial morbidity and mortality. We distinguish four major affective themes that emerged from the data from what are, in actuality, a cluster of related feelings. These include fear/anxiety, sadness/grief, anger/frustration, and trauma/stress.

Fear/Anxiety

Each of the frontline workers volunteered to work on the COVID hall because they knew "someone had to do it" and some of their colleagues refused to work on the positive unit for fear of contracting the virus. As one of the respondents said: "I did have a little bit of fear. I have four kids at home and a [spouse]. So, I was really worried that I'd take something back home to them, but I was very cautious." By "cautious," they meant wearing full PPE, changing clothing when they got home before entering the house, showering and washing their hair, and not visiting relatives and loved ones. In these interviews, fear is evident in relation to the circulation of the virus itself, and specifically in relation to how workers do or do not circulate among their own loved ones.

Interviewees also expressed fear associated with helplessness. They discovered that a group of residents had tested positive after initially being told all the tests came back negative, and their initial wave of relief was immediately overtaken by dread. One explained:

> Our unit supervisor walked in and was like, "Everybody's positive. We read the test wrong." Yeah, so I think that was the first day I literally cried because as soon as [they] told me that, I dropped to the floor and I just bawled like a baby 'cause I knew, I knew we were gonna be in for it after that. (P21)

This respondent's visceral response of crying "like a baby" embodied their all-too-correct fear about what was about to happen to the residents they cared for. This respondent cried during the interview when they talked about being alone with dying residents because their family members were too afraid to come into the COVID unit while their loved ones were transitioning (the term they used for someone who was dying). Fear, helplessness, and grief collided in these narratives.

Sadness/Grief

All the workers experienced grief and sadness and spoke of these emotions in-depth. They demonstrated these feelings in the interviews through crying and cracking voices. All five respondents, including the administrator, expressed a deep connection and respect for the residents they cared for on a daily basis. Participants evoked fictive kinship as they referred to residents as being like family, saying "they are the reason I get up and go to work every day . . . I really love them all." Remembering residents they loved who died was emotional for these caregivers. They all talked about crying, and two of them cried during the interviews. One explained, "If it weren't for [a colleague], I probably wouldn't have made it through that two and a half months, 'cause I literally, I cried on a daily basis." In one interview, the participant was overwhelmed with grief when describing how the virus took a resident she had a strong relationship with. She regularly took walks with this older, male resident she described as "healthy." He contracted the virus and died within days. She talked about his loss several times in the interview, and a coworker independently recalled how sad her colleague was when that particular resident died. Another frontline worker stated that it was too painful and sad to deal with and the only way they could "survive" the experience was to "just shut down." They explained:

> You can't feel anymore. I think after the tenth person dying, I was like, "Okay, I can't, I can't. If I keep feeling like this, I will not walk into that door." And after that, I was just like, "Okay, so they died. Okay, so they died. Okay, so they died." And now . . . we're going from the hall where everybody was and where we started, and it's not the same people, we've lost them, we've lost them all. And you're just like: "Why?" (P23)

Another participant shared how they struggled to control their own emotions in ways that had never happened before. They said:

> I've done this for a long time and never, ever have I not been able to make it out of the room [without crying]. . . . It just overwhelmed me at that point that all these people we were testing, you knew they were gonna come back

> positive, and you knew in your heart that they probably weren't gonna make it 'cause they're already sick to begin with. (P20)

Grief was tied not just to the affective encounters between staff and residents; staff bore witness to the suffering and grief of family members trying to console the residents. One interviewee recalled how husbands came to visit their wives daily by standing outside the windows. They explained:

> The resident doesn't even know they're there because of their level of dementia, but that husband is still there all day. One brings a bar stool and an umbrella, and he does that during the rain, whenever . . . he has a cooler with water, and he sits there at the window with her. So that's really sad to watch. It's really great that you're loved that much, but it's gotta be heartbreaking for all of them. (P20)

