1 PERSPECTIVES OF REGIONAL AREA AGENCY ON AGING STAFF AND LONG-TERM CARE ADVOCATES

A Rapid Qualitative Appraisal

Using Coronavirus Aid, Relief, and Economic Security (CARES) Funds to Purchase Animatronic Pets, by Sara Maloney (was then an Aging Specialist at Centralina Area Agency on Aging)

The first few weeks after the initial outbreak of COVID-19 in our communities were riddled with confusion and panic as we worked to continue providing services safely to older adults and their caregivers. The Coronavirus Aid, Relief, and Economic Security Act (CARES Act) created a great deal of flexibility for Older Americans Act programs during the COVID-19 pandemic. The North Carolina Department of Health and Human Services Division of Aging and Adult Services provided waivers to allow programs to deviate from rigid program standards that were not feasible during a global pandemic.

The CARES Act funds supported efforts to purchase items in bulk and distribute them to those in need. One of the more popular items during the early days of the pandemic was liquid hand sanitizer. Our agency was able to purchase the sanitizer for programs and for older adults who needed to feel safe when leaving their homes. There were significant and widespread shortages of this product in late March and April 2020, but we were able to purchase hand sanitizer from local distilleries and other companies that had halted the production of drinkable alcohol and were doing their part for their community.

Once we realized that the restrictions with COVID-19 would not be lifted after several weeks, we looked toward addressing social isolation and caregiver burnout. Caregivers who were home with loved ones with dementia who normally would have been at their adult day programs were struggling, so we purchased animatronic pets to distribute throughout our region (Greater Charlotte Area). Animatronic pets are robotic

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therapy pets that have lifelike characteristics like vibration purring, bark back technology, and built-in sensors that respond to motion and touch. The animatronic pets for this project were purchased through Ageless Innovation's Joy for All Companion Pets. The animatronic pets were received with smiles and gratitude as they provided social interaction and entertainment. One caregiver reported being able to finally take her husband out for a ride in the car because he sat holding his new animatronic dog, Spot, instead of repeatedly opening the car door while it was in motion. Another individual who received a robotic cat was very happy to have a cat that wanted to sit on his lap and give him attention. The other real cats in his household did not want to interact with him. The caregiver said the recipient could not stop smiling once she gave him his new cat. A local adult day program was thrilled to receive ten pets for their participants who were having to stay socially distant and could not continue their usual group activities. The new robotic pets allowed participants with dementia an individual activity that minimized the risk of spreading COVID-19. Over two hundred robotic cats and dogs were purchased and distributed throughout the region to local adult day centers, Departments of Social Services, caregiver programs, and directly to individuals. We received multiple letters of thanks and photos of happy older adults holding their new "pets." One of these photographs is included here (Illustration 1.1).

In addition, our agency purchased online social programs to alleviate social isolation for older adults who were cut off from their senior centers and other outlets for social stimulation. Get Set Up, including the purchase of tablets and internet if needed, was offered to all older adults sixty and over, allowing them to join online classes from around the world. Classes ranged from cultural cooking classes to learning how to operate a computer. We also purchased a caregiver education platform called Trualta to connect caregivers together and provide them with needed information in one central location. These web-based resources had not been available to the region prior to the COVID-19 pandemic and opened the door for older adults to have experiences outside their local community.

The global pandemic created a need for relaxed standards and more person-centered approaches for Older Americans Act programs and services. Many North Carolina state programmatic standards have not been updated since 1992, and the pandemic brought to light changes in the needs of older adults in the twenty-first century. Thanks in part to CARES funding and to the availability of a variety of programs utilizing new technology, older adults were given more person-centered options when aging in the place of their choosing.

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Illustration 1.1. Resident holding her animatronic pet. Photo credit: Sara Maloney, Centralina Area Agency on Aging.

Introduction

The purpose of this chapter is to capture the narratives of Regional Area Agency on Aging staff and state-level advocates for long-term care as the COVID-19 pandemic unfolded across the United States in the spring of 2020.[1] We demonstrate the importance of thinking in a more nuanced way about how we define "frontline" workers in a complex health emergency. This chapter focuses primarily on residential long-term care provided in nursing homes, assisted living and continuing care retirement communities (CCRCs) because reports at the time indicated that mortality and morbidity were being disproportionately felt by older adults in these communities.

