Voices of Long-Term Care Workers

Life Course, Culture and Aging: Global Transformations
General Editor: Jay Sokolovsky, University of South Florida St. Petersburg

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The consequences of aging will influence most areas of contemporary life around the globe: the makeup of households and communities; systems of care; generational exchange and kinship; the cultural construction of the life cycle; symbolic representations of midlife, elderhood and old age; and attitudes toward health, disability and life's end. This series will publish monographs and collected works that examine these widespread transformations with a perspective on the entire life course as well as mid/late adulthood, engaging a cross-cultural framework. It will explore the role of older adults in changing cultural spaces and how this evolves in our rapidly globalizing planet.

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VOICES OF LONG-TERM CARE WORKERS

Elder Care in the Time of COVID-19 and Beyond

* * *

Andrea Freidus and Dena Shenk

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PREFACE

A few weeks into the lockdown in April 2020, Andrea, Dena, and Christin agreed among ourselves to carry out a rapid qualitative assessment of the impact of the COVID-19 pandemic on the care providers of older adults in need of long-term care in central North Carolina. Andrea was then living in Florida and Dena and Christin in North Carolina (although we didn't meet in person for many months and then only once—outdoors). The entire process of developing the project, scheduling and completing interviews, coding, analysis, writing, presenting papers and webinars, and writing this book have been completed virtually. That in itself is a testament to the pandemic and demonstrates one of the few and clearest positives to come from this disaster. The flexibility, determination, and resilience demonstrated by the long-term care providers who shared their narratives, as well as the creative use of technology, have made this book possible. And so, we begin . . .

ACKNOWLEDGMENTS

We want to begin by thanking all of our research participants for being so generous and sharing so openly and honestly during a period of uncertainty, chaos, and exhaustion. We also want to thank Christin Wolf, an essential component of this research team, for her dedication and hard work throughout this endeavor. We supervised two undergraduate gerontology minors, who in Spring 2020, assisted with organization and analysis of policy and guidelines as well as news media focused on care for older Americans during the pandemic. William Bell created drafts of the policy infographic that appears as figure 0.3 in the introduction. We thank James Robbins for his help with editing and formatting. Finally, we are especially grateful to the two anonymous reviewers who gave invaluable feedback to strengthen this work and make it accessible to anyone interested in these issues and the voices of these dedicated workers. We each want to thank our family who got us through the pandemic and supported us in this project.

ABBREVIATIONS

CARES	Coronavirus Aid, Relief, and Economic Security Act
CDC	Center for Disease Control and Prevention
CCRC	Continuing Care Retirement Community
CMS	Center for Medicare and Medicaid Services
CNA	Certified Nursing Assistant
DSS	Department of Social Services
IRB	Institutional Review Board
LPN	licensed practical nurse
NCDHHS	North Carolina Department of Health and Human Services
NGO	Non-Governmental Organization
NIA	National Institute on Aging
QoL	Quality of Life
PPE	personal protective equipment
RN	registered nurse

INTRODUCTION

“WE’RE BUILDING THE PLANE WHILE WE’RE FLYING IT”:

A Case Study of Long-Term Care Workers during COVID-19 in North Carolina

Grace is a chaplain at a continuing care retirement community in central North Carolina who we interviewed in August 2020.[1] She described her personal and professional experiences related to providing care for older adults since the COVID-19 pandemic erupted in the United States the previous March. She framed the multiple impacts on workers caring for older adults in a long-term residential care community as well as the residents, professional staff, and families; she also alluded to the effects of the pandemic on community-based programs. She described her experiences in great detail:

> We got word on the 9th of March that we would not be able to host any memorial services on our campuses for the foreseeable future, because they [the administration] wanted to stop any large groups of outside people coming on campus. . . . And so we got told that week, “Hey, you’re not gonna be able to have those services here on campus,” and then on that same day, they said also, “We don’t want you to go into the hospital right now. We feel like chaplains could be a super-spreader on our campuses, if you’re going to the hospitals and coming back.” . . .
>
> Every day there was something new: “We’re gonna do this now. Now, we’re doing this. We’re gonna close this gate down. We’re all gonna go through the front gate. We are all going to get our temperature [checked].” For those two weeks, it just changed. I read a quote in the [local newspaper] that said, “This time is like we’re building the plane while we’re flying it.”
>
> I’m married and my senior adult mom lives with my husband and me. And so when we get home. . . we’re her caregiver. She’s not like somebody who’s home cooking dinner for me when I get home. I have to take care of her. And my husband’s really had to step up what he does because he’s working from home. And we’re not sending her to her day program. So my coworker and I

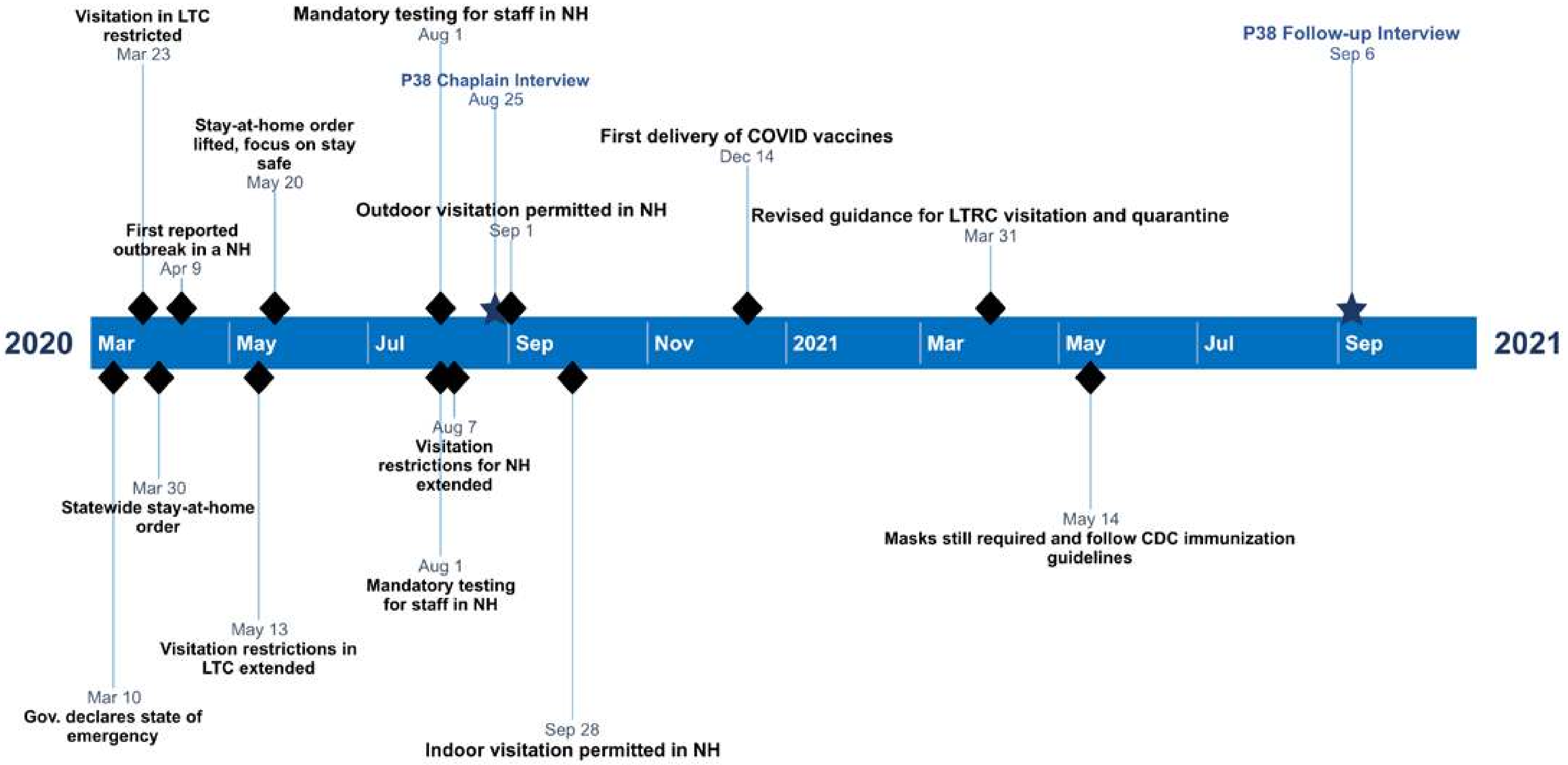


Figure 0.1. Timeline of Early Response to COVID-19 in North Carolina.

> both have not quiet homes where we just go and hibernate, but we have a lot of demands in our own homes, and so we're not just stressed at work, we're stressed at home too. But at the same time, we wanna show up and be there for our staff, and it's been weird just figuring out how to do that during this time. . . . I think our most important job is building relationships with people so that when the hard times come, we already have that foundation of a relationship. (P38)

Grace is one of seventy-six care providers we interviewed as the COVID-19 pandemic evolved. In her interview, she demonstrates the importance and challenges of communication, the need for a flexible human infrastructure, and the resilience and creativity of staff who care for older Americans. These are key themes we will see throughout this book. In the following interview excerpt, she explains her personal challenges early in the pandemic:

> I didn't sleep well that first month, maybe six weeks. I did not sleep well at all, because every night I would lay in bed and think, "Oh my gosh, have I brought this virus home to my mom?" 'Cause my husband's working from home, and my mom was at home, and we did have some caregivers coming into the house, but it was me that was out among the people. . . . And here's the truth, my mother-in-law died in July [2020] with the virus, and she was in a facility. She was end-stage dementia, and she was in a facility, and she contracted it through an employee who didn't know they had it, but they were doing routine testing. And so then they tested all the residents on her wing, and five of them tested positive, including my mother-in-law. And the other four were immediately sick and she wasn't. And she got to about day twelve of having been tested positive and all of a sudden she started developing symptoms. . . . And it was just in a few days, she was gone. And so it has impacted my family that way too. So I carry that with me. . . . But early on, I was so worried about bringing it home to my mom. And actually, we all did get exposed to the virus in my house through one of my mom's caregivers. . . . She didn't know that she had it. . . . She tested positive a few days afterwards. None of us actually got it, but none of us tested positive, I'll put it that way. (P38)

She talked about the impact of the lockdown on residents:

> I feel like the isolation from their families is just really a key thing. I have talked to one resident who's just despondent, and it isn't just the isolation from her family, she's nearly a hundred, and she's had some health issues this year. And she's feeling a little bit of [an] existential crisis. . . And sad, I feel the sadness, not only of the people that we've lost and I didn't get to visit them, but it's just the not being together on this.

She went on to discuss the resiliency required of the staff:

> We're not wired for all of the information, okay, that I get just in my phone and Facebook, you know? The amount of empathy and rage and all of that, we're just not wired just to know everything all the time. We just can't manage that. . . . And so it's just like, like you said, the perfect storm of just so much angst and so much unknown, and it's really hard. . . . You make a decision and it's the right thing, and then you make the decision and it's the wrong thing. And it's just been building the plane while you're flying it.

The Canary in the Nursing Home

In March 2020 alarm bells were raised when the virus swept rapidly through a nursing home in Kirkland, Washington. That outbreak infected eighty-one residents and took the lives of thirty-five people, including both residents and staff. The impact continued to differentially impact older Americans, especially those in residential care communities, with over 60 percent of reported mortality occurring in Americans sixty-five and older in North Carolina, the site of our research. In response to the Centers for Disease Control and Prevention (CDC) guidelines, governors across the country scrambled to shutter long-term residential care sites and initiate emergency infection disease control measures. At this time, we were invited by an international working group to conduct a mirror study on the impact COVID-19 was having on frontline workers in caring for patients with COVID-19 (Vindrola-Padros and Johnson 2022). We expanded their focus to study those caring for older adults in both long-term residential care and community-based programs.

Long-term residential care residents have been the most affected by COVID-19 in many countries, representing as many as half of all deaths for COVID-19 in a number of European countries, over three-quarters in Canada, and around 40 percent in the United States, according to some of the latest available data sources (Badone 2021; Inzitari et al. 2020). Despite heterogeneity in policies, responsibilities, and funding for long-term care in various countries and locations (Picard 2021; Spasova et al. 2018), long-term residential care communities share many common threads in infrastructure, organization, and workforce (McMichael et al. 2020). This includes low staff-to-resident ratios; low-paid staff; low skill-mix; and high staff turnover, creating environments with minimal resilience to adverse events (Inzitari et al. 2020).

The pandemic generated unprecedented awareness of the value and precarity of the long-term care system and its workforce (Scales 2021). The marginalized status of direct care workers was revealed through reports about their inadequate access to personal protective equipment (PPE), relevant training, paid sick leave, and other supports (Lyons 2020). Long-term care providers struggled to maintain services without enough workers, highlighting the shortages of direct care staff (Almendrala 2020). It became impossible to overlook direct care workers' essential role in providing care in places for those most at risk from the disease (Scales 2021). In an effort to capture the voices of and experiences of the workers, we began our research in May 2020, and our methods will be discussed below.

Effective communication, among all levels of staff, with residents/clients, and families emerged as a central element in understanding the experiences of those providing care for older adults during the pandemic. Other crucial issues include balancing social isolation and protection, flexibility, and access to and effective use of technology. The pandemic highlighted long-standing issues related to human infrastructure—including retention, turnover, the need for adequate pay with benefits, and lack of career pathways—but also illuminated the resilience and dedication of the caregivers. These themes are discussed throughout the following chapters.

We continued to talk with long-term care staff as the pandemic continued, and a year later, in August 2021, we received the following update from Grace:

> It has certainly been a year, hasn't it?? In our community, we did have a couple of outbreaks of the virus that were quite tough and because of that, it was an incredibly hard time. In the winter, we were able to get a large majority of our residents vaccinated, and that was amazing. One-on-one indoor visitation began to return to skilled and assisted living areas in the spring of this year [based on federal guidelines], and it was so good to see family members return to those areas. Of course, that has had temporary suspension with any virus issues in those areas, but that has not been a super common occurrence since the spring. . . . And since the beginning of April [2021], my co-chaplain and I have been able to lead in-person services each Sunday. . . . The one thing we have not been able to resume is hospital visitation since visitor restrictions are still in place at most hospitals. It feels good to have returned to some sense of normalcy, but I do believe we will be dealing with the emotional fall-out of the pandemic for years to come. The recent development [of the Delta variant] has brought back some anxiety to our campus, and we will see how that unfolds.
>
> For me, personally, it has been one of the hardest periods of my life. As you may remember, my husband and I were caregivers to my mother who lived in our home with us. That added a different dimension of stress to our Covid life. She died in December after a bout with aspiration pneumonia, and we had a virtual memorial service for her just after Christmas. . . . I returned to my therapist in January, the same person who helped me navigate my grief after my father's death four and a half years ago, and I am grateful for that.

> The last year and a half have been difficult both personally and professionally, and I have become very intentional about my self-care! (P38)

Long-Term Care in the United States

Long-term care is most effectively viewed as a continuum based on the needs and personal situation of the recipient. Ideally, a person would choose from a range of alternatives, including residential and home or community-based programs. In the US, however, long-term care for older adults was originally developed based on a medical model following the medicalization of everyday life and institutional care. As a result, most care is provided in institutional or congregate residential environments (see McLean 2007 for a history of the development of institutional care and nursing homes in the US). It is well established that medicine has become a powerful institution of social control able to determine as well as direct cultural and social values (Zola 1972). An effective way of exerting this control is by applying medicine, health, and illness concepts and approaches to ever-expanding ranges of daily living activities, processes, and states of being including aging and disability (Zola 2009). Aging Americans have historically been defined and managed by their physical and biological needs and limitations. As a result, models of care for this population have focused almost exclusively on the physical self and quantity of life, with less attention paid to the whole self, overall quality of life, variations within the population, or quality of care, broadly defined (Wolf-Meyer 2020). Elder care in the US is fragmented and relies on different streams of government funding and rules and regulations vary between states (Coe 2019). Medicare and Medicaid, the major forms of public financing for elder care, were developed over fifty years ago. Healthcare experts consider them to be too focused on acute care rather than the management of the chronic conditions and disabilities that beset older adults today (Institute of Medicine 2008). Moreover, the system has focused predominantly on congregate residential alternatives.

Since the early 1960s, but gaining substantive traction in the 1980s and 1990s, multiple models have been developed to implement culture change and person-centered care of older adults in residential long-term care communities to address these issues. The National Consumer Voice for Quality Long-Term Care (founded 1975), Pioneer Network (founded 1997), and the Green House Project (founded 2003) were precursors to the current effort to totally rethink nursing homes (e.g., Schulson 2020). An extensive literature documents the advantages of alternative models to traditional large institutions with rigid schedules that provide little autonomy for residents, who in these settings have reported feeling bored, lonely, and helpless (Agency for Healthcare Research and Quality 2014). At the same time, there has been an increased privatization of long-term care communities. As Armstrong, Armstrong, and Bourgeault (2020) explain from Canada, there has been a move to private (often for-profit) delivery of services and increased responsibility of individuals and their families.

Person-centered care is commonly recognized as a core concept guiding a change of philosophy from a traditional medical model to a more humanistic approach to care (Junxin and Porock 2014). Culture change requires a reorientation of institutional values, attitudes, and practices of the individual community (Koren 2010). For example, instead of a model focused on "nursing," an emphasis is placed on "homes," prioritizing quality of life as well as resident agency (Koren 2010). Other linguistic shifts ensued in an effort to capture this conceptual change. "Patients" are now referred to as "residents" and "facilities" are termed "communities" or "residences." Through sustained advocacy, residents in congregate residential settings were to be afforded individualized services to support their mental and psychosocial needs in addition to their physical requirements. There has been less attention paid to identifying local cultural features to preserve or reconfigure when implementing culture change (Briody and Briller 2017). Despite inroads to provide person-centered care, the cultural orientation of the medical model remains pervasive, along with its focus on the physical needs of residents. This focus was exacerbated during the COVID-19 pandemic and is evident in the data presented in this book. For example, the essay and poem at the beginning of chapter 2 highlight the efforts of long-term residents at the Coler Rehabilitation and Nursing Center. Figure 0.2

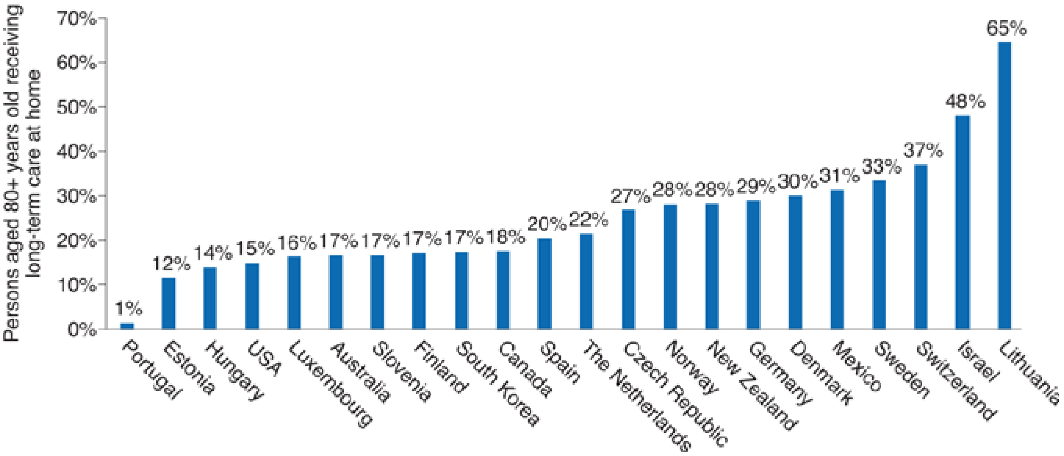


Figure 0.2. Proportion of Older Adults Receiving Long-Term Care at Home in Various Countries.[2]

All data are from 2018 except Canada, Mexico, and the US, which are from 2016, and the Netherlands and Slovenia, which are from 2017. Data obtained from OECD.Stat (2020).

presents a global comparison of the proportion of older adults receiving long-term care at home in various countries, illustrating that the US provides a very low portion of community-based long-term care to older adults in their homes.