Anger/Frustration

The COVID unit staff were isolated in a very real sense. They didn't feel like people were listening to them, which led to extreme frustration and anger. There was generalized anger at the virus itself for taking so many lives in such a violent way. Anger and frustration were directed at policies and procedures that did not take into account their perspectives and expe-

Illustration 2.2. Porch visit through plexiglass (PowerPoint slide 88). Photo credit: Attic Angel Assisted Living and Memory Care.

riences. Finally, there was a sense of anger and helplessness in relation to the broader community for not taking COVID-19 seriously enough and not following CDC and health department guidelines. During one interview, a participant became agitated and raised their voice as they discussed anger at death, not being listened to, and also at colleagues and other staff who did not acknowledge the suffering and grief this direct care worker experienced as they watched residents die. They shared:

> I had a lot of anger during this process: I was angry at the fact that these people had to die the way they had to die, and that no one cared. I really honestly felt like the people who were on the floor, living it day by day, got it, and the people who weren't there, it's like we couldn't get them to see it. . . . And it's like, "I can't process this person just died. Now, you want me to hurry up, pack their stuff up, . . . so somebody else who tested positive can come right in this room?" (P23)

Since this was an early outbreak, there was little understanding of the virus, and the participants expressed frustration at the administration's plan that was initially instituted to contain the virus. This nursing home has several different halls, and each could be somewhat isolated. One hall became a "COVID unit," and anyone who tested positive, along with their roommate, was moved there. Once in the COVID unit, both would be tested to see if they were positive. The frontline workers believed that close proximity to COVID positive roommates all but ensured that the other roommate would catch the virus. They watched initially negative roommates test positive and then die. One caregiver explained:

> We had two roommates. One tested positive, one tested negative, but just because the roommate tested positive, they moved both of them over to [the] COVID [unit]. So, she got tested again when they moved over there. Came back negative. Two days later, she was moved back out to her room. And then literally within a day of her being moved back, the PA [physician's assistant] sent her out to the hospital with a 102 fever, respiratory distress, and we knew damn well what was wrong with her. We didn't have to have a test to tell us. (P21)

Another participant echoed frustration about the decisions to move residents excessively, as administration and corporate worked out procedures. The administrator said it felt like there were one hundred room changes in one hundred days, which they acknowledged was an exaggeration but said they felt like that because it was so "mentally and physically exhausting." One CNA explained: "And our whole thing was, 'Why are they not listening to any of us?' . . . We were there, we're in the midst of this. We're trying to tell you what we need to do that might could help this situation. And you're not wanting to

Illustration 2.3. One-on-one activity in resident's room (PowerPoint slide 11). Photo credit: Attic Angel Assisted Living and Memory Care.

listen" (P23). This same respondent said they did not feel like they had a voice as "lower-tier staff," adding that even the nurses expressed concern about the movement of residents that went unacknowledged. The administrator expressed admiration for the corporate office that worked tirelessly to create and implement strategies during the early chaotic days of the pandemic when little was known about the virus and its transmissions. The administrator rightfully said, "Nobody was prepared for this." They went on to recall that at one point protocols and procedures changed almost daily in an effort to consolidate ever-evolving recommendations and policies from the federal, state, and county levels. In trying to juggle the needs of the COVID-positive patients, the protection of themself and their staff, as well as the quickly shifting policies and procedures, they did acknowledge that some mistakes were made, explaining, "I wish I could have known then what I know now."

Trauma/Stress

Trauma, stress, and exhaustion were discussed by all five participants in this case study. Trauma was expressed in several ways, including vivid descriptions of the violent deaths from COVID that residents faced in the nursing home since many had orders refusing transportation to the hospi-

tal for life-saving procedures. Two caregivers stated they suffered from post-traumatic stress disorder (PTSD). Sleeplessness, exhaustion, and disturbing images of death and dying haunted the staff following the major COVID-19 outbreak at their nursing home. One of the caregivers shared that when the initial outbreak occurred, the attending physician wrote prescriptions for morphine for all the residents, saying, "You're going to need it."