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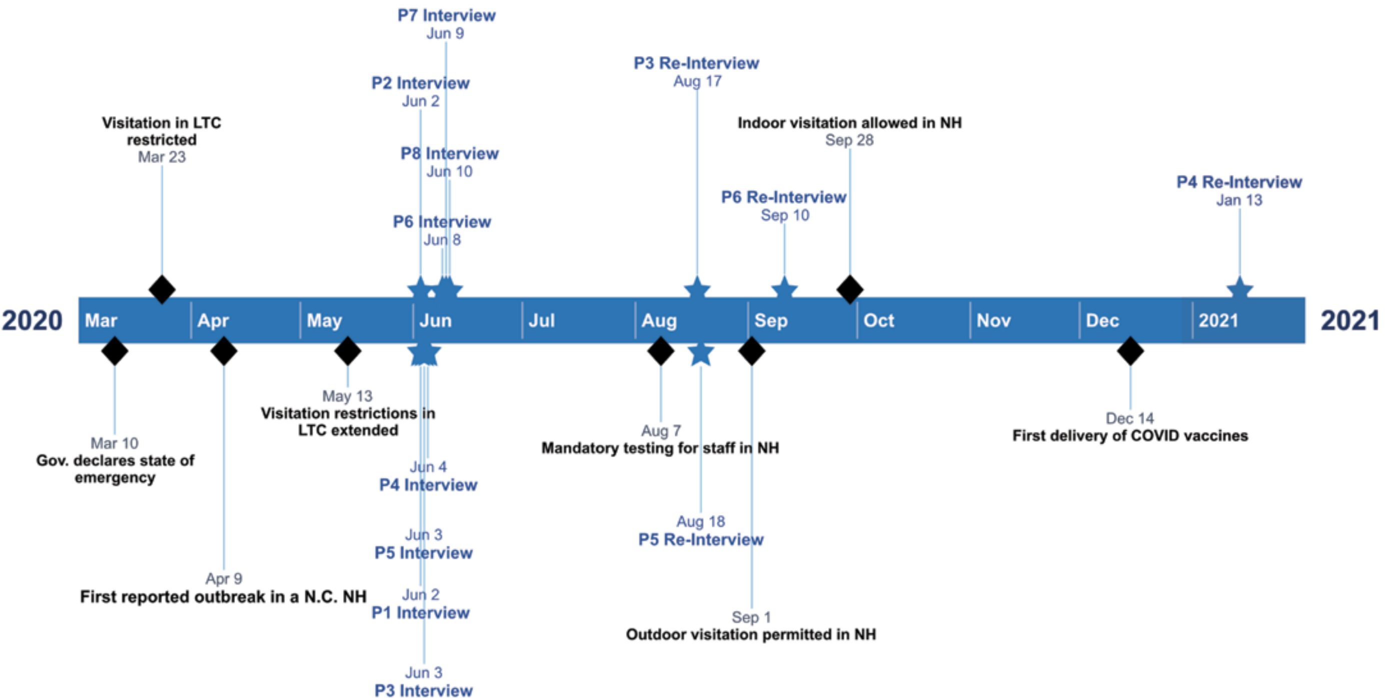

Figure 1.1. Timeline of Interviews Quoted in Chapter 1.

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What Was Going on in Spring 2020

To best interpret our findings, it is important to revisit what was happening in the spring of 2020 as we began collecting these narratives. At the time, little was actually known about the virus in terms of routes of transmission, possible treatments, long- and short-term impacts of the virus on those infected, and why some populations were more vulnerable than others. Communication around the virus was constant yet ever changing. For example, infectious diseases experts initially dissuaded masking and then shifted with the data to mandate masking in all public places. Anxiety, fear, conspiracy theories, political bifurcation, and panic peppered news headlines. Supply disruptions and hoarding notoriously led to toilet paper shortages and the production of new types of questionable sanitizers and disinfectants. Work shifted to being almost entirely remote aside from those workers newly deemed "essential," and schools were shuttered, forcing many children online or out of education altogether.

As a research team, we met daily via Zoom and regularly reflected on our personal anxieties about unknown risks and potential unanticipated, negative long-term outcomes. We feared public spaces, including grocery stores, and, like many, were forced to barter for toilet paper. We all felt isolated and expressed concern about what this isolation would mean for ourselves, our families, and our research participants. So very little was known, and the flow of changing information often felt overwhelming. Our research participants expressed the same anxieties and fears in regard to their personal lives but also in relation to their work. Personal protective equipment (PPE) was at a premium, if accessible at all. There was little reporting based on demographic information in regard to morbidity and mortality. Chaos around policy recommendations and what seemed like contradictory safety measures and protocols invoked anxiety and at times felt paralyzing to many tasked with caring for vulnerable populations. It was in this environment that we began conducting interviews via Zoom.