Caring for older Americans requires a committed and well-trained workforce sensitive to their evolving needs. Long-standing challenges in caregiving of older adults in both residential and community-based care include inadequate staffing, high staff turnover, low pay, insufficient benefits, and lack of a career ladder. "US long-term care workers are predominantly female, one-third are born outside the US, have high rates of injury, earn low wages ($18 an hour), have no health insurance through their employment, and often hold multiple jobs" (Van Houtven, Boucher, and Dawson 2020: 7). Specifically, the direct care workforce is dominated by undereducated, immigrant, and minority women who often live in poverty while working full-time (Coe 2019; Potter, Churilla, and Smith 2006). The direct care workforce in North Carolina is 91 percent women, 60 percent people of color, and 6 percent immigrants (PHI n.d.). The system perpetuates their immobility on the "sticky floor" (Smith and Elliot 2002)—that is, jobs that provide few options for promotion. Their working conditions generally include low wages, poor benefits, and staffing shortages that increase the possibilities of physical and emotional injuries (Potter, Churilla, and Smith 2006). COVID-19 has greatly magnified the "value and precarity" of the long-term care system and its workforce in the US (Scales 2021: 497). The high rate of turnover of healthcare workers, particularly in direct care healthcare occupations, has been an ongoing problem. A study of healthcare workers' turnover during the pandemic reported that although much of the healthcare workforce is on track to recover to pre-pandemic turnover rates, these rates have been persistently high and slow to recover among long-term care workers, health aides and assistants, workers of minoritized racial and ethnic groups, and women with young children (Frogner and Dill 2022).

As Stacey (2005) summarized from the limited literature on home care work, the tendency is either to romanticize the importance of the emotional ties between the caregivers and clients, or to emphasize the exploitative nature of the relationship. Our findings demonstrate how these issues have been highlighted and exacerbated during the COVID-19 pandemic and emphasize the resilience and dedication of the workers. Early reports indicate that the pandemic resulted in workforce shortages for home and community-based services provided in an enrollee's home and in group homes, while closures due to social distancing measures was the most frequently reported impact for adult day health programs (Watts, Musumeci, and Ammula 2021).

Complex Health Emergencies and Rapid Qualitative Assessments

The value of qualitative data to direct or inform evidence-based public health responses to complex health emergencies, in general, and infectious disease outbreaks, in particular, is becoming increasingly visible, although it is still marginalized compared to other research designs (Vindrola-Padros et al. 2020a). The Ebola virus outbreaks that occurred between 2013 and 2016 in West Africa were the first to truly illuminate the value of and need for rapid qualitative work that prioritizes cultural and local perspectives (Johnson and Vindrola-Padros 2017). According to Johnson and Vindrola-Padros (2017), the WHO convened an emergency health mission in collaboration with UNICEF to guide the "on-the-ground response" to the Ebola outbreak and explicitly recruited social anthropologists to work on the mission (Abramowitz et al. 2015). Data collected from previous pandemics, including SARS, MERS, and Ebola, while less pervasive in nature, have provided valuable lessons about how to care for patients during a time of emergency and also illuminate key concerns among frontline healthcare providers who treat infected and potentially infected patients (Khalid et al. 2016; Koh, Hegney, and Drury 2011; McMahon et al. 2016; Raven, Wurie, and Witter 2018)[3].

The rapid ethnographic appraisals referenced above are valuable because of key characteristics that ensure the generation of indispensable and timely information that is meant to directly inform interventions, policy, and programming. These characteristics include a condensed data collection timeline (documented studies range from weeks up to six months) and "research that captures relevant social, cultural, and behavioral information and focuses on human experiences and practices" (Vindrola-Padros and Vindrola-Padros 2017: 8). Additionally, rapid ethnographic appraisals are usually team-based so that data can be analyzed quickly, are cross-checked efficiently, and are rooted in anthropological theories (Vindrola-Padros and Vindrola-Padros 2017). These methods have proven effective in informing on-the-ground responses in real time as well as shaping policy and programming in preparation for future outbreaks (for example, see Forrester et al. 2014 on rapid qualitative research informing Liberia's Ebola response, and Pathmananthan et al. 2014 on using rapid qualitative appraisals to direct Sierra's Leone's Ministry of Health prevention control strategies).

In theoretical terms, policy reflects political negotiations that serve to guide, shape, or control behaviors and attitudes that reflect or even produce cultural and social norms (Eisenberg 2011; Shore and Wright 2011; Yanow 2011). Therefore, a multitude of narratives ought to be captured to ensure the most comprehensive policies are created that work to serve those most affected. In the case presented here, we capture the voices of the frontline network providing care for older adults in long-term care. Applied anthropology is well suited to take the lead in these kinds of appraisals due to our practice of taking a holistic approach, valuing local knowledge and culture, being able to capture a diversity of narratives and experiences, emphasizing community engagement and collaboration, as well as being able to communicate across steep gradients of power. We are especially charged with demonstrating how the knowledge we produce can and should inform policy and programming. This can be accomplished by effectively using our tools, acknowledging our limitations, tempering our claims, and providing the utmost transparency about both our process and our goals (Johnson and Vindrola-Padros 2017; Vindrola-Padros and Vindrola-Padros 2017; Yanow 2011).

Proponents of rapid qualitative research acknowledge the key critique of this methodology in its relationship to praxis, that is applying the findings. This concern is centered on the validity and accuracy of data analysis because it is an iterative process that begins in the early stages of the assessment (Vindrola-Padros and Vindrola-Padros 2017). There is concern about actionable preliminary findings being insufficient, underdeveloped, or incomplete because the research process has been at times labeled "quick and dirty" (Vindrola-Padros and Vindrola-Padros 2017). While "quick" is appropriate because of the time-sensitive nature of the research during an ongoing global health crisis, the notion that these data are "dirty" is easily challenged within the research design with the selection of the research team and purposive recruitment of research participants, which can lead to "deep and valid ways of knowing" (Pink and Morgan 2013: 351).

The current study used a rapid qualitative assessment focused on the frontline caregivers of older Americans in central North Carolina during the COVID-19 pandemic because these methods are particularly useful in identifying social structures, immediate needs from community perspectives, as well as drawing out local knowledge and expertise (Brennan and Rimba 2005). Our methods were adapted to the circumstances that made traditional ethnographic research impossible, so our interactions with caregivers were all via telephone and Zoom. In addition, we captured and analyzed the policies and programming that evolved throughout the pandemic. This is important as policy reflects political negotiations that guide, shape, or control behavior and attitudes that reflect or even produce social norms (Eisenberg 2011: 97; Shore and Wright 2011; Yanow 2011). Anthropologists are called to understand and eventually inform the policy-making process. This appraisal takes up this call to action by collecting qualitative insights from long-term care workers about their experiences, including their concerns, that are contextualized using policy analysis and epidemiological data in the anticipation of informing future policy from "the ground up" (Eisenberg 2011).

As the COVID-19 pandemic spread across the United States, federal, state, and local governments struggled to create policies and guidelines in response to the largely unknown and evolving crisis. At the federal level, the Centers for Disease Control and Prevention (CDC) and Center for Medicare and Medicaid Services (CMS) established guidelines that states and local entities used to shape local policies and practices. See Figure 0.3 that tracks the actions of the North Carolina Department of Health and Human Services (NC-DHHS) in relation to long-term care over the course of the pandemic. These guidelines had to be translated into action by those providing care to older adults.

Throughout the pandemic there was a massive amount of communication regarding the implementation of these changing guidelines. We attempted to develop a flowchart to demonstrate how communication was diffused and defused, but we gave up in frustration. We have incredible admiration for the administrators, managers, and staff who navigated this evolving terrain with the complexity of constantly changing restrictions and recommendations as the pandemic evolved and more knowledge about COVID became available. A rapid qualitative appraisal that captures the narratives of all long-term care frontline providers is an essential step in understanding what obstacles they faced and what resources and strategies are needed to avoid "sacrificing" themselves and the older Americans they serve in the future.

Methods

This research began as a mirror study conducted as part of the global efforts spearheaded by the Rapid Research, Evaluation and Appraisal Lab (RREAL) at University College London (Vindrola-Padros and Johnson 2020 and 2022; Vindrola-Padros et al. 2020). At an early meeting of the global teams, a group from Switzerland talked about studying the experiences of frontline workers in a nursing home, which caught Freidus's interest. Early attention in the US focused on the high rates of COVID-19 infection and severe impact on older adults, particularly those in congregate long-term care communities. Freidus contacted Shenk for assistance in identifying initial participants in order to study caregiving of older adults in need of long-term care in central North Carolina, and the project was born.

The formation of a knowledgeable and dedicated team is an essential step in ensuring the best possible results and enables the collection of quality data. Having an expert of both the topical and geographical area of fo-

COVID-19 RESPONSE

NC-DHHS

A BRIEF SUMMARY OF ACTION FROM THE NC-DHHS DURING THE COVID-19 PANDEMIC PARTICULARLY RELATING TO LTC

MARCH 10, 2020

Released "COVID-19 Mitigation Guidance" for congregate living facilities, such as LTC facilities, advocating for limiting visitation.

Also for general public, advisory against mass gatherings, suggest social distancing, self quarantine of travelers from outside US.

JULY 24, 2020

Secretarial Order #1: Visitation Restrictions for Nursing Homes

Restrictions of visitors and non-essential personnel at nursing homes , except for certain compassionate-care situations. Communal dining and group activities remain restricted.

AUGUST 7, 2020

Secretarial Order #2: Mandatory Testing for Staff in Nursing Homes

SEPTEMBER 1, 2020

Secretarial Order #3: Visitation for Nursing Homes

Allows for outdoor visitation at nursing homes that meet several public health requirements.

SEPTEMBER 21, 2020

Secretarial Order #4: Mandatory Testing for Staff in Nursing Homes

Replaces Secretarial Order 2 and applies only to nursing homes, including nursing home beds in hospital facilities.

SEPTEMBER 22, 2020

Secretarial Order #5: Extension of Secretarial Order No. 3.

SEPTEMBER 28, 2020

Secretarial Order #6: Visitation for Long-term Care Facilities

Updates visitation guidelines for nursing homes to allow indoor visitation.

DECEMBER 31, 2020

Secretarial Order #7: Rescission of Secretarial Order No. 4: Mandatory Testing for Staff in Nursing Homes!

JANUARY 6, 2021

NC-DHHS Secretarial Directive

Instructs individuals to take immediate action in an effort to protect themselves and others from COVID-19, using guidance from White House Coronavirus Task Force and the Governor's Executive Orders on COVID-19 and aligning with the COVID-19 County Alert System for North Carolina.

FEBRUARY 26, 2021

Rescission of NC-DHHS Secretarial Directive

MARCH 10, 2021

Secretarial Order #9: Rescission of Secretarial Order No. 6: Visitation for Long-term Care Facilities

MARCH 31, 2021

Guidance for Visitation and Quarantine in Long Term Care Facilities is released.

Figure 0.3. North Carolina Department of Health and Human Services long-term care COVID-19 actions.

cus leading the team is indispensable to the process. Shenk is the former director of the gerontology program at UNC Charlotte and has worked in the field of aging in North Carolina for more than thirty years. Once recruited, she utilized her extensive professional networks in the region and knowledge of the aging field to map the long-term care network and recruit research participants. Freidus is an applied medical anthropologist who has worked extensively on health-related disparities among vulnerable populations in the US and overseas. The third member of the research team was a graduate assistant, Christin Wolf, who conducted interviews, coded, and participated in organization and analysis.

We began by interviewing former students and colleagues of Shenk who are currently working at the regional and state level as managers, ombudsmen,[4] and advocates; these managers, supervisors, and advocates formed the first phase of the sample. We went on to interview workers across the continuum of long-term care in three overlapping phases. We envisioned the sample as a puzzle, and each piece provided a specific perspective on the situation of caregiving for older adults in central North Carolina during the pandemic. Shenk's intimate knowledge of the landscape was essential in conducting this project because she crafted a purposive sample that was not random but rather allowed for some degree of representativeness to be built into the design that we argue led to more reliable, valid, and actionable data from the onset (Vindrola-Padros and Vindrola-Padros 2017).

This three-phase rapid qualitative assessment captures a moment in time and shines a light on the perspectives of workers providing long-term care to older adults in central North Carolina during the first year of the pandemic. We conducted interviews with seventy-six people from June to November 2020. We included participants from all types of long-term residential care communities as well as workers providing in-home and community-based services. Phase 1 focused on administrative and nongovernmental advocacy groups that work with long-term residential care communities including residents, families, and the direct care providers within these homes, as well as providers of home and community-based aging programs. Phase two included a sample of administrators of long-term residential care communities as well as the workers providing hands-on care in fifteen residential care communities. We included workers in continuing care retirement communities (CCRCs[5]), nursing homes, assisted living communities, adult care homes and memory care for persons living with dementia. Participants in Phase 2 included dining staff, housekeepers, chaplains, marketing staff, certified nursing assistants (CNAs), medical technicians (med techs), activities staff, nurses, nurse practitioners, and administrators. Phase 3 focused on home and community-based care workers who provide services and assistance to older adults living in the community, including managers and staff providing information and referrals, staffing adult daycares, providing home care and home health care, distributing home-delivered meals, running senior centers, and providing transportation and some medical care. The three phases overlapped in terms of the timing of the interviews.

We conducted narrative interviews with a purposive sample from June to November 2020 and followed up with focus groups and individual updates as the pandemic evolved. We also tracked policy and guidelines as they were developed. The interviews were video recorded using a web-based platform and were transcribed verbatim. Similar questions were posed in each phase in semistructured interviews ranging from 23 to 145 minutes. In our effort to understand the experiences of these service providers, each participant was asked about the overall impact of the pandemic on their provision of care for older adults, as well as their key concerns. A total of sixty-seven hours of interviews were recorded with the seventy-six participants, and our team generated codes for these data through an ongoing, inductive approach. In order to protect anonymity, a number was assigned to each participant. This participant number or a fictive name is used in reporting on our findings. Only the few participants who are quoted extensively have been given a fictive name to foster readability, and most are referred to by their participant number (e.g. P#). This enables a reader to follow the interviews and discussion about a particular participant by recognizing their fictive name or participant number.

We continued to communicate with participants and received ongoing updates through the winter of 2021 as vaccines became available. We organized three focus group discussions with administrators of long-term residential care communities, activities coordinators, and home and community-based care professionals to obtain updates and share information among participants. These are examples of the work we did to foster communication and sharing of information and ideas within the community of aging service care providers as the pandemic continued. We included several workers outside central North Carolina in these conversations and focus groups in our efforts to understand what was happening in long-term care. At the same time, we began sharing our findings through conference presentations, webinars, journal articles, and book chapters. We have adapted some of these earlier publications in this introduction and several of the following chapters.

In each chapter of this book, we provide an in-depth analysis of various aspects of the ways in which programs and communities met the challenges to provide care to their residents and clients during the pandemic, along with a demographic table of the participants in that phase. Communication and resilience provide the overarching framework for understanding the narrative descriptions of their lived experiences.

Organization of the Book

This book includes eight chapters, plus this introduction and a conclusion, that present the narratives of a range of participants as we focus on care in a specific environment or an issue that emerged from our analysis of the responses to the COVID-19 pandemic by the staff, managers, and administrators who care for older adults in residential and home and community-based programs. We developed the chapter topics based on our analysis of the findings. The major themes of communication, resilience, and human infrastructure are highlighted in each chapter. Several of the chapters were published earlier as journal articles or book chapters. We have revised them and provided updated contextualization, but some overlap of the discussion of background and methods, for example, has been retained. This will enable people to read the chapters that are of greatest interest to them and not necessarily in the order we present them. While Freidus and Shenk wrote most of the book, we invited colleagues to join us for several of the chapters and these are indicated in bylines of those chapters.

The manuscript is structured so the first three chapters focus on three segments of the long-term care continuum and replicate the three phases of our research: 1) oversight and advocacy, 2) residential care, and 3) home and community-based care. In chapter 1, we analyze the interviews with Area Agency on Aging staff and state advocates that occurred during the early days of the lockdown of long-term residential care communities and ongoing reorientation of home and community-based programs. Key points raised focus on safety including access and use of PPE, infection control, limited testing, and staffing issues. In addition, participants expressed concerns about the physical and mental health of long-term care residents because they had been isolated from family and friends since the executive order closed these communities to all nonessential people.

Chapter 2 focuses on challenges in providing long-term residential care and is based on interviews with thirty staff caring for residents from July through October 2020. We include a smaller case study of a COVID-19 unit in a skilled nursing home in central North Carolina, where over twenty residents died in just under two and a half months. We report on the emotional and visceral experiences of direct care workers providing care during the pandemic. We draw on affect theory to analyze the narratives in an attempt to capture their feelings, sentimentalities, and sensory experiences. We organize the data into four affect categories: fear/anxiety, sadness/grief, anger/frustration, and trauma/stress.

In chapter 3, we shift focus to home and community-based programs. These were generally shut down in mid-March 2020, when managers of these programs quickly pivoted to communicate with clients and coordinated to ensure clients' basic needs were met. They struggled to keep up with evolving guidelines while facing challenges in regard to infection control, logistics, and access to and use of technology. At the same time, staff were experiencing personal challenges related to risk of infection and their own family responsibilities. Managers demonstrated a flexible understanding of human infrastructure and worked with staff to support sustainable solutions and personal resilience in order to ensure the continuation of resources and services to clients.

Isolation and loneliness were exacerbated by communication challenges due to restrictions stemming from the pandemic. In chapter 4, we draw on the narratives of activities staff regarding challenges in providing activities and engagement for residents and clients while maintaining evolving infection control mandates. For example, activities professionals in long-term residential care shared their creative efforts to provide engagement while residents were isolated in their rooms or forced into severe physical distancing restrictions. Home and community-based providers also pivoted to effectively address issues related to clients isolated in their homes. In both residential and community-based models, differential access to resources, especially technology, varied widely. For example, some residential care communities had the ability to stream original programming into individual rooms while others turned to using individual caregivers' personal phones to video call residents' families. We highlight human infrastructure challenges, including staffing to manage communication with families.

COVID-19 presented unique challenges for those caring for persons living with dementia. Most of the challenges identified in other chapters—including communication with residents and clients, safety issues, social isolation, and access to technology—are heightened when combined with memory impairment and various levels of cognitive decline. Chapter 5, coauthored with Christin Wolf, captures the experiences of workers including administrators, activities professionals, nurses, and CNAs who demonstrated high levels of resiliency in their efforts to pivot programming, infection control measures, and communication that would be effective for persons living with dementia.

Administrators and managers in both long-term residential care and home and community-based programs faced enormous challenges as they struggled to understand the COVID-19 epidemic and implement policies and guidelines that were constantly evolving. Focusing on the decision-makers at the local level, in chapter 6 we present the ways in which they continually integrated data and knowledge into programming necessary to meet the needs of staff, clients, and residents. Effective leadership required rapid assimilation of information and communication to keep residents, clients, and staff safe while providing services and care. Flexible human infrastructure was necessary to sustain both safety and the provision of modified services for in-home and community-based care in addition to long-term residential care.

Chapter 7, coauthored by Boyd Davis and Christin Wolf, provides a linguistic analysis of selected interviews from each phase and focuses on the efforts of the care providers to construct their identities and reframe their roles throughout the pandemic. As the pandemic evolved, staff and administrator discourse showed changes in how people positioned and found themselves repositioned with regard to their residents/clients, their coworkers, and the disease itself. Framing and often reframing their roles became a necessity as their reliable and expected world lost meaning. They utilized nine interviews, three for each phase of research, and used corpus-based analytic tools and techniques to identify key framing devices and emerging discourse patterns revealing their thoughts and fears during a situation that would not, and could not, stand still.

In chapter 8, written in collaboration with Megan Davies, Christin Wolf, and Sandra Staudacher, we compare our findings with those of their Swiss team that was part of the RREAL group, which conducted an independent qualitative appraisal of long-term residential care during COVID-19. US policy has led to extreme visitation restrictions since March 2020, while in Switzerland, visitation was more nuanced after an initial lockdown. Interviews with frontline workers in both countries illuminate ongoing tensions between the need to physically protect residents while maintaining quality of life (QoL). We analyze the effects of these divergent approaches. Based on our findings, we examine staff perceptions and experiences, including fear and anxiety while navigating risk of COVID-19 infection, navigating provision of care during the pandemic, implementing limited and evolving policies and guidelines, and ensuring engagement and QoL for residents amid ongoing isolation. We argue that these experiences are largely shaped by the models of care, with the US relying heavily on a medical model and Switzerland attempting to maintain a person-centered approach.

We conclude with a discussion of our experiences doing this work, lessons learned, positive outcomes, recommendations, and policy and programming implications as we look to the future.

Demographic details of the sample are included as tables in individual chapters. Most chapters also include a timeline indicating when each interview was conducted in order to contextualize individual experiences and perceptions during the evolving pandemic. For example, demographics of the regional Area Agency on Aging staff and advocates are included in chapter 1 along with a timeline indicating the dates of their initial and follow-up interviews. We include the sampling frame of residential care staff in chapter 2 and home and community-based staff in chapter 3. In the remaining chapters, we include a demographic table of the sampling frame and a timeline of the cultural context for the narratives included in the chapter. The timelines provide a glimpse of the environmental context at the time the interviews were conducted.