All the interviewees discussed the helplessness and violence associated with dying from COVID-19 that related to their traumatic experiences working on the COVID unit. One respondent explained this violence and their frustration at what they felt might have been preventable: "They're literally smothering to death, they're literally choking to death. And all you can do is sit there and hold their hand and try to make them comfortable . . . 'cause there's nothing else you can do. And then you look and you go, 'You know what? This possibly could have been prevented.'" (P21) Another participant similarly described the traumatic experience of watching residents suffocate: "Even the morphine wasn't helping. . . . They were still fighting for air . . . and it was like somebody holding a trash bag over their heads and smothering them" (P23).

One participant clarified that they had confirmed the residents' wishes and conferred with family for those who were unable to make their own decision. "We did send all residents that indicated they would want to be transferred to the hospital when their symptoms became the level for that type of intervention" (P20). Witnessing violence and death can be associated with PTSD, and two participants believed it was affecting their mental health in sustained ways. One of these two individuals stated plainly:

> Me, personally, with my experience, I have PTSD. . . . Going through this trauma, I'm still trying to come out of it. . . . I don't ever wanna do it again. . . . I say that I don't think I mentally could do it, but I sit here and I tell myself, like I just told you, if I had to do it, I would do it again . . . I probably wouldn't be the same, second time around, as this took a lot to get back to a normal life for myself after coming off of it. (P23)

Another said they suffered flashbacks that they relate to their sleeplessness and associated trauma: "It's just that I close my eyes and it's like I'm there again. I see and I hear. And that's something I don't wanna see and hear ever again" (P21).

Discussion

These narratives demonstrate the multifaceted, socially embedded nature of affective engagements that reflect the way we generate feelings through

circulation between a range of actors, objects, and policies. The virus, coworkers, family members, residents, and policy restrictions in turn structure how participants understand and manage their experiences. We argue that troublesome cultural values, social injustices, and structural failings, which are all too often easily ignored or erased, can be made visible through chronicling these affective dimensions.

By amplifying the voices of frontline workers, we demonstrate how their sensorial and emotive experiences can speak to the unjust human suffering they bore witness to, the underlying ageism that permeates our culture, and the social hierarchy that devalues these workers' labor and worth as they serve on the frontlines during this unprecedented global pandemic. This perspective is particularly important in light of the media coverage on the failures of nursing homes and the larger healthcare system to respond effectively to the pandemic. This media coverage generally positions administrators and residential long-term care staff in conflict with long-term care residents and their families. These workers' perspectives add a valuable, nuanced view of the heroic measures taken, including risk to the self, by administrators and direct care staff, to protect the lives of residents. We must keep considering the structural barriers that workers face within these residential long-term care homes that are informed by the broader sociopolitical context that—both historically and during the COVID-19 pandemic—limit their agency in caring for those they serve. Their expressions of fear, anxiety, helplessness, anger, trauma, and grief illuminate their individual devaluation by the larger society as low-paid healthcare providers, and that of their aging residents. Their palpable anger, frustration, and trauma speak to the violent, unnecessary suffocation and perhaps preventable deaths, as well as despair at the social hierarchy that prevents direct care workers' voices and perspectives from having value. Their fear is shared to some extent by all of us living in the chaotic age of COVID-19.

Notes

1. Related materials: www.opendoorsnyc.org/nhlm Nursing Home Lives Matter); OPEN DOORS (opendoorsnyc.org) (OPEN DOORS website); http:www.firethroughdrygrass.com (*Fire Through Dry Grass* documentary trailer); https://www.thecollectionnyc.org/ (The Collections website); NursingHome411.org podcast: "A Jail within a Jail: Inside a NYC Nursing Home with Co-Directors of *Fire Through Dry Grass*."
2. Adapted from Freidus, Shenk, and Wolf (2020a).
3. Surveyors employed by the North Carolina Division of Health Service Regulation (NC DHSR) conduct regular inspections and investigate complaints against nursing homes.