This chapter reports on Phase 1 of our rapid qualitative research appraisal examining the impact of COVID-19 on the provision of long-term care for older adults in central North Carolina. In this phase, we conducted semi-structured interviews with a sample of staff from a regional Area Agency on Aging and a statewide nongovernmental organization (NGO) that advocates on behalf of residential long-term care residents and their families. We examined the key concerns they had about overseeing the care of residents during the COVID-19 outbreak and unanticipated issues they faced in navigating their work during a global pandemic. Questions also focused on what resources they had made available, what needs were not being met, their concerns, and their successes. One of the major areas of

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focus includes the challenges that direct care workers faced in trying to meet the daily needs of residents and clients. We asked these advocates and regional staff about their concerns in regard to adequately staffing residential long-term care communities. Finally, we asked participants to identify specific policy and programming that worked well and what needed to be amended or initiated moving forward.

Methods

As stated in the Introduction, this is a three-phase project. It is important to note that these phases were not linear, but rather overlapped. In this chapter, we discuss findings from Phase 1.

Phase 1

In locating interviewees, we specifically targeted higher-level regional administrators and state-level advocates. We conducted in-depth, semi-structured web-based video interviews with eight participants, including two interviews with two participants (see table 1.1). Six participants—including ombudsmen,[2] the director, the assistant director, and aging specialists—worked for an Area Agency on Aging. Federal funding allocated through the Older Americans Act is filtered through the states to the regional Area Agencies on Aging that oversee Older Americans Act funded programming. The other two participants were the executive director and volunteer board chair of a statewide advocacy group for long-term care residents and families.

Table 1.1. Phase 1 Participants.

Participant #	Age	Credentials	Experience
1	58	MA-Gerontology	28 years
2	46	Graduate Certificate-Gerontology	24 years
3	36	MA-Gerontology	14 years
4	37	MA-Gerontology	17 years
5	32	MA-Gerontology	11 years
6	72	MSW, MPA	30+ years
7	60	MA-Anthropology	23 years
8	46	MSW	6 months

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Collaboration and communication with various stakeholders have proven essential when conducting rapid appraisals in order to ensure the data make its way to those with the ability to direct and guide policy and programming (Vindrola-Padros and Vindrola-Padros 2017). Therefore, we had several staff members of the Area Agency on Aging as well as the advocacy organization review our interview protocols prior to submitting them for final Institutional Review Board (IRB) approval. The purpose of this was to ensure we were collecting useful data that could help bolster these stakeholders' influence when negotiating policy and programming in relation to this complex health emergency once all phases were completed.

As described in the Introduction, we recorded the interviews and transcribed them verbatim, and then coded them using NVivo software. We completed a total of twelve interview hours in Phase 1, ranging from thirty-two minutes to two hours and forty-three minutes with each participant. Coding went through three phases. The team used a grounded approach that avoided the use of preexisting codes, in order to ensure that the narratives were driving the data analysis. This is especially important when conducting research on a complex emergency with a population that has not been studied in any similar context. Dena Shenk reviewed all the interviews and generated a master list of themes. This allowed for an inductive process driven by the narratives of the participants to capture their unique perspectives (Bernard 2006). After Shenk generated the initial codes, the other two researchers reviewed the interviews and contributed missing themes. The team condensed the themes into four broad categories, with additional subthemes. Andrea Freidus and Christin Wolf independently created the agreed-upon codes in NVivo and coded all the interviews. We then compared these data for accuracy. There was near-unanimous agreement on data analysis, with Shenk finding more data to fit existing codes but not creating or identifying new codes. In an effort to maintain a rapid time frame, the data collection, analysis, and write-up occurred simultaneously.

Findings

At the time of the initial interviews in early June 2020, fifteen out of thirty nursing homes in the catchment area reported COVID-19 positive residents and four out of fifty-three assisted living communities had COVID-19 positive patients (P3). In the state at this time, there were 61 outbreaks and 99 deaths in residential care communities—which include assisted living and family care homes—108 outbreaks, and 605 deaths in nursing homes (North Carolina Department of Health and Human Services 2020). Not surprisingly, the data presented in the following sections demonstrate that safety of staff and residents was a key issue for nearly all interviewees. Par-

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ticipants were most concerned about the lack of access to PPE and testing as well as inadequate staffing. In addition, these data also point to concerns about both the physical and mental health of residents. Finally, it was noted that all interviewees expressed concern about "not knowing" what is happening because they "can't get in" since all residential long-term care communities in North Carolina were on lockdown by the governor's executive order on 18 March 2020.