We envision this book being used in various ways by a broad range of readers in fields including anthropology, gerontology, sociology, social work, nursing, public health, policy, and administration. Individual chapters can be assigned as stand-alone readings for students, for example. With consideration for the broad intended audiences, we have used minimal abbreviations throughout the text. We have also made mindful language choices and tried to define terminology throughout the book. For example, early in the process people talked about the COVID-19 epidemic, which then evolved into referring to the pandemic, as the scope became apparent. We use the terms "COVID-19," "Covid," and "coronavirus" interchangeably. We use the terms "participant," "interviewee," and "respondent" interchangeably to refer to the aging service professionals who participated in our research. We use the terms "communities" and "homes" rather than "facilities" for all levels of congregate residential long-term care. You will notice, however, that the term "facilities" is used by some of the participants, including in some of the essays. Finally, the term "social distancing" was generally used to refer to the requirement of keeping people at safe distances. Several participants preferred the terms "physical distancing" or "safe distancing," which are in fact more accurate.

The essays at the beginning of the chapters highlight lived experiences presented as personal vignettes. Each chapter then illuminates and integrates the stories told in these essays. We hope we have set the stage effectively for our analysis in the following chapters of the narratives of these long-term care workers during the early stages of the COVID-19 pandemic.

Notes

1. Sections of this chapter are adapted from Freidus et al. (2020 and 2021).
2. Grabowski (2021).
3. For a discussion of frontline workers' experiences with Ebola and other respiratory infectious disease outbreaks, see also Freidus, Shenk, and Wolf (2021).
4. 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 long-term residential care communities. In our region, the ombudsmen are housed within the Area Agency on Aging. Long-term care ombudsmen assist residents of long-term care residential communities in exercising their rights and attempt to resolve grievances between residents, families, and facilities.
5. CCRCs are communities offering a range of levels of care on one campus. CCRCs, or life plan communities, are a long-term care option for older people who want to stay in the same place through different phases of the aging process.

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 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.

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.

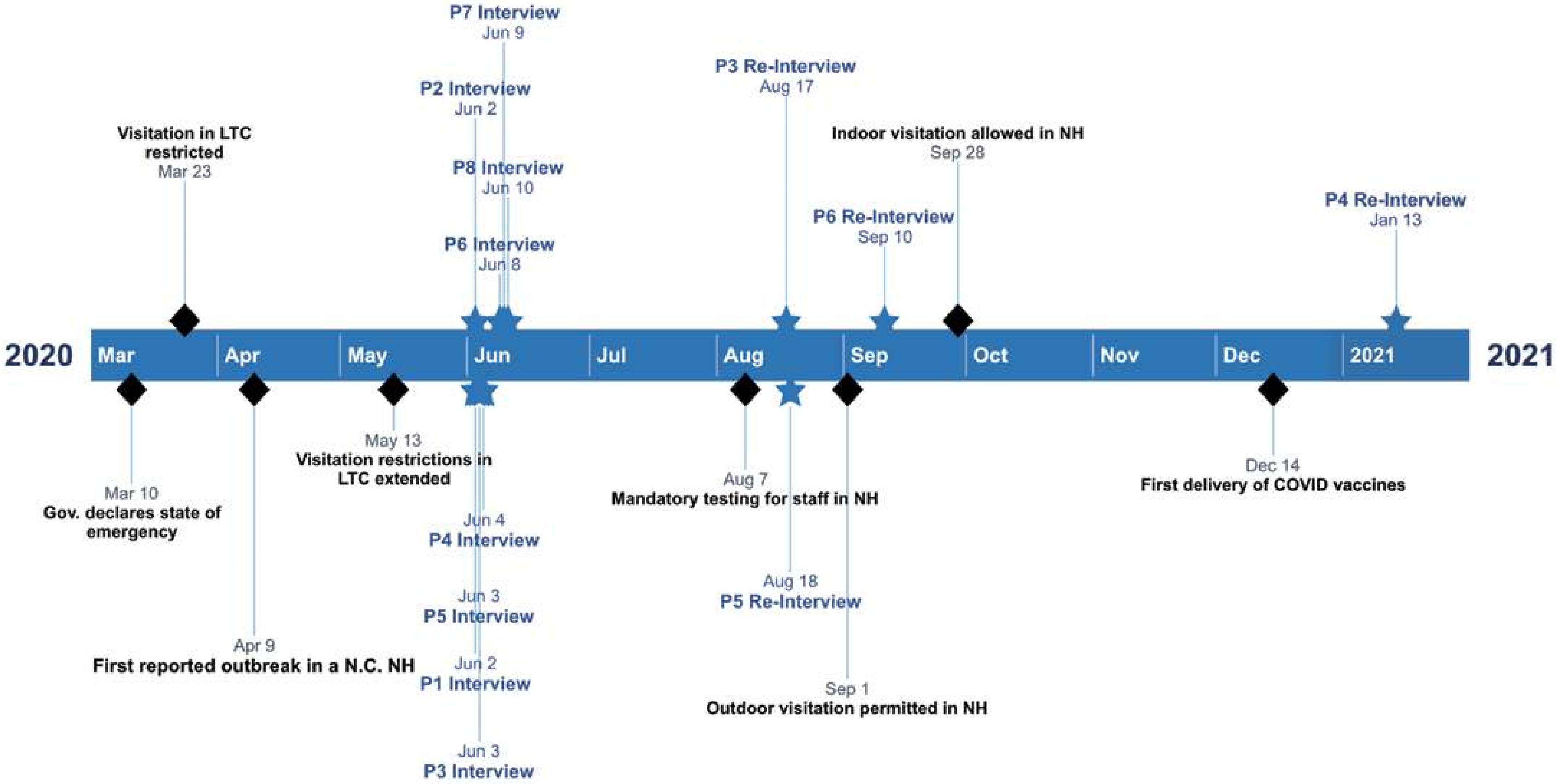


Figure 1.1. Timeline of Interviews Quoted in Chapter 1.

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 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

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. Participants 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.

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

> 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.

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 interviewees 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 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 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.

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:

> 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.

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 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.

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.

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

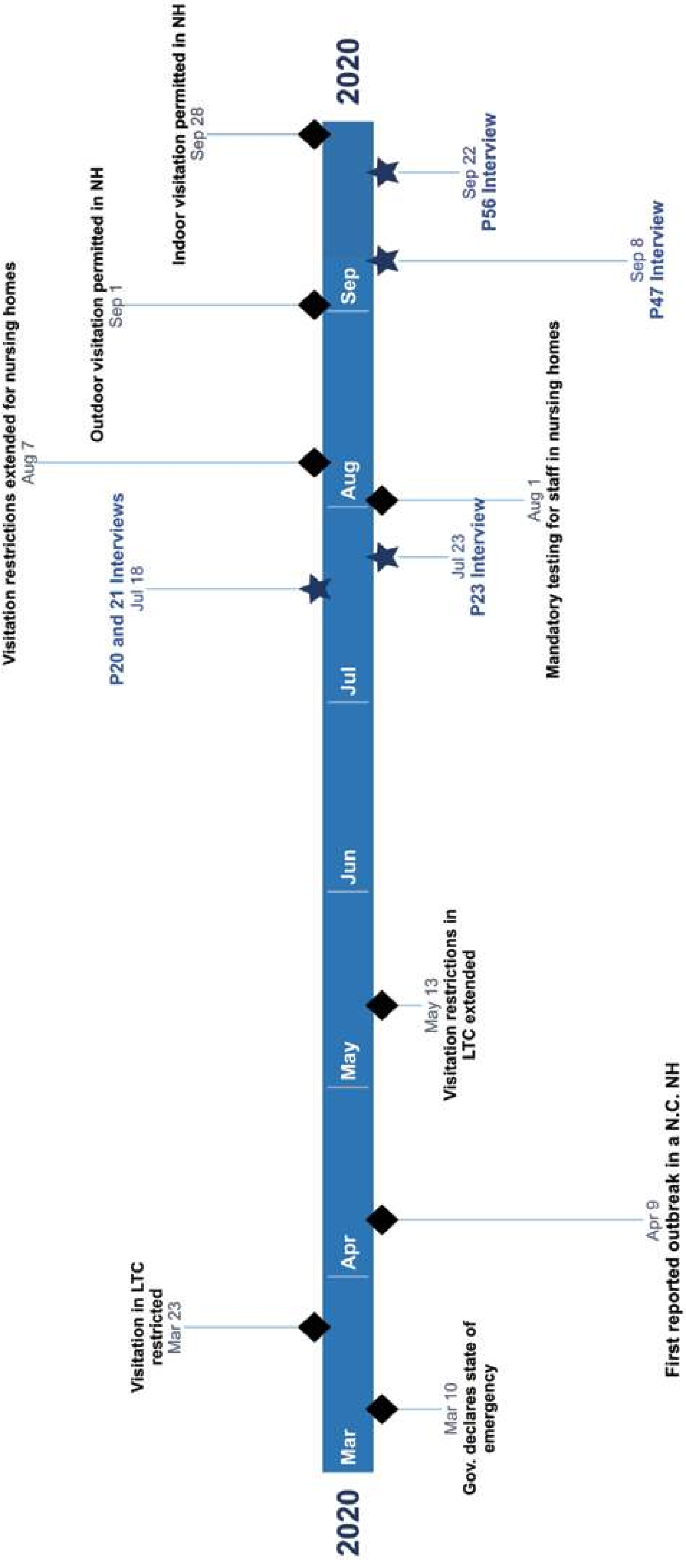


Figure 2.1. Timeline of Interviews Quoted in Chapter 2.

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 hospital 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, co-workers, 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.

3 HOME AND COMMUNITY-BASED PROGRAMMING DURING COVID-19

Finding Resilience in Crisis

COVID Chronicles

Focus on the Why, by Michele Allgood, Owner/Director, Gracious Living Adult Day and Health Care Center

During the COVID-19 pandemic, I felt it was important for me to remain focused on our mission, which is to ensure that participants' and their families' needs continued to be met. For those that were able to come, wanted to come, needed to come, we would be there. We would ensure there were "safe distances" in place and not "social distancing." "Safe distances" included the safety of cleaning tables, washing hands, and fogging the center with disinfectant. "Social distancing" would have meant that our participants would miss encouragement, cognitive stimulation, and the love that they receive from each other.

I will always remember the strangeness of Monday, 16 March 2020. I hung up the phone after speaking with a director from another adult day and healthcare center in Matthews, North Carolina. We shared the news of all other adult day and healthcare centers in Mecklenburg County closing. During the conversation, I revealed that I didn't feel it was necessary to close our doors, but that our enrollment might fluctuate. I prayed for guidance, and the only concrete message that I received was that I could not serve God's people in my living room, so I would need to keep the doors open.

That same day, I began receiving calls from families and social workers of the participants currently enrolled in the adult day and healthcare centers that abruptly closed their doors. I could hear their angst as they were scrambling to find a center to care for their loved ones while they worked. Many of the families that were served through these adult day and health care centers were frontline workers earning minimum wages that were vital to maintain their homes. I invited them to visit and tour the center. I still have them enrolled in our center to date.

On the next day, I met with my staff members and explained the current climate that we were in. I also noted that while some things would change, many would not. We would continue to use the same universal precautions we had always used. You cannot always look at someone and see with the human eye who has a communicable disease. We had been fighting communicable diseases each and every day prior to the pandemic, and we would approach COVID-19 with the same commonsense protocols that we used to approach rotavirus, hepatitis, and the many other viral strains that we come into contact with in a congregate setting: clean, and clean more.

During this pandemic we felt like we were left on an island, alone. We were given little to no guidance, which, in our case, was probably a good thing, since we were the only adult day and healthcare center that chose to stay open throughout this pandemic. If we had been given direction, it probably would have leaned toward the masses and required Gracious Living Adult Day and Healthcare Center to close. North Carolina Department of Health and Human Services and Mecklenburg County Adult Services allowed adult day and healthcare centers in Mecklenburg County to close their doors and, if they agreed to contact participants via the phone, be paid at the regular, very low reimbursement rate we received as the lone open facility.

Yes, we were alone. I felt let down by the other adult day care owners since prior to COVID we were requesting an increase in our fifteen-year-old stagnant reimbursement rate of forty dollars by Mecklenburg County. We were reminding Mecklenburg County of the invaluable services that we provide to the families we serve; however, when the other centers pulled those invaluable services from the community abruptly, their reasons for an increase appeared disingenuous.

In September 2020, seven months in, Mecklenburg County remembered that some of my population existed. They supplied our participants who were Home and Community Care Block Grant[1] funded with twenty pairs of gloves, masks, and a small bottle of sanitizer. The other participants of the center received one cloth mask after the distribution to the block grant recipients. My workers were not provided any appreciation bonuses or even a simple “thank you” from the county even though they were frontline workers who understood their assignment and showed up to work to serve the participants who so desperately needed them.

Staffing during this pandemic was very “different.” Twelve of the fifteen staff members understood that they needed to be committed to the participants and show up to serve them at “the best place for their best days.” One staff member called out Tuesday morning, citing that her back was hurting. The next week, she said she was “scared” to return, and then it was her "husband would not let her return." There was an endless string of excuses, and then she just stopped calling. I received papers from the Unemployment Security office stating that she had applied for unemployment. I requested a hearing. The hearing officer advised that there was COVID-19 funding that would take care of the employee's unemployment and our company would not be charged. I told the hearing officer that I wanted to continue with the hearing because we will all end up like the mouse that finally figures out where the cheese comes from; it appears free until you hear the "snap." She laughed and scheduled the hearing.

During the hearing, the employee cited her reason for not returning to work was that she did not have PPE available to her. I showed invoices and documented the supply of PPE that we had prior to COVID-19. Cintas was my supplier of gloves, masks, and sanitizer. I informed the hearing officer that we did not close at any time during the pandemic and the worker could return to work because we certainly had participants to be cared for. Her unemployment was denied.

We have communicated with our participants and families throughout the pandemic. The following excerpt is from an update we sent to participants' family members on 28 January 2021 when we were trying to get vaccinations for our participants and staff:

> Continue to pray for the hedge of protection Gracious Living Adult Day and Health Care Center has enjoyed throughout this pandemic. We have had four participant COVID-19 exposures (negative results), three staff exposures (negative results) with one actual case (participant not in the center). We truly thank all of our participant families for ensuring that we are kept abreast of any COVID-19 exposures, securing COVID-19 testing, providing their subsequent results, and removing their loved ones from attendance at Gracious Living for quarantines. We are only as safe as our families assist us in being. Thank you, thank you, and thank you!!

The COVID-19 pandemic spotlighted the importance of staffing, cleanliness, and proactively fighting *all* communicable diseases. We must be vigilant about not only what we do but why we do what we do. In the long-term care arena, the "why" should always be those we serve, including their families. We must not make hasty decisions without weighing the consequences of those decisions. Adult day and healthcare centers closed their doors, leaving a vulnerable, needy population to fend for themselves and a blanket of shame should be felt by those making that decision. We do not want any of our participants plagued with a commu-

Illustration 3.1. “Safe distancing” during the pandemic. Photo credit: Michele D. Allgood, program director of Gracious Living Adult Day and Health Care Center Corporation.

nicable disease, but we also do not want the social isolation, sedentary habits, and lack of routine to plummet them into a downward cognitive and physical slide.

Kellin Smith has worked in public transit for a county in central North Carolina for over twenty years. When the pandemic hit, he was working as a bus driver for older and disabled adults who needed assistance accessing services such as medical appointments and therapies as well as transportation to senior centers and congregate meal programs. Kellin is not someone we necessarily think of as a frontline, essential care provider. His role was clearly essential when he was quickly reassigned to deliver frozen meals to senior center clients who previously ate meals at congregate sites but now were isolated in their own homes. In his narrative, it became clear that his role expanded beyond ensuring the basic physical needs of his clients were met, to also creating social connection during long periods of isolation while many home and community-based programs were closed or limited.

Kellin discussed his experiences in vivid detail, describing his efforts to provide support as he delivered meals to the clients who he regularly drove to nutrition sites pre-COVID:

> So we have to not only make sure that it’s safe for us, we have to make sure that they’re safe also, so we usually make sure that we see their face. We leave their box inside their door, and then we go on to the next one, but I think it’s kind of a habit that we know the ones that we don’t see, that don’t receive the meals, and we stop by, and if [someone] would tell us that such and such stays here, we stopped by just to check on them and make sure that they were

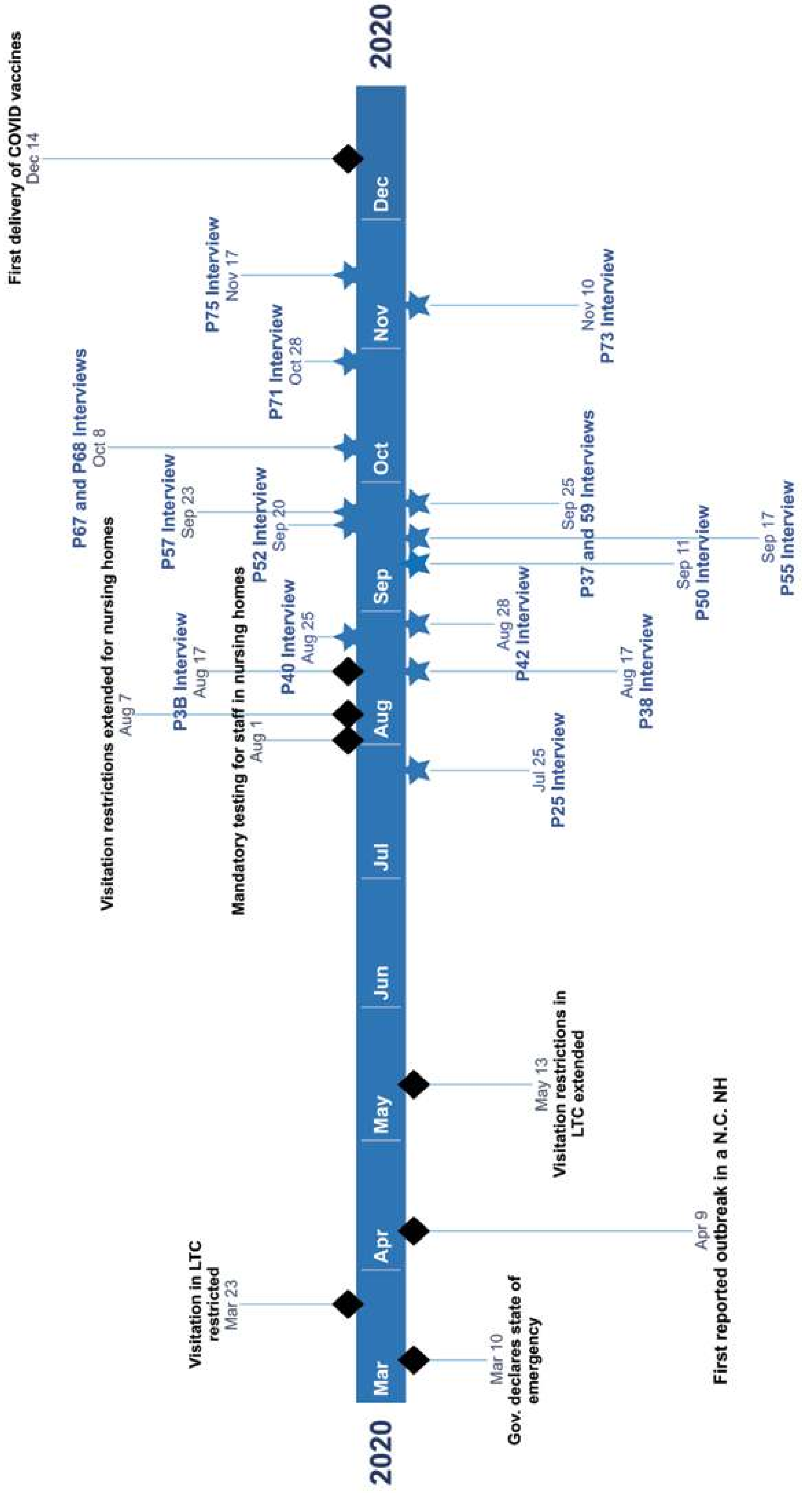


Figure 3.1. Timeline of Interviews Quoted in Chapter 3.