The Unknown

It was common to hear both Area Agency on Aging staff as well as NGO advocates express frustration and anxiety about not having a full picture of what was actually happening within residential long-term care communities. One interviewee stated that the following was their primary concern: "So, one, the regulators can't go in. The ombudsmen can't go in. Family members can't go in. So part of it is like, we have no idea what's going on in some of these facilities" (P4). Not letting family in was cited as problematic because they often provide an essential, if informal, level of oversight. Residents' families are often important advocates and active members in the caregiving of their loved ones.

This interviewee also expressed frustration because they were now reliant on administrators and staff to update them on what was happening within the residential long-term care communities they are tasked with overseeing. Some residential long-term care administrators can be less forthcoming, which can be related to both mistrust of agency staff and fear of negative publicity. The interviewee explained:

> I don't really have a heartbeat on what's going on in these facilities. . . . Good administrators will tell me like, I'll be like, "So, what's it really like? What's going on? Are you having trouble with your staff? Are your residents happy or are your family members mad?" If I have a good relationship with the facility, they'll tell me that, and I do have good relationships with them. But I have some that wouldn't tell me anything. I mean, like, I had one lie to me when they made it on the list [of facilities with COVID-19 outbreaks]. And I was like, "So you've got four cases! It's public record. I'm not dumb. Come on, don't lie to me." . . . So it's, it's that whole fear of "we don't really want anyone to know, because we don't know what you're going to do with that information." (P4)

Later in the interview, this same respondent said that many facilities avoided testing because they were disincentivized by the negative publicity that positive cases brought to their facilities when reported in the press.

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This interviewee references outbreaks as "public record," which is a result of advocacy groups informing policy at the early stages. Both facilities and the North Carolina Department of Health and Human Services were required to provide detailed reporting of COVID-19 cases and deaths within residential long-term care communities. While advocates and the Area Agency on Aging staff considered this a positive outcome, they still voiced concerns about the way cases were counted and the potential underreporting that was occurring, suggesting they were still struggling to know what was actually happening in residential long-term care communities. This interviewee went on to explain:

> I'm still a little intrigued how they're [North Carolina Department of Health and Human Services] getting the numbers. Anyway, I'm going to be really honest. So if you pull up the state list from DHHS [Department of Health and Human Services], for COVID outbreaks, yeah, I personally, I know of some facilities who've had some deaths, but those deaths occurred at the hospital. Or they were tested at the hospital, and I don't think that they're being included in the facility numbers. (P4)

It was unclear how individual facilities and hospitals navigated counting COVID-19 cases. What is known, regardless of these documentation issues, is that safety in these communities was of concern, especially as the prevalence and incidence of COVID-19 cases continued to rise. Overall, there was consensus around the fear of the unknown and potential misinformation about outbreaks, which is problematic when trying to care for residents and ensure their safety. The data presented here focus on safety, including issues related to infection control and accessing PPE, testing that is alluded to above, and long-standing issues of staffing that have been exacerbated by the risk associated with care in congregate communities.

Testing

When asked whether assisted living communities or nursing homes were being harder hit, one respondent explained that nursing homes were reporting more outbreaks, but acknowledged that there was still limited testing, especially in assisted living communities. At the time of this interview, conducted in early June 2020, the virus had been spreading for three months, but testing was still a problem. This interviewee explained their concerns with reports of outbreaks:

> There's five nursing homes, and there's only four assisted livings [with COVID-19 outbreaks in their catchment area]. We have fifty-three assisted

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> livings, [and] there's only four [outbreaks]. But to be the glass half-empty, it's because they're not testing. So I think it's inaccurate. . . . I'd love to think that it was real and that they don't have it, absolutely, but I don't know if I believe that. (P2)

They went on to reiterate that testing may be disincentivized: "I think facilities on the front end are very afraid to say, 'Yes, give me baseline testing' because they're afraid to be on the news, and they're afraid it'll look negative" (P2).

Nearly all interview participants expressed frustration about both the lack of availability of testing and also that the state had not made baseline testing mandatory in all residential long-term care communities. When one participant was asked about what they had heard regarding the availability of universal testing, they explained, "I hear a mix that we don't have enough tests, but then I hear from the facilities themselves that 'we could put through to get everybody tested. We do have access.' They're just not being told that they should. And every company is reacting a little differently." Another participant reiterated access to testing being an issue in part because the state pushed for long-term residential communities to be responsible instead of the government. They explained that while state officials claimed that testing was being conducted statewide, that was not the reality:

> What we hear on the street is that it is not true. The other thing that has happened is that other states have assumed the responsibility, both in terms of process and financing of testing residents and staff members. North Carolina is pushing that responsibility over to the facility. Now, nursing homes did get a wad of [CARES] money to help offset those costs.[3] Assisted living facilities have not gotten a dime. So now we get into the nature of this business. It is a for-profit industry. And it's all about the bottom line. And one, if there is not a requirement, and two, if you're not getting paid for it, three, they're not gonna do it. (P2)

While there may be a financial component, the fear of being reported in the press was also a disincentive to undertake universal testing.

On 11 May 2020 Vice President Mike Pence told governors that all nursing home residents and staff should be tested for the coronavirus in the following two weeks (Brosseau 2020). On 11 June the state of North Carolina ordered universal testing of all nursing home residents and staff (Fain 2020). On 25 June it was reported that this still had not happened (Brosseau 2020). Assisted living and other residential care communities were not yet included in this program.

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PPE and Infection Control Strategies

PPE includes, but is not limited to, face masks, hand sanitizer, scrubs and booties, and face shields. Since the inception of the pandemic, PPE was in high demand and short supply. While nursing homes were included on the priority list of institutions that should have access to PPE, they too suffered shortfalls. Assisted living homes were not included as priority communities and some home healthcare aides continued to have trouble procuring the necessary supplies. One participant explained that nearly all sectors of care for older Americans felt the shortfall:

> The PPE has been a real challenge for our service providers. I'm sure you've heard that . . . in terms of long-term care providers. But what's interesting is [that] we came to learn, and it makes sense, I totally understand that medical providers need top priority, but in terms of access to PPE, of course, it was short supply for everyone, right? And certainly, we've found that many of the aging service providers, you know, weren't even on the list really, in terms of being in line to get those, um, much-needed [supplies], whether it was masks or gloves. (P3)

Recognizing this issue, one regional aging specialist stepped in and purchased and distributed hand sanitizer with existing funds from a provider identified by the state. She dispersed the hand sanitizer to the various programs and agencies they contract with, to help them continue providing care. As she explained, "The federal government gave us the Families First [Response Act] Funding and the CARES Act Funding. In North Carolina, we still haven't gotten that out yet, because there's so much red tape, and the state has not been quick." This alludes to both the difficulties accessing needed resources as well as the financial challenges. (See the essay at the beginning of this chapter for further information.)

Interviewees suggested that there is a connection between the lack of access to PPE and issues related to staffing. For frontline care workers to feel safe in their work, they need access to PPE as well as infection control training (Matanock et al. 2014), One interviewee explained succinctly, "You can't have an adequate staff force. You can't have a healthy staff force. You can't have a well-trained staff force. You can't have any of that without providing them PPE" (P2B). Residential long-term care communities are not mandated by law to provide or stockpile PPE. Many of these are private communities that are capable of making PPE readily available but have not invested in these kinds of supplies.

Participants only marginally addressed the issue of infection control strategies. This can be attributed to the fact that none of the interview-

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ees had sufficient access to know the kinds of infection control strategies that were being implemented. However, one respondent pointed out the reality that if infection control was working well, there would not be as many outbreaks in these residential long-term care communities as were being recorded. They went on to express concern about the COVID pandemic because infection control has traditionally been an issue in these communities. They relayed that even state surveyors expressed that it was the result of infection control plans being "old, outdated, and antiquated" stating, "There are things that fall through the cracks all the time, and I think cleanliness and infection control and some of those standards that facilities have, they just were not held accountable to being on par" (P5). Later in the interview, this respondent discussed infection control in tandem with staffing because these issues are largely dependent upon each other. Staff members are tasked with understanding and implementing infection control, which is not always a priority for underappreciated and underpaid staff:

> Maybe because of some of the highlights of COVID, I think they [the administrators] may be looking at infection control. Maybe they'll have better standards at the end of it. Maybe they'll value CNAs in their job and their work and pay them a little more because there has to be that connection of when people treat their staff well and their staff are proud of their job, they do a better job in caring for people. When you treat them the way that they're being treated, they don't care. (P5)

Staffing Issues

Issues around staffing in residential long-term care are deep-seated and extensively documented prior to the pandemic. Under normal circumstances, Area Agency on Aging staff estimate that the rates of direct care worker turnover ranges from 150 to 200 percent (P1). Research into this high turnover has pointed to low wages and limited benefits, in addition to emotional and physical stress of the work, or "burnout" (Harahan 2010). Therefore, it was not surprising to interviewees that staffing would be an issue given the high risk of transmission associated with this virus in addition to the added care needed to protect residents and provide social support. One participant stated: "In the midst of all this stuff, staff aren't reporting to work. And I'm not so sure I would either. You're getting paid minimum wage, you're not given proper equipment, you may be a health risk as well. Why are you gonna show up at work, you know?" (P3). Interviewees are well versed in the lack of commitment to residential long-term

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care work associated with the meager compensation structure and lack of respect staff receive.