> doing okay, because to me, right now, they're closed up to the partners and not going out at all. So we just checked on them and made sure that they were doing okay, and I think seeing each other's face kinda helped them not only help us, but it also helped them to be able to see your smile and face, to be able to have someone to say, "How you doing?" . . . Basically, we have a route pretty much every day that we would run and making sure that they get in their nutrition also. So it was kind of a good thing, but we still got to kind of see how people were doing that we work with every day. So not only was it a smile on their face, it was a smile on ours . . . Now that they're doing okay. (P68)

Kellin was willing to accept unknown risks because of his dedication to serving clients he knew needed support and services, but also because he was able to gather knowledge in order to protect himself and the clients. He explained, "Information, I think, is one of the keys" to providing ongoing effective care to older Americans. In addition to using a mask and shield and ensuring social distancing, Kellin also sanitized the bus between each client. In what has become a familiar theme, Kellin and his colleagues were "building the plane while flying it."

This chapter focuses on the importance and challenges of clear communication, flexible human infrastructure, and the creativity and resilience of staff who support older Americans living in the community. The ongoing provision of supportive services was crucial to older adults living in their own homes throughout the pandemic and these issues are particularly visible in Kellin's story. The clients were relieved to see a familiar face during a time of isolation and potential loneliness. Due to his relationships with them pre-COVID, he was able to engage them in conversations that led to identifying additional services they needed and also alerted him to other people in need of similar services who had been missed.

Aging in Place

As discussed previously, while COVID-19 has centered attention on older adults living in residential long-term care, in fact the majority of older adults remain "aging in place" in their own homes within the community. We know that ideally, long-term care should be provided in the setting preferred by individuals and their families, and many people prefer to remain in their own homes. Meeting their long-term care needs while supporting older adults in the community requires a range of services, and these are not adequately available. A key principle of long-term care is that it should be delivered in a setting consistent with the preferences of the individual and their family members, and a large majority of long-term care recipients want care in the home and the community (Grabowski 2021). There has been significant attention focused on encouraging more "aging in place" because it has been shown to prevent much of the depression and helplessness associated with congregate living and results in a higher quality of life and more independence for older Americans (Iecovich 2014).

To sustain older adults in the community, a panoply of services is required ranging from food delivery, management of medicine and special medical equipment, in-home aides, home health aides, and transportation services to adult day care programs, and senior centers (Buch 2018; Iecovich 2014). One creative option is the village model through which members living in their homes can choose from the following services: transportation, minor home repairs, fun and interesting activities, "stay in touch" calls, computer assistance, and various other day-to-day needs with the use of vetted volunteers and a recommended service provider list. Unfortunately, these services and innovative models are largely underfunded, fragmented, understaffed, and unable to meet the level of community demand (Iecovich 2014). While home care workers are the fastest growing workforce in the country (Poo and Conrad 2015), the challenges are similar to those we have discussed for direct care workers in general. "The current situation of the eldercare workforce—low wages, long hours, inadequate training and little chance for career advancement—has led to high turnover in the industry and a resultant low quality of care for people who need it" (Poo and Conrad 2015, 89).

Most older people would choose to avoid residential long-term care. However, home and community-based service options are available primarily to those who can afford to pay for them or are eligible through Medicaid. Medicare funds medical care for older adults, but only pays for hospitalizations, physicians' visits, and short-term rehabilitation following a three-night hospital stay. For a period beginning in the 1980s, Medicare paid for personal care, or help with dressing, cleaning, and feeding (Boris and Klein 2012). The services were so popular, however, that Medicare costs rose and the home care program was discontinued in 1997 (Buhler-Wilkinson 2001). The only home care Medicare provides is skilled, intermittent care and occupational and physical therapy, not personal care such as bathing, dressing, or companionship. Medicaid, the major funding source for the medical care of the poor and disabled, does pay for skilled nursing care (e.g., wound or catheter care) and personal care services at home for those who are eligible. To qualify for Medicaid, older adults need to meet medical and financial requirements, including having few assets, such as a house or savings, making Medicaid a last resort for many people (Coe 2019). As a result, one-third of home care services are purchased directly by individuals, and elder care falls mainly to family caregivers (Buhler-Wilkinson

2001). Furthermore, Medicare and Medicaid have not kept pace with the development of a range of services that create care options beyond nursing care (Institute of Medicine 2008). Home care services are also purchased through long-term care insurance or private savings, but more effective systems could be made available utilizing the aging network, as Polivka explains:

> Over 30 years of experience and research findings have demonstrated that the non-profit Aging Network (developed under the Older Americans Act), with its service delivery and case management capacities and comparatively low costs, could build and administer the infrastructure for home and community-based programs and create well balanced long-term care systems much less dependent on expensive home care. These capacities, which were built over a 30-year period and largely funded through Medicaid waivers, are amply documented in comprehensive and comparative analyses of state long-term care systems conducted by AARP between 2011 and 2017 (Reinhard et al. 2017). (Polivka 2020a)

The data presented in this chapter contribute to arguments of the relative value and overall benefit of home and community-based programs, especially in relation to residential long-term care during a pandemic. During the COVID-19 pandemic, home and community-based programs were able to pivot creatively in an effort to serve the needs of their clients, including ensuring their sustained nutrition, some socialization, and maintaining the safety of both clients and frontline providers. We also report on the challenges they faced, including accessing and using technology, maintaining regular access to PPE, and overcoming personnel issues such as risk mitigation and flexible scheduling for those who found themselves with new childcare responsibilities. The sustained nature of the pandemic also exacerbated the loneliness and isolation of clients that home and community-based providers attempted to address. Despite these challenges, we argue that home and community-based providers were able to effectively serve their clients with a lower risk of COVID-19 infection compared to residential long-term care. The community-based providers, while they faced challenges and had to be flexible, were less traumatized than the workers in residential long-term care. While they were affected by staffing challenges, they talked about feeling safe and well supported by their supervisors.

Home and Community-Based Services Participants

Phase 3 of the research presented in this book focused on home and community-based care workers who provide services and assistance to older adults living in the community, including managers and staff providing information and referral, staffing adult day care programs, providing home care and home health care, distributing home-delivered meals, running senior centers, and providing transportation and some specialized medical care. We interviewed thirty-two participants in this phase, with the first interview taking place on 26 July 2020 and the last interview on 28 July 2021 (see table 3.1). The length of these interviews ranged from twenty minutes to one hour and twenty-five minutes, with a total of thirty hours of recorded interviews.

Table 3.1. Phase 3 Participants (Home and Community-Based Providers).

Position	**# of Participants**
Area Agency on Aging Program Coordinator/Aging Specialist	2
County Aging Program Manager (including nutrition and transportation)	2
County Social Worker	3
Certified Dementia Practitioner	1
Dementia Medical Provider: Executive Director and Physician Assistant	2
PACE—Outreach and Enrollment (Program of All Inclusive Care for the Elderly)	1
Director—Community-Based Services Network	1
Community Director of Senior Programs	1
Adult Day Care and Health Director	4
Adult Day Care and Health CNA	2
Senior Center Director	3
Senior Center Program Specialist	1
Senior Center Recreational Coordinator	1
Home Care and Home Health Community Outreach Director	3
Home Care and Home Health Consultant	1
Home Care and Home Health Aide	1
Home-Delivered Meals Provider	1
Senior Transportation bus driver	2
Total Participants	**32**

Pivoting in Response to COVID

Most community-based programs were shut down in mid-March 2020 in an effort to manage infection control and avoid the spread of COVID-19. Managers of these programs quickly pivoted to communicate with clients and coordinate with other service providers to ensure clients' basic needs were met. They struggled to keep up with evolving guidelines while facing challenges in regard to sustaining infection control, managing logistics, and accessing and using technology to maintain communication. At the same time, staff were experiencing personal challenges related to risk of infection and their own family responsibilities. Managers demonstrated a flexible understanding of human infrastructure and worked with staff to support sustainable solutions. They also displayed personal resilience in order to ensure the continuation of essential resources and services to clients.

Staff of many of these community-based programs pivoted immediately to contacting participants by telephone to determine their urgent needs and provide emotional support. They were able to assess clients' needs or provide companionship to those older adults now facing isolation at home, even though initially programming was limited. Some staff were reassigned, as one program coordinator shared: "My understanding is many of the staff were actually pulled over to help out with day care for emergency responders', first responders' children and things like that. So because they're under that Parks and Rec feed or umbrella, they've been pulled over into some of that kind of county response" (P3B).

A significant challenge was addressing the needs of the many older adults who typically relied on receiving meals at the adult day care and day health programs and senior centers. These services were suspended as most of these centers were temporarily closed. One senior center recreation specialist explained: "Some of them did need food, actually, because the senior center sometimes, for some of them, was their only meal, 'cause we give them that main meal, and some of them got bread and coffee in the morning" (P55). Mindful of the urgency of meeting the nutritional needs of clients and community residents, these workers coordinated with area nutrition services and food banks to seamlessly implement home meal deliveries. A senior center director shared:

> If you require meals, then what we do is we will get your name and phone number and get them to DSS [Department of Social Services], and then they will provide you with meals. Right now, DSS is doing seventeen hundred meals delivered. And what they do is a ten-day supply, and they [the meals] come just like a little tray like you used to get on the plane. They're frozen and

> all you have to do is put it in your microwave and heat it up, and then you have meals for ten days. You get meals, milk, you get bread. (P50)

Rising to the challenge of adding more than five hundred fifty people to their home-delivered meals roster, the county nutrition services stood out as exemplary in the earliest days of the pandemic (see chapter 6 for more details). They pivoted quickly and efficiently, as one nutrition program manager discussed: "I remember this was a Friday and the challenge for us was . . . how to integrate with the already existing home-delivered operation, . . . remember with the same number of vehicles . . . and drivers. So we really had to start strategically like thinking, . . . how we're gonna start deliveries on Monday for more than sixteen hundred people instead of eleven hundred" (P42). They brought in a team of drivers who usually drove people to medical appointments pre-COVID and had access to one additional refrigerated truck. The county also continued transportation for medical appointments, following changing guidelines throughout the pandemic, and one van driver expressed their appreciation for the safety precautions their leadership took:

> So I think in the time when it all first hit, everything was kind of up in the air, nobody really knew what to do, anybody, but then they got the information that you needed and they started working on it as quickly as possible to make sure we had what we needed. So, of course, we all still felt nervous and scared and had no idea, but I think they did a pretty good job in getting us what we needed and getting us. . . keeping us safe. Helping us stay safe. (P67)

Many community-based program staff continued regular telephone contact with clients and some developed online programming for those now isolated at home with little contact with family or friends. One senior center director explained their pivot to making wellness calls and developing creative solutions such as developing tailored exercise plans for their clients to do in the safety of their own homes.

One adult day care and day health program stayed open throughout the pandemic, with twenty-five to thirty participants coming each day. (See the essay at the beginning of this chapter.) The program director explained: "For family and participants who needed us, we were going to remain open for them." They used a fogger with a disinfectant that is effective against COVID, partitions, and physical or safe distancing, believing that "those that needed to come, needed to come" (P49). Note the use of the terms "physical distancing" or "safe distancing" rather than the more commonly used term "social distancing." Several research participants stressed the need for physical safety within a framework that ensured social interaction and engagement, noting that the term "social distancing" was actually not accurate.

Home care agency staff, who provide care to clients in the clients' homes, faced different challenges. One director of outreach and enrollment stated:

> Our owner was very hands on deck as soon as COVID hit. [They] and our nurse were very at the frontline with our caregivers, supporting them. We had our client care coordinators on the frontline as well. We were constantly providing gloves, sanitizer bottles, masks. We still are providing them for them to come and collect those supplies from the office, so I would definitely say it's been a joint effort. (P25)

Home care agencies that relied on in-person assessments of potential new clients quickly adapted new means of assessing and enrolling clients via online meeting tools and then mailing or emailing enrollment forms. This was effective but created a lag before home care services could begin for the newly enrolled older adults seeking assistance. Another director of community outreach attributed her agency's successful pivot to a joint leadership effort in making the safety of staff and clients their top priority.

Mitigating staff fears related to COVID-19 infection and employment status became an integral consideration for those in leadership roles (see chapter 6). One CNA discussed the importance of continued communication from leadership during the closing of the adult day care program where she works:

> As we were closed, leadership or administration stayed in touch with us, occasionally sent everybody out, maybe a continuing ed kind of package to do, or videos, just to do something, which was good. And then we had a meeting on-site a few days before we opened back up. We all sort of went through and hashed through everything, and it was a little bit of getting used to the new routine. (P71)

Challenges: Technology, Infection Control, Personnel

The initial onslaught of COVID-19 brought about logistic challenges for owners, directors, and frontline workers caring for older adults in the home and community-based sector as they scrambled to make decisions about whether to remain open and how to continue to provide care and support, how to obtain funding to support their efforts or in the event of closure, and how to support and retain staff. Additionally, infection control guidelines and mandates were rapidly evolving and posed a major challenge to administrators, staff, and clients. Forced to decipher information about COVID-19 and discern how to best implement and comply with safety measures in a sea of mixed messaging, caregivers rose valiantly to this challenge. These challenges alone would seem insurmountable to many, and then personal issues layered into this mix, making the resiliency and determination to serve older adults in the face of such hardship heroic and worth closer examination.

Technology

Beyond the use of telephone calls to assess the needs of clients and provide support, technology offered innovative ways to offer services to older adults who were quarantined in their homes during the periods of time when most adult day care programs and senior centers were physically shut down or offering minimal programming. Acknowledging the need for activities and a sense of community, many program directors and caregivers turned to virtual programming to provide these critical components to their clients. One executive director of a community-based services network told us, for example, about the challenges of involving participants in virtual activities:

> Well, it's not as much as the in person, and I think a lot of that stems from the technological aspect of it. Some folks just have trouble with Zoom calls and Google Meet, so it's been down a little bit, but we're still carrying on trying to offer that. . . . We've done virtual game days where we'll get a group together and then one of our volunteers administrate that and will either play online *Jeopardy!* or some sort of a puzzle game or whatever, just to try keep to that going. (P37)

While several participants discussed adding some virtual programming during their closures from March to July 2020, one community center stood out in their ability to quickly transition the majority of their services to an online format. Factoring into their successful pivot was the immediate needs assessment conducted to determine what types of programming each participant was interested in continuing during the pandemic, whether they had access to the technology required for virtual programming, and whether they had assistance from friends or family members if needed to set up and begin these online activities. The center director explained:

> After a few weeks, when it became apparent we weren't going to be opening up any time soon, we went back and started polling the participants. Do you have a computer, do you have an iPad, a cell phone, a flip phone? Do you use the internet? Do you use Zoom? Do you use FaceTime? What do you use, and then are you interested in using Zoom if somebody teaches you? And once

> we did that, we started getting people onboarding to Zoom. I reached out to the children of a lot of these people and said, "We need your help." Once we had a core group, we set up a Zoom test, and we had a full screen and it was so cool. (P52)

The challenge of implementing technology-based programming varied greatly, depending on the clients' access to cell phones, tablets, computers, and internet, as well as their comfort level and technology skills.

Infection Control and PPE

Especially early in the pandemic, it was a challenge to get accurate information. The director of a nonmedical home care agency who also worked as a caregiver during staffing shortages related to COVID-19 succinctly expressed the need for appropriate communication and information surrounding basic infection control measures in order to make in-home caregivers feel safe enough to return to providing in-home care: "I practice safe procedures and all of that, and I'm okay with going to a client I already knew and I'm ready to start up, back up with them. So, again, it was checking in with all of our caregivers, even the ones that were not ready to come back and get back out into the workforce" (P73).

Even when information was provided by infection control nurses following CDC guidance, surges in demands and prices for basic items needed to ensure proper infection control created a challenge. A co-owner of a medical home care agency talked about the initial efforts to secure PPE for the home caregivers: "And even that was a struggle because everybody was running out so fast, and all the prices rose to where you really was like, 'Okay, am I gonna pay twelve to twenty dollars for this box of gloves that used to be four to five dollars?' So it was crazy, it was crazy. And it kind of still is, 'cause it's still a little scarce on those PPE supplies" (P75).

Personal Challenges of Staff

In addition to the logistic and infection control challenges, caregivers deal with personal issues that affect their physical and mental well-being, and in some instances their ability to perform the duties required of them. For example, discussing challenges associated with school closures as a result of COVID-19, one program manager pointed out that in-home aides are largely women who were now responsible for caring for their own children who were no longer going to school each day. She explained, "And then there was the impact where the workforce that worked for the home agencies, these working, largely working women, have their children now at home and not in school, that they weren't able to work, or they were concerned about COVID" (P40). Even when caregivers found ways to continue working, the additional responsibilities for children added stressors associated with online learning and providing the structure their children needed. Multiple participants who were coming to grips with their own isolation and fears surrounding the pandemic, discussed anxiety and depression. One participant said, "It really is an isolating experience," and "this is your world basically right now" (P40).

Kellin Smith, who we heard from at the beginning of this chapter, expressed the motivations shared by several participants about why they continued to show up each day despite the personal challenges they faced on top of the challenges waiting for them once they got to work. He shared his desire to be there for his clients and community and be able to support his family by remaining employed: "I was gonna be one of the ones that was able to still come and perform my job to the safest . . . to my ability that I could. We can continue to do our job because when I see it, I see that they depend on us. Then we turn it around, we depended on them too" (P68).

Challenges Related to the Ongoing Nature of the Pandemic: Isolation

As the pandemic continued, physical and mental decline of clients, in addition to the loneliness that many were experiencing during the ongoing isolation, became a frequently expressed concern. A community coordinator of senior services described:

> Just the pure isolation that it caused, you could hear it in their voices, especially the ones who were used to coming to the senior center often two or three times a week. . . With all of that socialization, all of those friends, it was really, really hard. At the beginning, they didn't mind it 'cause they were so fearful, then they began to realize what a hole it left in them to not have those contacts with those people. . . . Hugs are freely given [at the center]. So they miss those. . . it became evident soon that social isolation, as well as the emergency needs, were gonna be key in our calls every time. (P57)

The ongoing isolation brought on by the pandemic and closures of senior centers as well as adult day and health care centers produced devastating effects and what have come to be called the non-COVID deaths from COVID-19 (see Shenk and Freidus 2020). Caregivers spoke of deaths of older adults that they attributed to COVID-19 even when the person had not contracted the virus. For one manager, the isolation that she knew her clients were experiencing motivated her to continue to show up and do her job and be available for the older adults needing the services and human connection that she and her staff could provide.

> Well, what is the message here? And there's so much sadness right now and isolation, and how has that really impacted a lot of people, but then we're also thinking, "Well, okay, what can I think from a more positive side of it?" . . . So it kinda helps keep me a bit motivated, reminds me why I'm here. I have to remind myself, I have to tell myself, "I'm not here just for my kids and bringing food home to the table, but there are people that really have a need for us, and there's a reason why our program exists to serve in your community." (P59)

We will consider these issues and effects of social isolation and loneliness further in chapter 4.

Discussion

While the issues present differently for home and community-based providers, there is overlap in some of the issues compared to those identified for residential long-term care. Initially, in both models of care, workers struggled to procure the necessary PPE and also reported challenges navigating rapidly changing knowledge about the virus and its transmission as well as the evolving policy recommendations. Pivoting to new forms of service delivery and efforts to engage yet physically protect clients and residents was difficult yet not insurmountable for those providing support through home and community-based services. When assessing what factored into successful pivots and creative solutions, the theme of leadership emerged. Leadership sometimes was identified in the typical top-down form, but was also seen in the creative decision-making of those who felt personally responsible for the older adults for whom they care. Those caregivers who were able to smoothly navigate the challenges of COVID-19 frequently mentioned having supportive supervisors and administrators and particularly good communication within their agency or program.

Key differences emerged in the narratives of home and community-based care providers compared to those in congregate long-term care. Upon reflection, the workers who served home and community-based clients did not report the same levels of trauma as those in residential long-term care who experienced the direct loss of residents and bore witness to the everyday suffering older Americans experienced that were associated with long-term isolation and loneliness (see chapters 2 and 4). Providers also watched as residents were not afforded agency in nearly all aspects of their lives as residential communities were shuttered and most residents were forced to isolate in their rooms for some extended period of time during the pandemic (see chapters 2 and 4). Conversely, clients who remained in their homes (along with their family members as decision-makers in many cases) were allotted agency to determine whether or not workers could come into their home and how/if they would receive services (e.g., food delivery or online activities). While many senior centers remained closed throughout the pandemic, adult day and healthcare programs opened expeditiously and implemented policies meant to safeguard clients. Families and attendees had power to decide when they felt it was safe to resume participation. Overall, as suggested by the findings in this chapter, home and community-based staff had more agency and flexibility in regard to pivoting and providing services.

The COVID-19 pandemic made visible long-standing structural concerns regarding ageism and care for older Americans. Chapter 2 demonstrates the devastation the virus inflicted on residential care communities. Residential long-term care has historically been criticized for focusing more on the physical needs of residents and less on their social and emotional well-being. Strides have been made in shifting to person-centered care, but the limitations of this evolution became evident when the pandemic caused a reversion to focusing on protecting the physical body, almost exclusively, to the detriment of many residents. This experience was traumatizing to care providers. In contrast, home and community-based staff had a very different experience, as did the clients in their care. While home and community-based clients did experience isolation and loneliness, they were afforded more agency and a wider range of options regarding engagement and the procurement of services, including nutrition. Most people would rather live in their own homes because of the freedoms it affords them, and during the pandemic it seemed a safer environment, suggesting another reason this alternative should be an available option for people in need of long-term care.

Notes

1. In North Carolina, Home and Community Care Block Grant funding is the system for distributing federal funds for community-based services from the state to the county level. It is intended to promote the visibility of aging programs at the local level by giving counties increased flexibility with respect to funding aging services through the Home and Community Care Block Grant.

4 ACTIVITIES AND ENGAGEMENT

Avoiding Isolation and Loneliness

How Do We Keep People Wanting to Be Alive? by Colleen Knudson

In residential long-term care, the focus was on keeping residents physically safe. This was dictated by closing facilities to the community, wearing PPE, stopping group activities and communal dining, limiting visitors, and enforcing strict infection control. The knowledge that seniors with comorbidities were at extremely high risk of dying from COVID frightened us. We were terrified of possibly bringing the virus into the community, of being the person who opened the doors for illness and death to those in our care. We had all seen the news broadcasts with the footage of nursing homes across the nation going into lockdown, the few staff still in the buildings burnt out and drowning in grief. The weight of that possibility was crushing, and then the staffing crisis joined the pandemic. They were a formidable pair.

Nurses, CNAs, and other long-term care facility staff left the healthcare field in droves. Staff were schooling children at home, working double shifts, and navigating personal health issues. The addition of watching those in their care decline pushed many to quit their jobs and stay at home. The possibility of carrying the virus to your home or facility during the pandemic was a heavy burden.

Most staff isolated themselves from their friends and family; missing the birth of newborn babies, loved ones passing, weddings, showers, graduations, holiday gatherings, and other events. This isolation was challenging for staff, but doubly so for residents. Many of our residents are in the last years of their lives. They have a limited number of celebrations left to experience. Missing these events was incredibly painful for them and emphasized their distance from family. A FaceTime call or Zoom to join the events was sometimes a blessing, and other times it just amplified the anger that they could not be together with their loved ones. A significant reduction in residents' abilities to be in person with their loved ones jump-started the decline.

While staff isolated themselves, we could at least travel back and forth between our homes and jobs. The residents had only their facility, their room. Many residents need physical assistance to get outdoors or to another area in the building. With a staffing shortage and residents fearing COVID, many stayed in their rooms daily. Humans are not meant to isolate; we are social creatures, with our wellness directly correlating with the number and strength of our relationships. The pandemic reflected this, as residents' well-being declined without their usual daily engagements. Residents who were used to being out of their room multiple times a day for meals and activities were now coming out maybe once a day or not at all.

As an activity professional in an assisted living community, my job is to engage people in purposeful and meaningful activities that create a good quality of life. The new reality was figuring out how to do this with limited resources, including fewer staff members, smaller budgets, less time, facility closing, and quarantines. As the days went on, we began to see changes in our residents. They were sleeping later, often napping, losing weight, moving less, and sometimes not wanting to get out of bed. Others were repeatedly tearful, confused, and anxious, needing more time and attention from staff to feel safe and healthy.

This decline was devastating for a team on the edge of burnout. Many residents' increased emotional and physical needs, while the residence was short-staffed, were highly challenging. Seeing those in your care continue to decline despite your exhaustive efforts creates a feeling of helplessness, guilt, and failure. Our attempts to be more than caregivers, to be family, friends, beauticians, and pastors, were not enough to stop the depression and anxiety of many in our care. As the well-being of residents continued to decline, despite extensive efforts from staff, we began to ask ourselves whether the cost of physical health and safety was worth the mental deterioration of those in our care. How could we assist those in our care to *want* to be alive in their new reality? Physical existence meant nothing to them without purpose and quality of life.

Staff went back to discussions of what gives life meaning: comfort, connection, culture, joy, and purpose. Residents were giving up because they lost sight of, and access to, what was most important to give. Our Life Enrichment team focused on resources we had to bring back purpose and connection in residents' lives. We reached out to our community, volunteers, donors, and local schools.

Weight Loss

Many residents were feeling depressed and moving much less, which meant they were not hungry. Many were no longer interested in meals without eating in a communal dining setting. For residents diagnosed with dementia or Alzheimer's, there was no longer someone eating opposite them to provide mirroring and cueing. More independent residents were used to going to the grocery store every week. They missed having fresh produce and bakery items.

We initiated food and treat carts weekly to provide calorie-dense and favorite items. Carts were purchased and decorated in various themes to replace group activities to provide enjoyment, reminiscing, and sensory stimulation for residents. Staff had the opportunity to dress to match the

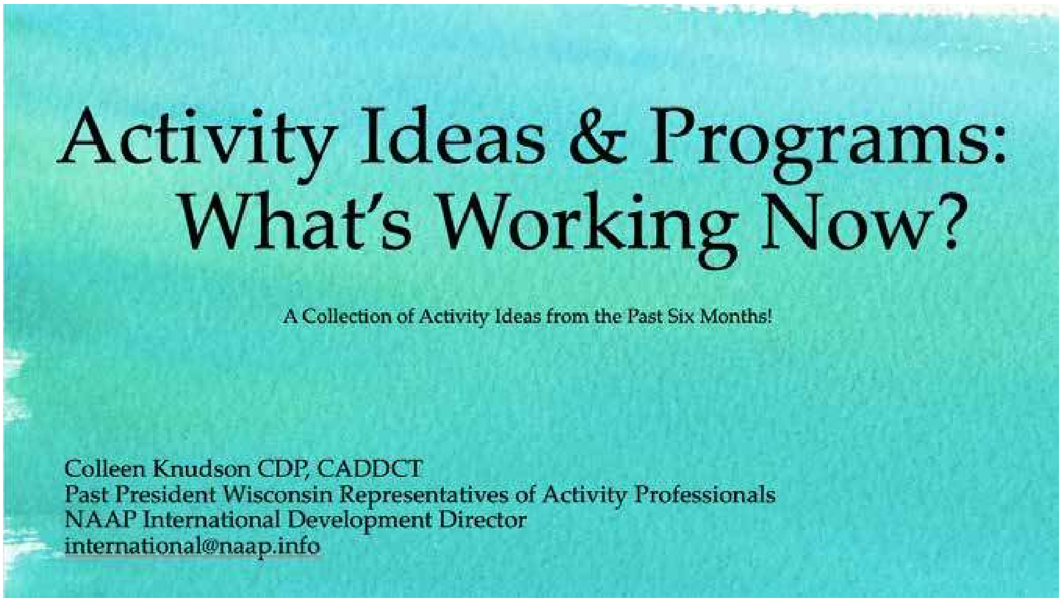
Illustration 4.1. Staff member serving cupcakes door to door (PowerPoint slide 61). Photo credit: Attic Angel Assisted Living and Memory Care.

theme, which provided great opportunities for conversation. We reminisced with residents about summer ice cream treats, Oktoberfest, tailgating, baking, and other joyful memories.

There was also a weekly happy hour cart, which was such a hit that residents began asking about the cart at breakfast! The mix of decorating themes, reminiscence, and sensory stimulation with each food item, resulted in most residents participating and greatly assisted in combating weight loss. The carts gave the residents something to look forward to and strengthened the relationships between residents and staff.

With decreased staffing, no communal dining, and no family visitors, some residents in our memory care unit took longer to eat meals and had reduced intake during meals. We worked closely with our student interns, who completed the majority of their internships virtually, to eat meals virtually with residents who benefited from mirroring and socialization for engagement during meals. This intervention was highly successful, so we also offered this to the residents' family members. The iPad was set across from the resident, allowing them to mirror and engage with the person on-screen.

For residents who had relied on weekly grocery shopping, we set up a variety of interventions. We established scheduled days/times for drop-offs. During these hours, family and friends could drop off any items for their loved ones. Residents could also place weekly grocery orders with staff. Staff communicated the items to volunteers who would virtually place the orders, pick them up, and deliver them during drop-off. Last, we turned our trishaw into a farmers market cart. Each week, Food Ser-



Activity Ideas & Programs:
What's Working Now?

A Collection of Activity Ideas from the Past Six Months!

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Illustration 4.2. What's Working Now PowerPoint slide.

vices would work with me to load the trishaw with fresh produce, baked goods, milk, and other items to be sold and delivered to our independent apartments. Residents were aware of the days/times that the cart would be out, and I stopped by each room for orders and delivery.

Other key issues of concern during the height of the pandemic that we focused on as activities professionals include decreased movement, isolation, and boredom. A list of activities and ideas for each of these categories follows and details for implementation are included here.

Decreased Movement

- In-house TV channel: Exercise, seated yoga, seated kickboxing
- Virtual internships: two of our caregivers completed a virtual internship with us for their university coursework
- Student Interns created exercise videos, instructional art, and other programs for our internal channel
- Student Interns created exercise stations outside in the gardens and walking path
- Active sports in hallway/resident doorways (e.g., golf and bowling)
- Walking
- Explore the building and grounds
  - Art Walk
  - Wellness Bingo
  - I Spy and Scavenger Hunts

Isolation

- Types of visits offered: one-on-one, hallway, outdoor
- Video visits with family and friends (Zoom, Skype, FaceTime)
- iPad and CD players/CDs
- Intergenerational interactions via technology: Classroom visits with follow-up mailings
- Student Onterns: Social bingo, Pictionary, and Wheel of Fortune
- Student Onterns: Spent a lot of time chatting with residents over Zoom, reading books, making art projects, playing games, and eating meals
- Family social via technology: Virtual Mother's Day tea, Zoom book club
- Community pals: Telephone calls, letters, artwork, cards, crafts
- Chaplain Class titled "Quarantine Coping Skills": Grounding, resiliency, grief and lament, meditation and connection (e.g., provided Angel crochet bookmarks, finger labyrinths, and prayer flags)
- Karaoke, hallway minstrels
- Overhead music with daily inspirational quote

- Spreading hope and cheer: Resident ambassador outdoor walk and signaling
- Acts of kindness: Heart messages
- Outdoor plexiglass visits, window visits, booth visits, car parades: Decorations/gifts/desserts
- Dog pen pals
- Mini whiteboards for communication and reminders

Boredom

- Independent activities: Room supplies
- Happy Heart Hunt
- Positive word collage
- Internet/app brain games
- Learn something new
    - Prerecorded exercise classes
    - Internal channel, CDs, DVDs, links
- Outdoors: Cookouts, concerts, staff parades, animal parades, dog parades

Staff Appreciation

- Posters
- Yard signs
- Outdoor decorations
- Heart trails
- Chalk drawings

> "They [administrators and other staff] say, 'Oh, we are doing a great job.' But to me it doesn't seem like it's a good job, because I think they're [residential long-term care residents] lonely as all get out and need the interaction, but everybody's scared." (P51)
>
> "Almost every resident in every level of care, no matter their age or ability, everyone's mental health, mental health and physical functioning, because they can't go to exercise, they can't get out and about to go walk, they really. . . They're struggling in every aspect right now. Lots of loneliness and lots of boredom." (P13)

These are quotes taken from our interviews with activities coordinators in residential long-term care communities during the early days of the pandemic who witnessed firsthand the isolation and loneliness of residents. Isolation has proven to be a defining feature of COVID-19 for everyone living in lockdown conditions across the globe, but especially those in residen-

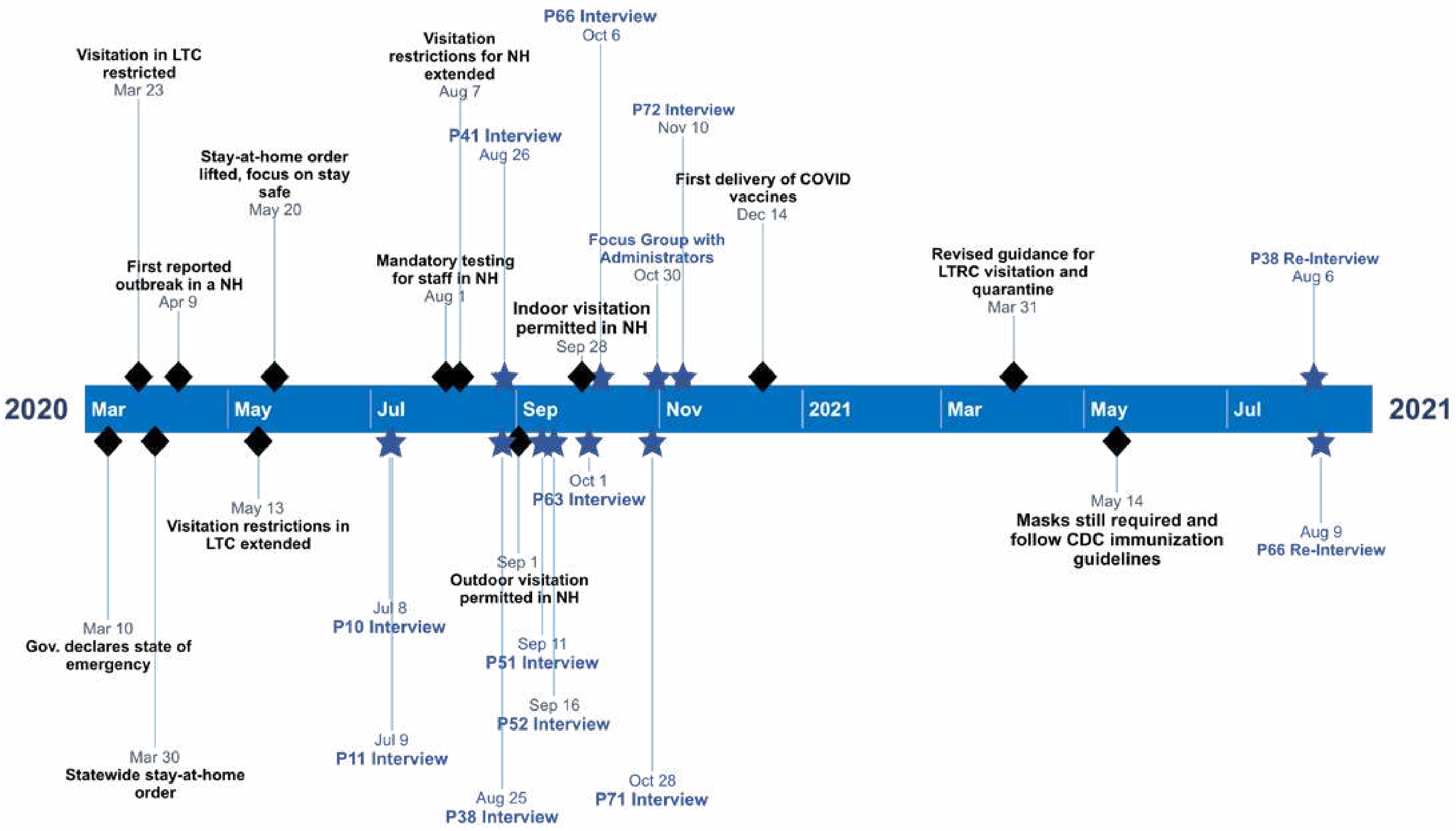

Figure 4.1. Timeline of Interviews Quoted in Chapter 4.

tial communities, older Americans fearful of leaving their homes because of the differential rates of morbidity and mortality for their demographic, and those no longer able to receive services with their peers at congregate sites. This chapter focuses on how frontline workers tackled isolation with a special emphasis on the experiences of activities coordinators and others who are normally tasked with engaging older Americans to prevent social isolation during non-pandemic times.

Social isolation is defined as the objective state of having few social relationships or infrequent social contact with others, while loneliness is a subjective feeling of being isolated (Wu 2020). In the United States, approximately one-quarter of community-dwelling older adults are considered to be socially isolated, and 43 percent of them report feeling lonely (National Academies of Sciences, Engineering, and Medicine 2020). Studies have found that social isolation and loneliness are major risk factors that have been linked with poor physical and mental health status, including increased blood pressure, heart disease, obesity, diminished immune system functioning, depression, anxiety, poorer cognitive functioning, increased risk of Alzheimer's disease, and mortality (DiNapoli, Wu, and Scogin 2014; Nicholson 2012). Social isolation has been associated with an approximately 50 percent increased risk of developing dementia, a 29 percent increased risk of incident coronary heart disease, and a 32 percent increased risk of stroke (National Academies of Sciences, Engineering, and Medicine 2020). We need to be cognizant that the social isolation resulting from efforts to decrease the spread of COVID-19, at the same time increased the risk of these negative outcomes, potentially having a profound impact on the health and well-being of older adults who were in lockdown (Wu 2020).

In this chapter we share the observations made by workers regarding the physical and mental decline they witnessed during the pandemic. These are important insights to capture as we heard of and bore witness to the devastating impact isolation had and continues to have on older Americans in need of long-term care. We interviewed twenty-one workers who focus on activities and engagement in residential long-term care communities and home and community-based programs where they work. We present the experiences and adaptations made by workers trying to engage older Americans in an effort to prevent decline, isolation, and boredom. Their narratives highlight the need for creativity and flexibility in the kinds of services provided as policies changed and affected the activities that were available and the subsequent limitation in regard to opportunities for engagement. Other themes identified include the power and challenges of technology and the need for effective communication. We begin with the observations made by workers regarding the physical and mental decline of the older adults they were caring for during the pandemic.

Table 4.1. Residential Long-Term care Activities Professionals and Home and Community-Based Workers Involved in Engagement.

Participant #	Position	Credentials	Experience	Location	Age
11	Program Coordinator	BA-Health and Physical Education	11 years	Memory care assisted living	61
38	Chaplain	MA-Divinity, Continuing Education	9 years	CCRC	58
41	Activities Director	CNA, some college, activities course	16 years	Assisted living	48
43	Community SW	BA, MSW, LCSW	4 years	County	49
49	Program Director	BA-Business Admin, CDP*	8 years	Adult day care	55
50	Director	BA-Business Admin, Gerontology Certificate	20 years	Senior center	60
51	Life Engagement Director	BA-Criminology and Sociology	6 months	Assisted living	61
52	Director, Sr. and Adult Programs	BA-Journalism and Spanish	5.5 years	Senior enrichment program	49
54	Executive Director	BA-Business Administration	21 years	Adult day care	70
55	Social Services Program Specialist	BSW	3 years	Senior center	59
57	Recreation Coordinator Senior Services	MSW, MPA	16 years	Senior center	64
61	Program Director	MA-Gerontology	6 years	Senior center	32
64	Recreation Specialist	BA-Sociology, Gerontology minor	2 years	Senior center	28
66	Executive Director	BA-Psych, MA-Gerontology	20 years	Adult day health	49
70	Intake SW	BA-Sociology, Gerontology minor	3 years	Department of Social Services	50
P71	CNA	BSN, MSW	3 years	Adult day health	57
P72	Family Resource Manager	BA-Sociology, MA-Counseling, CNA	4 years	Dementia day health	56
P73	Agency Director	BA-Psychology and Equine Management	9 years	Home care	60
P74	Life Enrichment Manager	BS-Science, CNA	2 years	Memory care assisted living	27
P75	Co-owner	CNA	9 years	Medical home care	40
P76	Consultant	MHA	18 years	Home care	43

*CDP = Certified Dementia Practitioner

Illustration 4.3. Staff member and alpacas visiting residents through window (PowerPoint slide 87). Photo credit: Attic Angel Assisted Living and Memory Care.