At the same time, many residential long-term care workers live at or below the poverty line and cannot quit or take substantial time off. The result is presenteeism (Widera, Chang, and Chen 2010), or the idea that one must work even when they are not feeling well. This can be problematic when confronting a virus with high infectivity rates like those seen with COVID-19. Workers who tested positive for COVID-19 were required to take at least two weeks of leave, and most of it was unpaid. One respondent relayed:

> Therefore, when we have the pandemic of people starting to maybe not get well or not feeling well, Andrea, instead of them thinking, "I should go home for two weeks and fight this and take care of myself. If I don't go into work, I'm not gonna get paid. If I don't get paid, I can't pay the rent. My children and I will be homeless. My children will be in the dark because I won't be able to pay the power bill." (P8)

This participant did not believe these workers acted out of malice, but rather were forced to make an impossible choice. The interviewee explained, "It was not with an ill intention or ill will. It was because they were between the rock and the hard place, that people said, 'I'm gonna ignore this sniffle. I'm gonna ignore this fever I think I have. Let me take some Advil, Tylenol, and I've gotta go work my shift'" (P8).

In relation to the compensation issues, many of these providers work multiple jobs in order to make ends meet. One participant explained:

> because Certified Nursing Assistants, CNAs, are not high-paid jobs, and even some of the nurses do it, they moonlight at other buildings. So, some staff work at multiple buildings or they work at the hospital, or they work at home health or they caregive for people. So, there's so much, I wanna say, potential cross-contamination, even unknowing that it's happening. So, I just think there's a lot potentially that could be harmful and hurt staff and residents unwillingly. (P2)

Additional institutional challenges were exacerbated by the pandemic, at times putting direct care workers and residents at increased risk. For example, in an effort to quarantine residents, many residential long-term care communities designated areas as "COVID floors" or "COVID units" once an outbreak had been identified. Under ideal conditions, staff attending to these designated areas would not rotate onto the non-COVID floors or areas. However, because of a shortage of staff, participants expressed concerns that some communities did not have that luxury. Similarly, in assisted

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living homes that also house memory care units for people living with dementia, it would be beneficial to divide staff into units and not reassign them to different areas daily. One respondent explained:

> A lot of facilities have just been really good about how they schedule people. So, I have an assisted living that has memory care. The staff only stay in memory care. The staff only stay in assisted living. There will be no crossover. If a facility has the luxury of doing that, that's helping your infection control, so you don't have different people in there being exposed to different folks every day. (P4)

Memory care comes with its own concerns warranting special attention, as we explore further in chapter 5. Memory care units refer to either standalone assisted living communities for persons living with dementia, or units housed within assisted living homes or nursing homes. These communities are unique in large part because residents with dementia are often "healthy" and mobile, but struggle with understanding what is happening in terms of a complex health emergency, the use of PPE, and the social distancing recommendations. All participants were particularly concerned about safety for these residents. One interviewee stated, "I think if the virus gets into a special care unit for folks with dementia, you can [pause] those people can't participate as well in active quarantining, and you can't lock them in a room. And they maybe will take their mask off. They won't remember why" (P2). Another interviewee who works primarily with assisted living communities, which includes the majority of memory care units, expressed the same concern.

> They've [the staff] been really good about keeping residents in the room, but they're bringing them up to the door to do activities or bringing four people out to the common area to do an activity. You can't do that in a memory care. They're wandering all over the place. So I have no idea how they're making that work. I really, I really have no idea, and I would love to be able to see it. But I can't. If you ask them [the staff], they just say "We're doing our best to keep them apart." (P4)

Participants expressed some frustration in trying to assess outbreaks in memory care units because unless the memory care unit is a stand-alone facility, there are no specific data about these residents. Instead, they get counted among the general population at nursing homes or assisted living communities, making it unclear whether the memory care units are more susceptible or differentially experiencing morbidity and mortality. The dearth of detailed data about those residents who have been impacted are of concern to advocates and agency staff.