Physical and Mental Decline Due to COVID

Concerns for safety led to extensive isolation of residents living in residential long-term care and older adults living in the community since the beginning of the coronavirus pandemic. The impact that social isolation was having on both staff and the older adults they care for was a key finding that emerged beginning with the interviews with regional services providers and advocates in Phase 1 of our research. These concerns were repeated in the observations made by frontline workers regarding the physical and mental decline they witnessed during the pandemic. A nurse practitioner in a residential care environment explained:

> I'm just getting frustrated, I think, because I feel like this is not a sustainable way to handle this type of issue. And this is not going away, and it won't be the only virus that affects people like this, and . . . this is not gonna disappear. And so, I feel like those conversations . . . need to be had about "how are we going to handle this in a sustainable way that is not affecting, I think, the mental health of everyone?" (P10)

As discussed in chapter 2, the social lives of residents living in congregate care changed dramatically overnight. All aspects of their lives were profoundly impacted when these communities were shuttered and residents were forced to stay in their rooms. Family visits ended, congregate dining was suspended, and socializing was dramatically limited. These changes had a major impact on this population, which led to noticeable physical and mental decline. One activities director in an assisted living community described the isolating environment residents were experiencing during the lockdown:

> For residents, of course, it's boring for them. And of course, it's isolation. It's isolation from their families, isolation from something simple like eating lunch. . . . You're eating lunch, and dinner, and breakfast in your room every day on a little table. It comes in a Styrofoam box. You're not having the dining room experience and at eighty and ninety years old, you want the dining. . . . You want to go in the dining room and see people. And you wanna get up and put your clothes on every day, and put some lipstick on and go out and see the world. You just don't wanna be isolated. (P41)

This activities director identified the negative impact of closing dining on residents who customarily ate together in the dining room, which was also experienced by those who were accustomed to eating at congregate dining sites, or adult day and healthcare centers. In addition, group activities in residential long-term care were severely limited, and residents were isolated in individual rooms while participants of community-based programs were now isolated at home. For residents in residential long-term care, family and friends were not able to visit, so the staff were often the only people they saw in person.

Caregivers in home and community-based programs continuously affirmed that physical and mental decline occurred as a result of the isolation brought on by COVID-19. For those in their care who survived, they felt it was too soon to tell whether this decline could potentially be reversed when older adults were able to be reunited with friends and family, and returned to their senior centers, adult day care and day health centers, or other places they gathered for community and engagement. While a family resource manager at a private adult day program acknowledged the decline in some of her clients, she did speak of some reversal of this decline in one participant once virtual programming started. However, she remained skeptical when pressed as to whether she believed the negative effects would be long- term for others, and that was difficult for her to come to terms with. She stated that while the center was closed,

> we started seeing people virtually and people had declined. One participant is now at home because our four hours a day wasn't working for her daughter who was working full time. So she ended up bringing a caregiver into

> the home and [the participant] ended up being virtually every day with us. But she and her caregiver join together virtually and so that's a resource for them. . . . The depression, and all of that, had her just totally withdrawn when the virtual started and it [virtual programming] brought her back. . . So we have seen decline, significant decline, and we've seen people come back. (P72)

They still believed there had been some irreversible decline due to the isolation, which they and other caregivers found very troubling.

Relatedly, well over a year after the shutdown, in a follow-up interview, an executive director of an adult day health program shed some light on this issue while demonstrating that the element of the unknown still existed and was difficult for the caregivers. When asked whether they had seen any reversal of the physical and mental decline they had spoken of in their initial interview, this participant answered:

> I don't know that I have seen improvements. Now, initially, when they came back, we might have seen some, but we're a year out now. I don't know that I can say that I have seen improvements recently, but most of them have dementia, which is progressive. . . . It was much easier a year ago after being closed for three months. That was dramatic, that was a dramatic decline for so many people. (P66)

Caregivers in both residential long-term care and home and community-based services talked about the impacts of the long isolation. One registered nurse (RN) who worked as a CNA had the following to say in reference to explaining the large number of older adults who had died during the time their adult day healthcare program was closed:

> I had a little sixty-some-year-old Down syndrome lady who passed during that time. Somebody told me, she said, "I think she must have just died of a broken heart." Because she lived in the facility, full time, but she came to us during the day for an outing, and her family got her out. And so she couldn't come to us, nobody could come in and see her, and she. . . I think she might have felt like she was being punished, "why can't I, why can't. . ." And then she passed. (P71)

Grace, the chaplain we met in the Introduction to this book, also described a similar situation with regard to "the correlation between people who were living this isolated life and people whose COVID symptoms maybe weren't that bad, but still it took them on out because they were already just emotionally fragile just from the isolation" (P38). The decline that these caregivers and staff noted among the older adults they care for was a concern felt most directly by the activities professionals and community-based program staff tasked with engaging this population.

Illustration 4.4. Program participants involved in planting outside with a staff member. Photo credit: Michele D. Allgood, program director of Gracious Living Adult Day and Health Care Center Corporation.

Next, we focus on the evolving and transitioning of approaches to activities and explicit challenges to maintaining engagement that occurred in residential long-term care before turning to the experiences in home and community-based care. We present these separately as there were particular differences and challenges in efforts to maintain engagement between those in residential care and those shuttered in their homes in the community.

Activities and Engagement in Residential Long-Term Care

At the beginning of the pandemic, when residents were restricted to their rooms, activities staff creatively developed in-room and hallway activities. For example, residents remained in their doorways to play hallway bingo or participate in exercise groups. Mobile carts with activities were introduced to distribute individual activities to residents including puzzles, books, and coloring and word-find activities. As the lockdown restrictions were eased, activities professionals added small-group and outdoor activities, weather permitting. These included, for example, chair yoga and exercise classes in small groups or pods. They had parades outside and socially distanced activities like water balloons and water guns. One activities coordinator shared: "So we've come a long way, and I am actually really proud of the ways we've adapted and the technology I have learned to do and I am not as afraid of now. So there are some positives" (P38). These professionals showed great creativity and flexibility in their efforts to engage their residents. Another participant described using a giant blow-up bowling set she purchased that residents could play in the foyer two at a time. Activities were shifted to the hallways and porches when the weather made outdoor activities possible.

While engagement of residents living in residential long-term care is often viewed as solely the responsibility of activities professionals, there are opportunities for engagement in every interaction by those providing care. As one activities director explained, their special care community for people living with dementia considers engagement a part of the responsibilities of all staff members:

> We make it clear to our staff, whether it's CNA, dietary, that we are here for the residents. . . . So we're not asking that they engage the residents in a thirty-minute program, but we do encourage them to take the time, five minutes, seven minutes, ten minutes, out of their schedule, here and there, to engage the residents in something that perhaps they've connected with that resident. And it could be sitting down and coloring, it could be singing a song, it could be just taking a walk with them, a stroll outside. So, it's all hands on deck. (P11)

During COVID it became particularly important for all staff members to focus on engagement with every resident and client they came in contact with, especially when dining was shifted to in-room service. The culmination of changes that led to isolation meant that older Americans needed to be engaged in more one-on-one activities. This added stress and anxiety for the already exhausted staff. An activities coordinator discussed the emotional challenges over the long period of time:

> I think in the beginning, because it was just all so new, and I knew that we needed to do all that we could do to make sure that we were keeping the residents healthy and ourselves, it wasn't so so bad. I just knew what was in front of us, and I knew what we needed to do, but as time has passed, just that every day of having to deal with this, to continue managing it, it hasn't been easy. . . I think it became a challenge for me to do the things that we do here to make sure that they, the residents, are staying healthy. (P11)

While this anxiety and exhaustion was experienced by nearly all frontline staff, some individuals had more challenges than others, which was often determined by access to resources. Availability of technology was a key component of care during the pandemic that could either facilitate or inhibit the ability to care for residents. Some residential care communities were able to quickly create and stream original programming into individual rooms while others resorted to using individual caregivers' personal phones to video call residents' families. Communication for residents was essential to their well-being and access to technology framed the experiences of staff in terms of being able to assist in connecting families with their loved ones who were quarantined inside their rooms or residential communities.

Staff noted that the lack of family visitors increased their workload because before COVID many family members assisted in providing care, engagement, and dining support. Staff were quickly charged with facilitating "visitation" and fostering communication between residents and their family members. In-person visitation pivoted first to window visits, then outdoor porch visits. Much of the communication between residents and their families utilized technology including cell phones, FaceTime, and Zoom, which had to be set up and facilitated by activities staff and sometimes

Illustration 4.5. Sensory activity with physical distancing and plexiglass divider. Photo credit: Michele D. Allgood, program director of Gracious Living Adult Day and Health Care Center Corporation.

CNAs. Later in the pandemic, outdoor and then indoor visits were allowed, but these all had to be monitored by the staff. One activities coordinator stressed the challenges of communicating effectively with residents' family members with limited access to sufficient technology, in order to keep them informed and reassure them of residents' well-being. At the same time, it was crucial to foster adequate communication and engagement for the residents. The coordinator explained:

> I'm still asking for a second iPad 'cause I can't stress, keeping in contact with family members, I support that. I want them [residents] to be able to stay in contact with the "outside world," is what I call it. And I've requested that, and I think they [administration and corporate] finally clued into the one [iPad] that I have is kinda old and we need two. And they've [administration and corporate] tuned into that. (P41)

We now turn to the unique challenges faced by staff working in home and community-based programs during the pandemic. The centrality of technology and communication are themes that emerged as essential in both models of care and did directly impact the outcomes for older Americans during the COVID-19 pandemic.

Maintaining Engagement in Home and Community-Based Programs

As discussed in chapter 3, most senior centers, as well as adult day care and day health programs, closed in March 2020, as advised by the county and advisory boards following state guidelines. One exception was a private adult day and healthcare center whose director explains her decision-making and experience in the essay at the beginning of chapter 3. Most programs quickly turned to phone contact with their participants and virtual programming. Similar to residential care staff, community-based staff demonstrated incredible creativity in pivoting to virtual programming and providing a range of opportunities to help engage clients who were now restricted to their homes and often isolated from family and friends. For example, Kellin Smith, the bus driver we heard from in chapter 3, engaged with his clients when he delivered home delivered meals. He was able to discern how they were handling the pandemic and report to his supervisors on what kinds of additional needs they had.

The in-home service providers proved to be quite malleable to the emerging needs of their clients and continued to go into the homes to provide care for any client who was willing to have them come. One home care provider explained how they proceeded to continue to provide in-home care after just a couple of weeks while checking with staff daily about their health. The available staff were able to continue to provide services to clients who were willing to have them come into their homes. Most home-based clients and their families wanted to continue to receive services as a way to avoid loneliness while meeting their everyday needs. Engagement was possible with home care and personal care aides who were available to care for those clients that remained. One home care agency director explained: "We had to cut down 'cause we have a few caregivers that do multiple clients, so we had to cut them down to maybe one or two clients and that would help with the cross contamination. . . As far as the ones who're at home, all of them still wanted us to come in" (P63).

An essential element of maintaining engagement and avoiding loneliness for older adults in home and community-based programs throughout the pandemic was effective communication. As we discussed in chapter 3, and revisit in more detail in chapter 6, most community-based program staff assessed client needs through phone calls. Acknowledging the need for engagement and a sense of community, many program directors and caregivers turned to virtual programming in an effort to provide these critical components to their clients.

The greatest communication challenges were with the clients who were primarily sequestered in their homes, often isolated from family and friends. After one senior center closed, the staff began contacting program participants to find out about their technological resources and need for meal delivery services. One program director contacted the clients' children if necessary, who facilitated their parents' use of Zoom so they could communicate with their friends and families as well as begin participating in newly offered online programming. They explained:

> After a few weeks, it became apparent that we weren't gonna open again anytime soon. So we went back and started polling the seniors . . . and so we pushed and pushed and some of them said they didn't wanna do it [virtual programming]. But then once we felt like we had a really great core group . . . we set up a Zoom test and we had a full screen, and it was so cool because everybody hadn't seen each other. (P52)

These findings demonstrate both the need and ability to exert great flexibility in understanding and meeting the needs of clients in their homes. Shifting quickly to virtual programming, asking about emerging needs related to increased isolation, and engaging with new technologies and communication strategies were essential to meeting the needs of older adults now isolated in their homes. It is important to document the successes and challenges that occurred in the evolving landscape as the pandemic continued and as we consider the threat of future pandemics.

Navigating Uncharted Waters

Preventing the deleterious effects of social isolation during a global pandemic proved a daunting task, especially in the early days of the pandemic when little was known about the virus. Those tasked with ensuring the mental and physical well-being of older Americans were unsure of how to alter the everyday engagement and activities for their clients and residents.

Staff Challenges Responding to Evolving Policies in Residential Long-Term Care

The shifting landscape of infection control and policies made adapting particularly challenging in large part due to the unanticipated length of the pandemic. As one activities coordinator from a corporate-owned assisted living community stated:

> I've been limited on what I can do. At first, they told me, "Well, you can't have more than eight people." And so, during my exercise class, I'd have to cut it to eight people. That's hard to do. And then it was like, "You gotta have less than that," and that's hard to do, and then it's like, "You can't have any group settings." So, I was like, "What do I do? Do I even have a job?" (P41)

They talked about how the rules kept changing daily early in the pandemic until the lockdown when they had to provide engagement for residents who were isolated in their own rooms. We talked with them in August 2020, and they explained how they had adapted:

> I put everything I can on an activity cart, and I'll go from room to room and do different things with residents. First, I start off with the higher functioning residents because for them it's a quick visit. It's like, "I'll give you some puzzles, some crosswords, a daily bingo sheet, coloring, and all that stuff. I'll give you those things and you can work on them independently at your own time." So I kinda have to hit those folks first. And then, I go back to the people who are room-bound, aren't getting phone calls, aren't leaving their rooms, aren't happy, aren't walking, can't see. I have to go back and spend that time with them. (P41)

Activities coordinators became responsible for expanded, complicated, and time-consuming documentation in addition to their quickly evolving job of individualizing activities in a changing infection-control landscape. One activities coordinator described the changes they experienced as an activities professional in assisted living:

> I'm sorry, whatever your job, your duties that you do have changed. In my department, activities. . . I don't concentrate on just parties and stuff now. Things have changed for me. For instance, even when I'm going in rooms, I've gotta wipe down everything. I need to keep up with family members who are visiting or who are FaceTiming now. My documentation is probably changing now. . . (P41)

This activities coordinator went on to explain how documentation was historically fairly routinized and repetitive but now it had to provide more details about individual engagement as activities were somewhat specialized based on the needs of the residents. As policy and program changes occurred rapidly, they were broadly experienced by staff members.

Use and Availability of Technology to Foster Communication and Address Social Isolation

Related to the issues of social isolation discussed in this chapter, data collected in the early stages of this work revealed that the use of technology to address social isolation was an issue for most residential long-term care communities as well as home and community-based programs. The use of tablets, smartphones, baby monitors, and headphones to aid in connecting families with their loved ones proved invaluable although often insufficient. One staff member explained:

> I was worried about them not wanting to be alive anymore, I really was worried about some of the residents just being in a pit of sadness and starting to see their families more, and . . . doing the distance visitation helps so much to see them and have them come inside or just sit across at the conference room with them and visit. . . It was amazing. And they would cry and cry afterwards and saying how that just felt like years to them, they haven't seen their family. (P31)

Some long-term care communities were well equipped to make this adjustment and used available resources to stream programming to residents in their own rooms through their in-house systems. However, the majority of long-term care communities did not have this type of access. Our findings revealed that it was not uncommon for workers to use their own cell phones to facilitate video calls between residents and their loved ones. As one participant stated: “family call staff members’ cells or they call and bring the phone to the resident.”

For persons living with dementia, the use of technology was less useful even though they were most vulnerable to the effects of isolation. Interfacing with technology whereby loved ones attempted to communicate with them was often disorienting. In chapter 5, we discuss the particular issues and challenges faced in using technology and fostering effective communication for persons living with dementia.

Staff in community-based programs turned to making telephone contact with their participants who were now stuck at home. They were able to identify clients who were isolated and those in need of support and assistance, and worked with other programs to be sure these needs were addressed. Technology was important in avoiding loneliness in both residential and community-based long-term care during the lockdown, but involved significant challenges.

Discussion

Only with time and ongoing analysis will we fully understand the ramifications and lasting effects caused by the social isolation induced by COVID-19. Our findings demonstrate that isolation caused significant physical decline in the form of weight loss, and gait and balance issues as well as mental decline observed as lack of focus, social withdrawal, and irritability, which are classifiable symptoms of depression and anxiety. While some reversal of symptoms, notably weight gain, was identified once services resumed, a more robust study and follow-up are needed to determine the extent and duration of these effects.

COVID did shine a light on the issues of social isolation and loneliness particularly for older adults in need of long-term care, and the enormous challenges that staff faced in providing safe and effective care. Issues related to engagement and avoiding isolation and loneliness suggest the need to provide adequate staff resources and keep our in-person programs and services strong, along with increased use of technology and telehealth, as we move into the future.

Staff in all models of long-term care showed the value of a flexible human infrastructure. Participants, especially activities staff, demonstrated resilience, creativity, and an unwavering dedication to providing engagement for those in their care. This led to innovative programming as well as lifesaving interventions. Staff roles were expanded and in some cases, staff were reassigned with many staff willingly taking on new and more challenging responsibilities. Activities staff discussed their efforts to exchange ideas and share best practices with others in similar positions. One interviewee explained how they sought ideas from other activities staff as well as the National Association of Activity Professionals.

> I do try to reach out to other activity directors to see what they're doing in their facilities, and of course, online, YouTube, to see all the videos that other facilities are doing, and we've been doing a bunch of COVID videos too, if you have a chance to check our videos out. We did a video. We did posters that said, "We're all healthy here." And we played music, and we did a parade. And so we've done videos on YouTube. But yeah, I just check out other facilities to see what they're doing. I'm always wanting to know what other folks are doing, 'cause I'm in this building all the time. (P41)

The essay at the beginning of this chapter highlights the efforts of activities staff in one residential long-term care community outside North Carolina to provide effective engagement under evolving restrictions, and the work of the National Association of Activities Professionals. In shortsighted responses by some long-term care communities, some activities personnel lost their jobs because they could no longer create engagement activities in the ways they had in the past. Those older Americans who they served undoubtedly suffered as a result. Instead, as our findings demonstrate, it is imperative to support these providers and honor their essential roles with more support and resources, not less, and encourage all long-term care providers to focus on engagement with the people they care for.

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 employees 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 behaviors[1] 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 healthcare 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.

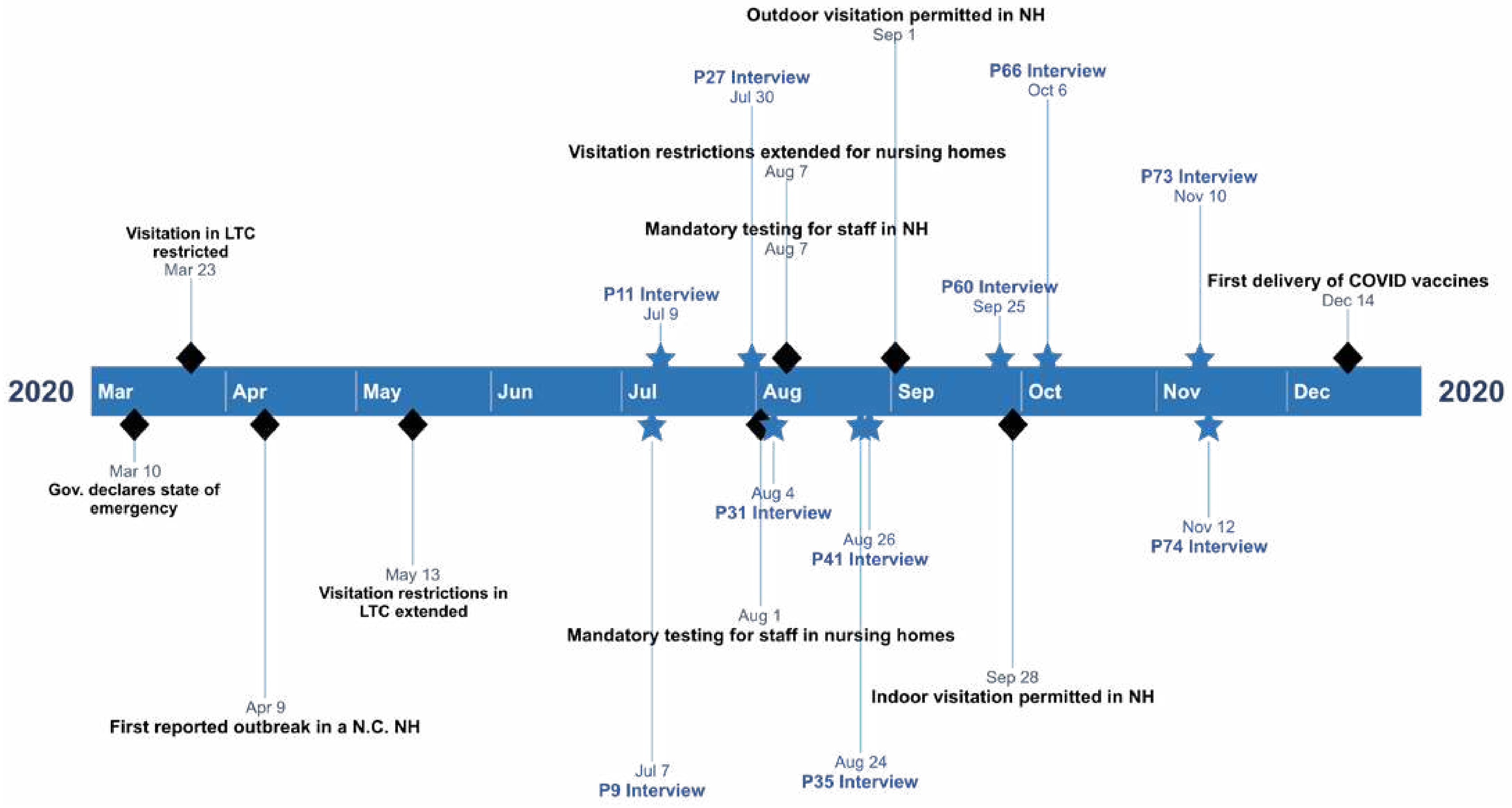

Figure 5.1. Timeline of Interviews Quoted in Chapter 5.

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 heartbreaking. 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.

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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).

6 THE PERSPECTIVES OF ADMINISTRATORS AND MANAGERS

Providing Long-Term Care Throughout the Pandemic

Reflections on My Personal and Professional COVID Experiences, by Hayden Keziah

In early February 2020, I contracted COVID. Back then, it was still very much unknown, had no real treatment plan, and had not yet been declared a pandemic. I was the first patient diagnosed at the hospital in my town. I had accepted a new job at a nursing home in Charlotte, but had not yet started, and after two weeks in the ICU I wouldn't be cleared to work for almost two months. Those weeks in the hospital were some of the most horrifying, lonely, and uncertain times in my life.

When I was released from the hospital, I began Zoom calls with the team at my new facility to meet them while I waited to start, hoping to make up for lost time. I was nervous for this new venture, as I had just moved from out of town and hadn't worked in the industry since the pandemic began. The decision to change jobs was based on being close to my family, but the timing could not have been worse. I took on this challenge of COVID-19 in a new city, nursing home, and with a new company. Looking back, it seems even more eerie just how much I did not know what headed my way.

During the summer of 2020, once I had begun working, we completed our first round of testing and discovered over thirty positive cases among the residents. My supervisory team sprang into action and donned PPE to help move residents and create a COVID unit. These were our very first cases, so we had to set up barriers, move and clean rooms and beds, change information in our EHR [Electronic Health Records] system. There is so much involved beyond just isolating a patient. One day, the housekeepers all decided to walk out, all at once. They did not want to be around the COVID patients. I had just survived the virus, and I felt an obligation to help and reassure all the residents and staff. I went to the back parking lot and there stood all six of my housekeepers, screaming about how unfair it was that they would have to do their jobs and help move residents. Family and friends had gathered in their cars. Across the parking lot, the entire team of department heads stood in full PPE, head to toe, ready to help. It was a stalemate like I had never encountered. I couldn't fathom the lack of dedication the housekeepers had to the residents they see each day, and the reckless abandon they showed by abandoning their post when they were needed the most. But more than anything, their attitude toward being around those residents with the virus worried me that it would make those residents feel diminished. If that was their attitude, I'd rather have them leave than stay and drag the team down.

After the police came to help disperse the employees who had resigned but refused to leave the property, I was standing in my gown, mask, goggles, in ninety-five-degree weather, sobbing. I could not believe this was my life. This was a pivotal moment in my career. I felt truly helpless, overwhelmed, and exhausted. It's important to note that the primary emotion was not fear, like some may think. It was a loss of control that sent me into a fight (or flight) reaction. I was determined to do whatever it would take to care for the residents I was legally responsible for. And I knew the residents were scared—scared of the unknown, scared of dying, and scared that they would be separated from everyone they know and love while they quarantined. But my core staff rallied around me, and we got everyone moved by the end of the day, picking up the slack created by the absent housekeepers. It was incredible to watch the teamwork that formed in the aftermath of a walkout that nobody expected.

I remember being the one who called family members and told them their loved one was positive for COVID, after I had just left the resident's room and delivered the same news. Again, this was in the very early days of the pandemic, and everything was uncertain and scary. Families cried, and pleaded for us to help their loved ones. And I promised them I would do just that. It was powerful to be able to provide to families of residents in my facility what the staff at the hospital was able to provide to my family just a few short months before. It was humbling to have everything come full circle. My empathy was specific to the situation and allowed me to lead without fear of the unknown. I did know what the virus was like, and I knew how to comfort those who were afraid.

Working past the outbreaks was difficult, including having to find supplies at local stores and borrowing from other facilities or using makeshift items since the supply chain was so disrupted and unclear. Giving staff every tool to work safely was of the utmost importance. However, the rules were constantly changing and it felt as though long-term care facilities were penalized for a phenomenon and disaster out of our control. It

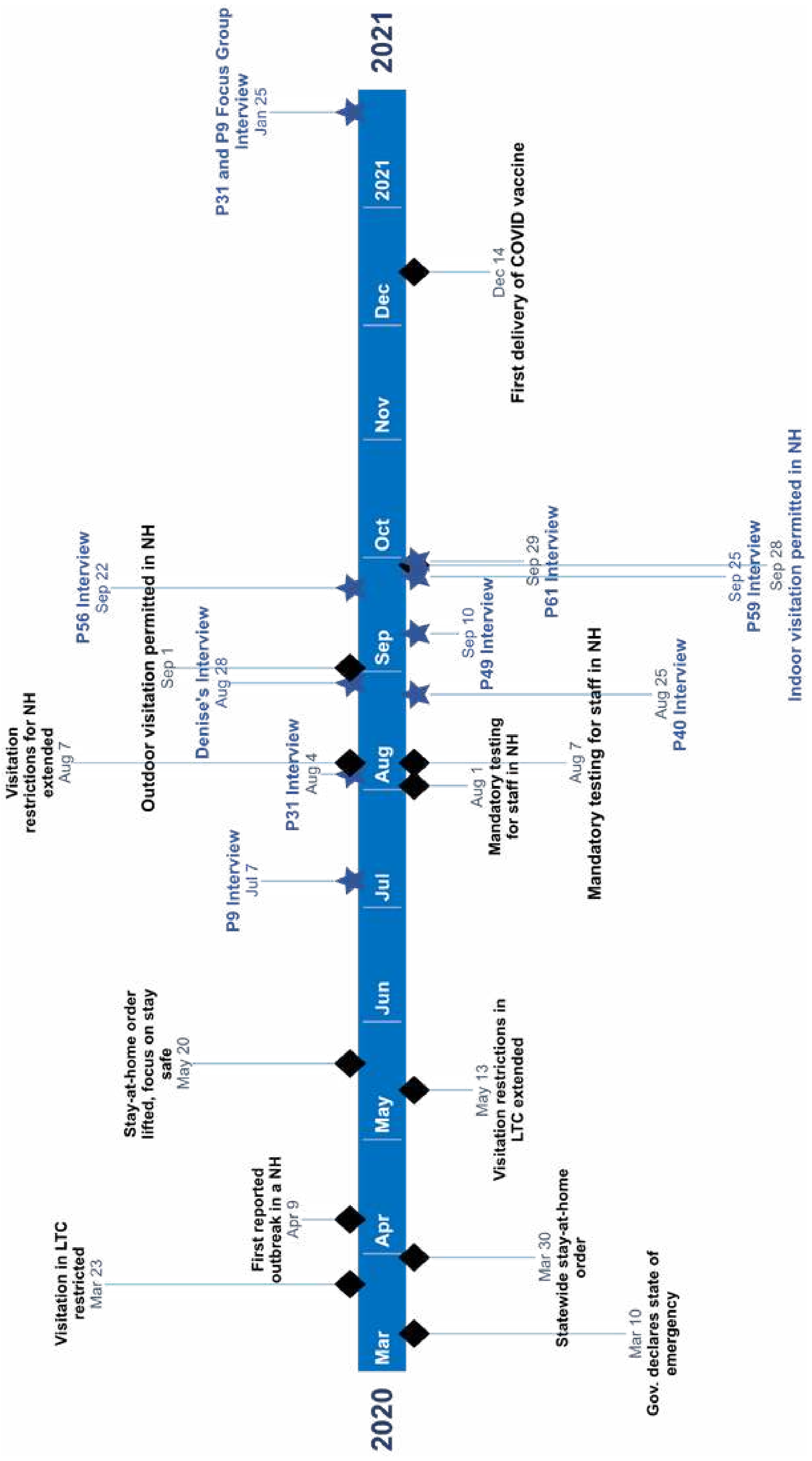

Figure 6.1. Timeline of Interviews Quoted in Chapter 6.

was infuriating to be villainized in the media and sometimes by your own organization, when you are the "boots on the ground" keeping things running, managing things most folks could not even imagine. It was up to us to do the best we could with what we had at our disposal. We did not have the option to "stay home and stop the spread." We had to step up for our residents.

I dried my tears and wiped my sweat and got back to work. And that's what I've been doing ever since.

> "I have felt it [mental stress]! There is so much on your shoulders. It is a lot of responsibility because you have to make sure everybody is doing what they are supposed to be doing." (P31)

This quotation is from an executive director at an assisted living community who we interviewed in August 2020 and January 2021. At the time of the first interview, she had successfully fended off COVID in the assisted living community while still maintaining some level of social engagement for the residents. She was stressed, anxious, at times overwhelmed, but also demonstrated great resolve and optimism regarding the care of her residents. She had been working with older Americans for over ten years and was able to draw on her experiences, her strong connections with residents and their families, as well as an engaged and highly responsive corporate infrastructure to navigate the pandemic in a way that seemed effective and manageable within an ever-shifting infectious disease landscape. Her optimism was well earned as the community was one of only a handful that had not experienced any outbreaks or COVID-related deaths at the time of our first interview during the summer of 2020. She was realistic, though, about this accomplishment, stating: "We take pride in what we have done here, but it can happen anywhere [an outbreak of COVID] and that's the scary part." She was foreshadowing a major outbreak that would occur in her community following the holiday break in 2020, which she would later deem a "super-spreader event" as residents went home to visit families for the holidays and brought back the virus. She described the outbreak to us:

> Well, uh, we went the entire pandemic up until Christmas, the week after Christmas, with no cases, not one case. Then we got hit hard. When I say we got hit hard, we got thirty-seven residents, which, we only have fifty-five residents, so that's a lot. Thirty-seven residents and fifteen staff. And we, to date, have six deaths. It's been hell. It really was hell." (P31)

They decided to move the residents who tested negative for COVID to hotels because they were at capacity and couldn't convert wings to COVID units. It was costly, scary, and incredibly difficult for both residents and staff. Upon reflection, she stated plainly this was not a good plan for her community and that more thoughtful protocols, as well as preparations for future outbreaks, needed to be put into place. Below, we review how her responsibilities changed in response to the pandemic, as well as some of her lessons learned. We also draw insights from administrators across the long-term care continuum, including those providing home and community-based care, because they faced both similar and unique challenges.

For example, Denise is the program manager of senior nutrition, with over twenty years of experience overseeing twenty nutrition sites in the county. She stressed the collaborative nature of their work in partnering with a variety of faith-based organizations, NGOs, and other service providers to ensure that a wide swath of services, beyond nutrition, were available to improve and sustain the quality of life of older county residents. These partnerships proved effective in enabling them to pivot and collaborate creatively in order to meet the needs of clients. She explained:

> It was very interesting how we kinda. . . 13 March, it was a Friday, I remember, and we heard the [congregate meal and senior center] sites would shut down. [Eighteen hundred people were enrolled at congregate sites.] In one day, it was teamwork, we started calling people, physical phone calls were made, asking people, "Do you feel you would benefit from nutritional support?" (P42)

Over those three days, they expanded from eleven hundred to sixteen hundred people receiving nutritional support at home. They effectively integrated these new clients into existing routes, increased and altered their use of six drivers and pulled in two more who were no longer transporting clients to and from a variety of appointments across the county, and shifted nutritional requirements because food vendors were overwhelmed due to skyrocketing demand and shortages in the supply chain. They also rented more storage space for food so they could stock up on meals and staples in case shortages continued. There was also an increased demand from pastors calling about members of their congregations and individuals in the community who didn't know where to turn when people were afraid to go to the store or family were afraid to visit and bring food. While the logistic challenges were daunting, because of long-standing community partnerships that were in place, most clients' needs were met in an efficient and effective manner. Denise was able to support her mission of providing resources to maintain older Americans in their homes and keep them safe.

While the primary focus of our research was to capture the narratives of those frontline workers who were providing hands-on care or delivering the actual services and supplies to older Americans during the first year of the pandemic, it is also essential to consider the actions and challenges that decision-makers were confronting during the quickly evolving pandemic in both residential long-term care as well as home and community-based programs. These leaders are responsible for the quality and safety processes in long-term care that then influence the performance of the workforce, job satisfaction, and staff retention (Siegel and Young 2021).

In this chapter, we highlight the experiences and responsibilities of administrators and managers as they attempted to preserve the physical and mental health of residents and clients. Key themes include 1) the logistic challenges and successes administrators experienced; 2) emerging or changing bureaucratic demands related to infection control as well as work associated with the resources made available or unavailable; and 3) the role of communication in navigating the pandemic including between administrators and governing agencies (e.g., CDC, CMS, NCDHHS), corporate offices, with staff, and with clients, residents, and families. We also include administrator narratives that capture key lessons learned as well as the personal sacrifices many of these workers made to preserve the health of those under their care.

This chapter is based on our interviews with a sample of seven residential long-term care administrators and sixteen managers of home and community-based programs. As displayed in table 6.1, the residential long-term care administrators represent four different corporate groups: two are independently owned and one is church-affiliated.

The types of programs and positions of the home and community-based managers included in our sample are displayed in Table 6.2.

Table 6.1. Residential Long-Term Care Administrators.

Level of Care	Position	#	Date	Ownership	Funding
Nursing Home	Administrator	9	7/7/2020	Corporate*	Medicaid
Nursing Home	Administrator	56	9/22/2020	Corporate*	Private
Assisted Living	Administrator	15	7/20/2020	Church-Affiliated	Mixed
Assisted Living	Executive Director	31	8/4/2020	Corporate*	Private
Assisted Living	Administrator	44	9/2/2020	Corporate*	Private
Memory Care	Administrator/ Co-owner	60	9/25/2020	Independent	Private
Adult Care Homes	Administrator/ Owner	27	7/30/2020	Independent	Private

*Each is part of a different corporate group

Table 6.2. Home and Community-Based Directors and Managers.

Agency/Program	Position	Participant #	Date	Funding
Medical (dementia)	Executive Director	36	8/24/202	Non-profit
Community Services	Executive Director	37	8/25/2020	Non-profit
Home-Delivered Meals	Executive Director	58	9/25/2020	Non-profit
County Adult Programs	Manager	40	8/25/2020	County
County Senior Nutrition	Manager	42	8/28/2020	County
County Transportation	Manager	59	9/25/2020	County
Senior Center	Director	50	9/11/2020	County
Senior Centers	Recreation Coordinator	57	9/23/2020	County
Senior Center	Program Director	61	9/29/2020	County
Adult Day and Healthcare Center	Program Director/ Owner	49	9/10/2020	Mixed
Adult Day Care Center	Executive Director/ Owner	54	9/17/2020	Mixed
Adult Day Health Center	Executive Director	66	10/6/2020	Mixed
Home Care	Agency Director/ Owner	73	11/10/2020	Mixed
Home Care	Co-Owner	75	11/17/2020	Mixed
Home Health	Director/Owner	63	10/1/2020	Mixed
Senior and Adult Programs	Director	52	9/16/2020	Mixed

Logistic Nightmares and Notable Successes

Shifting services and transitioning roles were themes discussed by all the administrators and managers we interviewed during the pandemic. The rapid onset of COVID-19 required the ability of leadership across all forms of home and community-based and residential long-term care to pivot quickly to meet the needs of the older adults they provide care for and to help keep them safe. This required creativity and flexibility on the part of administrators in the creation of new policies and guidelines. In all cases, administrators were forced to ask caregivers to adapt to new procedures or even request they change their roles entirely. This was especially the case with the shuttering of community services as well as residential long-term care communities that were facing increased tasks and staffing shortages.

Many faced impossible logistic scenarios when attempting to institute necessary changes to programming. As discussed in the opening paragraphs of this chapter, Denise, the program manager of senior nutrition for the county, explained the strain that logistics—including food supply, storage, assessment, delivery, and funding issues—placed on their ability to efficiently meet the nutrition needs of her clients. When congregate dining at the nutrition sites was shut down, she had to quickly enroll clients who would pivot to needing in-home delivery in order to support their nutritional needs. At this time, the country was experiencing food shortages and a plethora of supply chain issues. Denise felt this as the program manager of the county's nutrition program for older adults. She recalled:

> The food vendor . . . could not keep up with the demand, the production demand. But since we are a large customer, . . . they offered us what they had in store, which were not part of our regular meals, but I had to adjust [and] make sure that these meals still met the nutritional guidelines and for reimbursement for funding purposes. . . . And we accepted the meals that they had in. . . In the back of my mind, that was a worry that we were gonna have enough meals. . . . I actually had about seven or eight pallets of meals that we purchased. . . . We didn't have room in our own warehouse, and we had to get storage space, . . . [to] store extra meals just in case if the vendor was falling short of meals or on a delayed schedule. . . . So those are more like operational logistics. (P42)

An owner and program director of an adult day and healthcare center that remained open shared similar concerns with nutrition services regarding food shortages, which were compounded by income loss. She explained: "Despite the fact that we didn't have as many participants, so that's less income, and I couldn't find certain meats, I have to feed them. And it was like going to the grocery. . . You couldn't get ground beef and chicken, . . . Everything was coming at us. But when you're doing it, you're not realizing what you're doing." (P49)

Dealing with funding shortages as a result of COVID was noteworthy during the shutdown, which was the case even as CARES money was made available but was slow to access. One program director of a senior center spoke of these specific financial losses that occurred alongside the need to spend money to pivot services during the pandemic: "We've lost a lot of money. I'm sure that a lot of people have. We're sitting close to around a $350,000 loss, and it's just continuing to mount up" (P61). Even though slow to access, CARES funding was identified as an important resource to enable flexibility as the environment changed. The same senior center program director explained:

> We are getting some CARES funding. . . . We attempted a Bingo outside, when you could have twenty-five people outside, and our patio has no shade, and we were sweating profusely. It was disgusting, actually, so part of the CARES funding we're requesting to have an awning put on outside to have some shaded area that we can also continue, if this should ever happen again, we can do more outdoor programming and not be so uncomfortable, but we can also extend programs outside to provide that social distance now that we're able to open. (P61)

Another major challenge was providing adequate staffing along the entire long-term care continuum. Most residential long-term care administrators requested their staff, who often work more than one job in order to earn a sufficient income, work only in their community to limit the potential spread of COVID. Similarly, in-home healthcare workers were limited in the number of clients they served. At the same time, some staff were unable to work because of their own illness or their fears of getting sick or endangering their families.

School closures as a result of COVID-19 were difficult for some staff to manage. A county program manager of services for adults along with the owners of in-home aide agencies pointed out that in-home aides are largely women who were now also responsible for caring for their own children. Administrators and managers discussed the need to accommodate these issues in scheduling staff.

The essay at the beginning of this chapter focuses on the example of the nursing home administrator who had numerous staff resign as soon as the COVID outbreak occurred. She discusses this difficult scene when they suddenly had a group of residents test positive and all the housekeepers walked out. Based on this traumatic experience, she explains her strategy to mitigate this potential mass exodus moving forward:

> *Now* I have a backup plan for the backup plan. Everybody is cross trained to do anything they need to do. . . . We've even thought about housekeeping knowing how to do dietary's job, you know, everybody knows how to do laundry so if something happens you can step in. . . you're not relying on people who are gonna fly the coop. (P9)

Facing excessive and constantly shifting challenges, the administrators and program managers reported on both the nightmares and successes as they looked back at the earlier phases of the pandemic. They also highlighted the new bureaucratic requirements that emerged alongside the pandemic.