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Meeting Physical Needs of Residents

In addition to expected concerns around safety, all participants expressed concerns about how COVID-19 impacted the ability of frontline care workers to meet both the physical and social needs, including mental health, of residents. It is the responsibility of direct care workers to meet the basic needs of residents. The data presented in this chapter suggest that this was already a strained workforce, and the pandemic compounded that stress. How this translates into the care of residents was of concern to long-term care advocates and career Area Agency on Aging staff who are well versed in these issues. One interviewee with over twenty years of experience explained the greatest challenges as follows:

> the social isolation component in addition to just basic care. So, what we know is that facilities were short-staffed, and short-staffed only through the evidence of what needs could not get met. . . . I can only tell if I'm short-staffed at the point that horrible things begin to happen, right? So, we know that there was turnover to the tune of about 150 to 200 percent in long-term care facilities before this [pandemic]. We know that they continue to struggle with that. So, the logic will tell you that the amount of staff available to actually conduct regular good ongoing basic care is probably a real challenge. (P1)

Of particular concern was how stress levels compounded by a pandemic might lead to residents not getting adequate care. This same participant explains it as an already "volatile situation" that is going to potentially get much worse and cause the residents to suffer. They further expressed:

> Labor is short, everywhere. So basic care is the one thing, but then, you know, I don't know that they're doing a good job. . . . But historically, these healthcare workers at long-term care facilities did not have really good solid support benefits. . . . What I think is that you end up with a very stressed workforce, under stress already, now being additionally stressed for not having sufficient staff . . . and the additional stress and all of that rolls down to the resident. You know, at the end of the day, all of that rolls down to the resident who is either not going to get the kindest person in the world, is going to get somebody who's very rushed, you know, is not very nice. (P1)

Another concern was the disruption that occurred when these communities relocated residents onto or off COVID-19 halls or floors and even moved them to different communities. This posed a high risk to residents' health and safety. One participant explained:

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> So, they moved out long-term care people to other facilities, trying to house all of the COVID folks, I think, in an effort to keep it contained and to have overflow for the hospital. . . . That was not pleasing to families or residents. So, the flip side of that was, I know that what they were trying to do, and I know their intent was good, but you've just displaced eighty people who lived in a facility and treated them like it was not their home. (P2)

Another respondent added, "Now you've got other issues. You're talking about a frail, elderly population, you move 'em and your death rates also go up. So you've got morbidity issues associated with just moving from one place to another within a facility" (P2). Moving residents into and out of their homes affects both their physical and mental health. In addition, it makes it difficult for families to connect with and keep track of their loved ones.

Meeting Social and Mental Health Needs of Residents

A major concern expressed by every interviewee was how social isolation was affecting residents. As we began interviewing in June, many residents had not physically seen or been in close proximity to family or friends for three months since the governor's executive order went into effect in March 2020. By mid-June, there was not a plan in place to open these communities in the near future. One participant said:

> Those individuals [in residential long-term care communities] are having to stay in their room, so even though they live in a place that has a lot of people to have a conversation with, they can't. And that's been a really tough thing. . . . You're expecting that, towards the end of your life, you can be surrounded by family and those that you love and be treated with respect and dignity, and not that the aides and the staff in nursing homes aren't doing that, but I don't think they have the time during, especially if there's a COVID outbreak in their communities, to meet the needs of each individual. (P5)

Interviewees said that some facilities had "gotten creative" and brought residents into the doorways of their rooms to play bingo or even just have conversation across a suitable distance. In addition, several participants said that when technology is available, staff members are able to set up FaceTime or similar calls to encourage connection despite restrictions. Unfortunately, not all staff members have access to the necessary devices, nor do they have the capacity to schedule and facilitate these kinds of interactions. While this might work to mitigate some of the isolation experienced by residents, those in memory care units face unique challenges that make social isolation more troubling.

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It is well documented that people living with dementia experience increased quality of life when they are provided with routine and engagement with loved ones and those who are familiar to them (Alonzo 2017). The loss of these connections is clearly troublesome. One interviewee stated:

> We are getting reports . . . from those memory care units, where they're really kind of grasping at straws to figure out how to keep them engaged because so much of their care isn't really. . . it's more of like a social model of it than what the staff can provide. It's a lot of those family members coming in, doing extra things—taking them [residents] out, bringing kids in, and bringing pets in—that you can't do right now. So I do have a concern with that, if this goes on for a long, long time, right, no matter how well the facility is planning, there could be a lot of decline in those residents. And I do worry about that. (P4)

In addition, participants said that many residents in memory care units find it difficult to interact with care workers who wear masks because they can't see their face, read their lips (if they have hearing loss), or follow their expressions. One advocate explained that this can be disorienting, and can even lead to non-COVID yet COVID-related death as a result of agitation, depression, anxiety, and loss of appetite (see Shenk and Freidus 2020). That respondent stated, "There is going to be, and there is, a pandemic of older Americans that are going to die, and COVID-19 will not be the cause of death on their death certificate. But what caused them to die is the aftershock of COVID-19" (P6).

Discussion: Rapid Qualitative Appraisals and Impacting Policy and Guidelines

This chapter presents important findings from a case study using this methodology in relation to residential long-term care that was impacted by COVID-19 in the early phases of the pandemic in the United States. To summarize, we found that communication and transparency are crucial to ensure the health and well-being of both frontline workers and the residents they care for in these communities. When the executive order was enacted, and the doors to these communities were shuttered, the ability for Area Agency on Aging staff, advocacy groups, surveyors, family members, and friends to access these residents was halted. While the executive order was an important step in terms of infection control, there was no plan implemented to maintain consistent contact between the administration and residents with these key stakeholders. In addition, the safety measures needed were often insufficient as these communities were not prioritized

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even though they were disproportionately impacted. Testing, access to PPE, and support for staff were inconsistent. As a result, nearly all our interview participants voiced concerns about both the physical and mental/psychosocial health of residents. Social isolation and the ways in which mental health causes physical deterioration were identified as needing immediate attention.

This chapter also demonstrates the utility of using rapid qualitative appraisals during a complex health emergency. In particular, we demonstrate how methodological undertakings that arose during previous health emergencies can be modified based on the nature of the pandemic. Previous rapid qualitative appraisals proved essential in ending devastating outbreaks such as Ebola and SARS because of the ability to capture the narratives of those providing the necessary care to infected and potentially infected patients (Forrester et al. 2014; Johnson and Vindrola-Padros 2017; Pathmanathan et al. 2014). COVID-19 has expanded the definition of "frontline" workers to include those working with older adults in residential long-term care communities because they have been so hard hit.

It is important to document and learn from these experiences to ensure the safety and quality of life of those living and working in residential long-term care as we move through the pandemic and look to the future. We can only accomplish this through partnerships and collaborations with frontline workers and staff, including advocacy groups, Area Agency on Aging staff, direct care workers, and long-term care community and programs management. One participant with substantial policy experience suggested that there was a real opportunity to inform and direct policy especially after the initial outbreak and its insufficient response. This individual stated:

> The future, you know, the sort of the post-pandemic response is where I see the opportunity is to be able to say, you know, "What should we have had in place that we didn't, what should we now have in place that we would like to have, and what is it that we need to do to get to that point?" (P1)

Looking ahead to the near and more distant future, interviewees indicated the need not just for guidelines that may be implemented inconsistently, but also for mandated requirements that can be enforced. There are competing perspectives on what priorities ought to be and how best to meet the needs of residents in terms of physical and medical safety as well as mental health and social well-being. These data contribute specific insights into issues related to safety for residents and staff specifically; a special focus on infection control and testing, as well as the impact of social distancing and staffing issues; and stresses on the health and well-being of residents themselves.

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These data also provide knowledge about the kind of policies that needed immediate attention and allowed safe access to residents by families as well as Area Agency on Aging staff and advocates as an essential first step. Advocates ultimately worked with the North Carolina Department of Health and Human Services to develop a plan for phased reopening that began with safe visitation. As discussed in chapter 4, there is consensus that the social isolation caused by long-term closures negatively affected both the physical and mental health of residents. Therefore, a clear plan that includes reopening, which prioritizes creative ways of providing safe access to families and friends, will always be essential during complex health emergencies. At the time of these interviews, the "unknown" reported on by participants demonstrated the need to maintain effective mandatory reporting and communication systems, or an "emergency outreach communication plan" that ensures the utmost transparency between Area Agency on Aging staff, advocacy groups, families, and friends, with administrators and direct care workers in the residential long-term care communities.

In addition, known infection control protocols alongside a minimum sufficient stockpile of PPE in preparation for a sustained or future outbreak need to be maintained and standardized. Many of these communities have the resources to stockpile supplies but did not have them readily available when the COVID-19 outbreak began. This undoubtedly impacted safety and the willingness of some staff to continue working. Finally, specific policies need to ensure the provision of additional resources, support, and compensation for direct care workers in an effort to boost morale, acknowledge the additional emotional labor required of them to alleviate the social isolation of residents, and limit their need to work at multiple locations.

Notes

1. Sections of this chapter are adopted from Freidus, Shenk, and Wolf (2020b).
2. Under the Older Americans Act, each state is mandated to have a state ombudsman to oversee the staff and volunteer ombudsmen. Ombudsmen investigate complaints made by, or on behalf of, individual residents in residential long-term care communities. In our region, the ombudsmen are housed within the Area Agency on Aging.
3. It should be noted that federal CARES money did enhance Medicaid payments, but it was restricted to nursing homes and did not include assisted living communities unless they housed Medicaid recipients. At the state level, they did enhance Medicaid and Medicare payments as well as provide some direct appropriations.

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