Bureaucratic Challenges

The issue of added paperwork surfaced in multiple interviews with owners, administrators, and program managers. These bureaucratic issues—including grant applications, financial forms, vendor agreements, new enrollment forms for individuals needing in-home services, and audits that required completion and compliance—inhibited the ability of caregivers to serve their clients quickly and efficiently. Denise, the county nutrition manager provided detail regarding this issue:

> So we really have state registration forms and for audit purposes and for reimbursement purposes. There is actually paperwork that needs to be done. . . . For homebound people, we normally do home visits, but we had to end up doing all telephone visits. Telephone assessments for everybody who was considered as new clients, and we had to make sure whether they were homebound, they met criteria. . . and really need home-delivered meals not just because of COVID. . . . And then we also had to do paperwork, a different type of packet for people who could be potential congregate. . . or it could be just people who did meet the homebound criteria. . . and so adding all those people is in itself a lot of work, but that gave duties to our staff. (P42)

Much like the reallocation of resources and reporting, infection control included an abundant array of new procedures and requirements for both residential and home and community-based care. Administrators reported having to procure as well as track the use of PPE by staff and, in the case of residential care, residents. As testing became more available, rigorous requirements were put in place. Simultaneously, there were evolving demands for testing both residents/clients and staff. All positive tests had to be reported to the CDC as well as the NCDHHS. In addition, quarantining had to be standardized and tracked for staff of both residential long-term care and home and community-based programs on exposure and actual infection. For congregate residential care, quarantining includes tracking residents' activities outside the residential community (i.e., trips to doctor's offices and hospitals) in addition to setting up spaces within the nursing home or assisted living community that allow for safe quarantine environments. As vaccines became available, administrators had to encourage, educate, document, and report the vaccination status of staff. In congregate residential long-term care, residents were also monitored regarding vaccination status. The administrator of a nursing home explained the stress she felt between the challenges of the new procedures she had to navigate every day that existed inside a "harsh regulatory environment" and news media eager to point fingers and even demonize the skilled nursing community:

> In a SNF [skilled nursing facility], it is a full time job, just the reporting. [We] did hire a new CNA to be a wellness coordinator to provide numbers for the reports. [There was] respiratory screening of all the residents, cross-referencing screening and testing of my staff and payroll. . . . We missed three staff being tested and the state came in and gave us a citation. It's such a harsh regulatory environment anyways and now they will use this with any headline they ever write about us—SNF has poor infection control, etc. It's ridiculous. (P9)

These bureaucratic challenges all added to the workload of the administrators and managers who are responsible for providing safe, effective care for residents and clients, as well as a safe working environment for their staff. In a media analysis we conducted, it was clear that the majority of coverage around COVID-19 outbreaks and high mortality among older Americans painted a negative picture of what was occurring in long-term care communities. The caustic media environment put the spotlight on the outbreaks and deaths that were occurring at a high rate, adding to the challenges and stress experienced by the administrators and managers who were navigating this nightmare.

Communicate, Communicate, Communicate

As the pandemic progressed, and knowledge about the virus increased, so too did policies and programmatic requirements. These changes were discussed, advised, and at times legislated at all levels from federal mandates and guidelines to state and local bodies. These policies did not always coincide and often emerged on different timeframes. This was a difficult landscape for all administrators and managers to navigate as they were often inundated with competing demands and guidelines. It is not surprising that throughout all our interviews, participants at every level of care in every type of care scenario discussed the value of good communication as well as frustration with poor or inadequate communication. Administrators and managers in residential long-term care and home and community-based services experienced both overlapping and unique communication demands.

Communication was especially critical in both home and community-based and residential long-term care when state-mandated lockdowns occurred. As programming and policies evolved quickly, administrators had to ensure consistent and clear communication with their residents and clients, as well as with their staff regarding infection control and shifting responsibilities (i.e., group activities changed to individual or pod activities), and families that could no longer visit their loved ones or whose loved ones could no longer attend adult day care or senior centers or congregate nutrition sites. These efforts began with consideration of the government mandates and communication with professional organizations and corporate offices and advisory boards.

Communicating with Corporate Offices, Advisory Boards, Other Administrators, Vendors, and Professional Associations

Administrators and managers had to gather information and confer with various professional organizations and supervisory boards as they struggled to interpret federal, state, and local mandates and guidelines and make decisions about how to provide safe and effective care for the residents and clients. Participants working in residential long-term care discussed in detail how they navigated the evolving knowledge about the virus and instituted changes in procedures regarding infection control, quarantining, social (or physical) distancing, and vaccines. One administrator of a skilled nursing community that experienced a major outbreak in the early months of the pandemic explained:

> But it seems like we get one hundred [messages about COVID] per day. . . but when you get five different entities—your federal government, your state government, your local government, your corporate policies, and your facility policies—and they're all doing something different, that's really difficult to keep track of. It's difficult to figure out who's got the best way of doing things. (P56)

This same administrator lauded their corporate office for their efforts to distill the information into tangible policies and procedures on an evolving basis. They also found the weekly check-ins with others in their corporate group to be helpful as staff at other residential long-term care communities were able to share their experiences and communicate back to corporate their failures and successes. They explained:

> She [their regional director] kept us all together and on the same page as best she could. So by having those weekly calls. . . we're able to bounce ideas off of each other, off of other administrators. Every administrator and every DON [director of nursing] on that call. We're able to go through different scenarios, we're able to hear experiences such as, "Hey guys, we just had a state team walk in and they gave us this tag for this infection control issue. Make sure you guys aren't making that same mistake." So I think we had knowledge and power because of the masses that we had of DONs and buildings and corporate structure. And if it weren't for that, it would be exhausting having to keep up with all that if we didn't have that. (P56)

This administrator alluded to the potential differential experiences faced by various residential long-term care communities. Our data indicate that corporate-owned congregate residential communities typically did have easier access to PPE and more support in determining effective approaches to combating the virus. On the other hand, owners and administrators of independent residential long-term care communities stressed their flexibility, creativity, and resourcefulness as they processed the incoming information and navigated the changing environment in order to keep their residents and staff safe.

In home and community-based programs, managers faced equally daunting challenges as the distribution of services fundamentally changed for all programs. The advisory boards of most programs directed the managers to shutter their programs but retain staff. County funding pivoted to allow programs to be reimbursed for adult day care participants, for example, as long as staff communicated with the clients by telephone to assess their needs and provide ongoing support. A senior center director explained how they determined participants' interest and ability to join virtual programming:

> So what we did is we split up the list and we started calling people to say we're closed. . . After a few weeks, it became apparent that we weren't gonna open again anytime soon. So we went back and started polling the seniors: "Do you have a computer? Do you have an iPad? Do you have a cell phone? . . . Do you use the internet? Do you use Zoom? Do you use FaceTime? What do you use? And then, are you interested in using Zoom if someone teaches you?" And once we did that, we started getting people onboarded to Zoom. . . We set up a Zoom test and we had a full screen and it was so cool because everybody hadn't seen each other. (P52)

They also delivered kosher meals to their regular participants who were no longer receiving that service since the program was closed: "The only thing that we had done from the beginning is we were delivering meals, so we started delivering meals every two weeks, and we tried to give them enough for at least a meal a day for two weeks and they could freeze things that they could freeze and things like that" (P52).

Denise, the county program manager of senior nutrition, was very effective in shifting from congregate dining to in-home delivery, which occurred essentially overnight between Friday and Monday. She was also able to continually add home-delivered meal recipients as the pandemic continued and more and more older community members needed nutritional support as the congregate nutrition sites and other community programs were closed and they were unable to go out grocery shopping. She highlighted the resilience and flexibility of staff as well as her ability to communicate with strong community partners who could expand their services. She explained:

> Of course, the entire operation of home deliveries was team-based, so people who manage the [congregate] site operations started helping the drivers. . . [I] realized to extend services on a much larger scale I had to leverage resources. . . We did get CARES funds. . . And one of the things that we kind of used part of those funds for nutrition support, and I think this has kind of helped me realize, in order for me to sort of extend the services on a much larger scale, and I have to leverage resources that are already available, like I have to work with community partners, so there are two nonprofit organizations that I thought about, and we were able to get funding in place. (P42)

Denise, the nutrition program manager, was noted by other program managers for her effectiveness in responding quickly to the expanding need as they increased their delivery of home-delivered meals. This was due in part to the strong ties and effective communication between community agencies. This decision-making at the administrative level also required strong communication with staff in order to be implemented effectively, to keep staff safe, and to provide safe care for their clients.

Communicating with Staff

These staffing challenges required communication with individual staff members to ascertain their changing availability and scheduling needs. The county program manager for programs for adults pointed out the need to better accommodate and communicate even more effectively with staff to ensure their continued engagement with evolving programming and assure staff that their safety was a priority. They described:

> Okay, so I'd say one thing that has worked well was the mobilizing for staff to work remotely, because they felt supported. . . because it's always better for people to be able to work with accommodations than to have to take FMLA [Family and Medical Leave Act] and have half of your workforce out. And it also gave the message that our health and our safety was a priority to the county, and I think that did wonders for morale. (P40)

Alternatively, Denise, the nutrition program manager, noted the communication breakdown that occurred when everyone left the office and worked remotely. She bemoaned the lack of communication that no longer happened as people did not talk or see each other every day, and she felt this had a negative impact on morale. She saw this as an important lesson learned that needs to be integrated into remote responses moving forward.

In addition, Denise highlighted communication breakdowns with their vendors (including contracted agency staff), such as home health agencies, especially regarding policies vendors had in place concerning infection control for their staff but also for the recipients of care. She explained:

> Where I'll say I fell down is it would have been better if early on, I had gotten information from the vendors about their policies regarding infectious disease control. I think they were writing them as it went along as the CDC was giving guidance as the state was getting guidance, and that's a moving target, but probably earlier on it would have been good for me to have gotten that kind of information so I could share it. (P42)

In discussing this situation, she related a scenario whereby a client's family member tested positive for COVID but did not disclose this information to the social worker, agency, or staff person who visited their home to provide services. It was not until the adult day care center reported the occurrence of COVID to the county Department of Public Health that they were notified. She also explained that staff members themselves did not always disclose their exposure or infection:

> From the vendor side [the home health,] aides were not always, or haven't always been, forthcoming with their employer about having a family member who tested positive or going to get a test themselves. We kinda look at individuals who work with, I'll say a low-income job, need the money and make decisions for themselves, knowing that they may not be able to work if they disclose things so. . . that I'm not quite sure how we could do better, but that's something that did not go well. (P42)

As noted in chapters 2 and 3, some CNAs, housekeepers, and homecare aides felt supported by their supervisors. Others, however, felt administrators and managers were making decisions without listening to their concerns and utilizing input from their hands-on experiences.

Communicating with Residents and Clients

The administrators and managers all explained that many residents and clients were confused by mandates or frustrated with the substantive disruptions the pandemic caused. One residential long-term care administrator said plainly that the only way to address their anxieties, frustration, and anger was through constant communication and explanation of COVID mandates and policies. They said, "You cannot overcommunicate your commitment to residents. You just can't overcommunicate it. You have to show them that you're serious about it [COVID and prevention] in order for them to feel safe. And that's our job, is to protect them and make them feel safe" (P44).

Administrators and managers stressed the importance of communicating the constantly changing rules and limitations to residents and clients. Residential long-term care residents were required to remain in their rooms for months with their only in-person interaction provided by staff. These lockdowns were generally reinstated whenever there was an outbreak in the long-term care residence. Enforcement of mask wearing and social distancing was exceedingly difficult—especially with regard to persons living with dementia, as discussed in chapter 5. Home and community-based providers struggled to provide essential services to clients while keeping the clients and themselves safe. This required extensive communication with clients to ascertain which services were essential and when clients were willing or unwilling to have workers in their homes (see chapter 3). This required consistent communication with clients and their families, as we discuss in the next section.

Communicating with Families of Residents and Clients

These communication demands also extended to family, many of whom were distressed because they could not be with their loved ones, including some living at home. Administrators in residential long-term care had to institute new forms of communication to connect families with residents, and several started sending regular email updates to residents' families (see the discussion in chapter 4 of innovations that allowed virtual and outdoor visits). Administrators emphasized that it was particularly important to have staff or themselves reach out to loved ones when residents, especially those with dementia, struggled to use new forms of communication and, of course, when residents were ill or declining. As one administrator explains in the essay at the beginning of this chapter, she was the one who called family to tell them of the COVID diagnosis during their early outbreak. She had experienced a severe case of COVID herself and was hospitalized back in February 2020 and felt she knew what the virus was like and how to comfort those who were afraid.

Extensive media and social media coverage has focused on the frustrations and complaints of residents' family members who were unable to visit with their loved ones and questioned the intent of administrators and staff. For example, an active Facebook group "North Carolina Caregivers for Compromise because isolation kills too!" was created in September 2020 as part of a nationwide reaction to lockdowns and limitations on visitation. This was especially disheartening to administrators and staff who were struggling to follow guidelines and keep residents safe from COVID.

In terms of home and community-based services, one manager lauded the ability to quickly communicate with clients and their families about their needs and make sure they were met. This is impressive as many services shifted overnight when adult day care and other home and community-based settings were closed. They explained:

> What we also did well at a micro level is I think my staff did a remarkable job assessing their individual clients and families to see who needed what, and to prioritize that and then to bring forward to me. "This is okay over here, but what this person really needs is a refrigerator. . . she's taking care of her elderly parents and her six-year-old grandchild, she doesn't have a functional refrigerator, can we get some money for it?" So just those. . . There's a micro level keeping people safe and just trying to help them out. (P40)

This shifting landscape proved stressful and demanding on staff at all levels. It is also important to acknowledge that beyond their best efforts to serve their clients and residents at this time, they also were experiencing an uncertain, risky environment and their commitment required managing personal stress and making personal sacrifices.

Personal Sacrifices and Personal Stress

Continuing to work and committing oneself to the care of particularly vulnerable older Americans during an uncertain, deadly global pandemic is heroic. Our interviewees discussed why they were willing to take on risk and continue serving clients and residents despite their own fear and anxiety. For example, one transportation manager used the isolation that they knew their clients were experiencing to motivate them to continue to show up and do their job and be available for the older adults needing the transportation services and human connection that they and their staff could provide:

> Well, what is the message here? And there's so much sadness right now and isolation, and how has that really impacted a lot of people, but then we're also thinking, "Well, okay, what can I think from a more positive side of it?" . . . So it kinda helps keep me a bit motivated, reminds me why I'm here. I have to remind myself, I have to tell myself, I'm not here just for my kids and bringing food home to the table, but there are people that really have a need for us, and there's a reason why our program exists to serve in your community. (P59)

Staffing issues are unfortunately common in long-term care, and staffing challenges were greatly exacerbated by COVID in several ways. For example, workers were unable to work when they were sick or quarantining, and most programs tried to limit the number of residents or clients each worker served in an attempt to mitigate exposure. As stated above, staff were now dealing with personal challenges including keeping their children, grandchildren, parents, and others they live with safe. Many were not comfortable providing hands-on care and being exposed to COVID daily. All these issues added to the excessive challenges managers all faced in providing effective staffing in both residential long-term care and home and community-based settings including home care and home health aides going into peoples' homes. Discussing challenges associated with school closures as a result of COVID-19, one program manager of services for adults (P40) pointed out that in-home aides are largely women who were now responsible for caring for their own children who were no longer going to school each day.

At the same time, these administrators and managers also pointed to the great resilience and dedication of their staff, providing positive examples of staff who really stepped up and demonstrated their commitment to the people in their care. One participant stated:

> I know there's a silver lining in everything. So I think if anything, it's taught us to be resilient. It has definitely, you know, you always have sort of a sixth sense about some of your caregivers and what they're willing to do and able to do, and it has been astonishing to me how really awesome, so many people have just stepped up, and . . . they've taken risks to themselves and stayed with clients that can't be left alone. (P73)

Both professional and personal demands were described by each of the administrators and managers. Anxiety and depression were discussed by multiple participants who, while they were facing extreme challenges dealing with the pandemic at work, were coming to grips with their own isolation and fears surrounding the pandemic. A program manager of services for adults expressed these thoughts:

> I probably, like Michelle Obama [as described in her autobiography], have kind of felt that low depression. I haven't been to a restaurant, I think since February, other than getting takeout. But it really is an isolating experience and COVID, because it's what I see every day when I watch MSNBC, and because it's what I do in my job every day, there's just a whole lot of pandemic talk. . . and the world of my world revolves around that, and I'd say that's getting. . . That kind of gets to you. . . the fact that this is your world basically right now. (P40)

The administrator of a nursing home that had experienced a major outbreak early in the pandemic openly discussed their feelings and concerns as they thought back on that devastating period:

> There was probably four or five days in a row where I would sit back and no one would be around me, and I would blame a lot of it on myself. . . Not that I could have done anything or could have prevented it, I don't think, but I would say, "If I had done this or if I had done that or if I had. . ." A lot of second-guessing. And I would, I'd get very emotional. There was a day, I let three funeral home directors in because they had to pick up bodies and that, that's extremely difficult, and people didn't have to die. . . Now, for us we ran a high hospice volume of patients, and so these people were very compromised, and I tried to tell myself that, "Hey, [name], there's only so much you can do and that you could have done and so. . ." But yeah, there was probably a good week to two-week period where it was very difficult for me, and I didn't show it in front of anybody. . . but my [spouse]. But yeah, it was difficult. At the end of the day, as an administrator, we take full responsibility for everything that happens in this building. That's our role, and I took that to heart. (P56)

The combination of intense professional challenges along with the personal stressors they were experiencing at the same time was particularly difficult for the administrators and managers who had to make hard decisions in the constantly changing environment throughout the pandemic.

Discussion

A recent study of long-term care leaders in North Carolina and Pennsylvania reported:

> During the pandemic, long-term care administrators were expected to maintain infection control protective measures in an everchanging regulatory environment in order to maintain the highest level of safety and well-being for residents and staff. They were responsible for establishing isolation wings/hallways, ensuring that staff had personal protective equipment and knew how to properly use it, implementing work protocols to treat COVID positive residents and staff, and provide care and services when staff couldn't work due to exposure or testing positive themselves. (Lane and Liu 2022)

As discussed in this chapter, residential long-term care administrators and managers of home and community-based programs were faced with inordinate challenges as they engaged in constant decision-making throughout the pandemic. They had to implement safe care practices to protect their staff and residents/clients while following evolving federal, state, and local policies and guidelines.

One of the more common themes among administrators and managers is the need for a committed, flexible workforce. Adequate, effective staffing is currently at crisis levels for the many reasons we've discussed and changes are necessary. As the nursing home administrator who had her entire housekeeping staff walk out as soon as the COVID outbreak began advised, it is essential to cross-train the staff so that they can step in to fulfill different roles when it becomes necessary. This is not necessarily common practice, although that was a lesson imparted to Shenk by a nursing home administrator in Denmark more than thirty years ago. That is one of the lessons learned and relearned during the COVID pandemic, and in the conclusion to this book we will continue to explore these lessons learned.

7 A LINGUISTIC ANALYSIS

Roles and Professional Identities in Defining Reality

Boyd Davis and Christin Wolf

Understanding Social Identity in Times of Crisis and Change, by Pilar Blitvich

In sociolinguistics, the concept of social identity has been used to explain how individuals' self-image derives from the social categories they belong to (Tajfel 1979), and it is related to the emotional and evaluative consequences of belonging to specific, recognizable groups (Tajfel 1982). Identities are intrinsically relational: who "we" are can only be fully grasped in relation to the "other." By understanding how individuals' thoughts, emotions, actions are impacted by real/imagined "others," we can evaluate their sense of belonging and how they think about themselves (Hogg and Vaughan 2009). However, this is not always straightforward. Discussing identity in a globalized world, Blommaert (2013) argued that the questions regarding who "we" and "they" are had become much harder to answer. In times of relative social stability, "we" have quite a clear sense of who "they" are and, therefore, of who "we'' ourselves are. Crises and world-scale changes destabilize "them," making it a category in constant flux, about whom very little can be presupposed. As a result, "we" also becomes a much more fluid and vastly more complex category.

It is not surprising that another global phenomenon, triggered by the COVID-19 pandemic, would have a major impact on how "we" think about ourselves in relation to "others." A virus, whose potential devastating effects for human life were difficult to gauge, spread throughout the world, also threatening to collapse financial and social structures. Crucially for this discussion, it was the "others" who embodied and transmitted it, and it was necessary to reposition them as "dangerous" and socially distance from them. As a consequence, in isolation, who "we" were, as sons, daughters, parents, club members, professionals, and so on, had to be rethought and recalibrated.

Very few professional practices were as affected by COVID-19 as health services; long-term care providers stood at the front lines of the battle against the virus, fighting it with limited knowledge and resources, overwhelmed by the number of cases and deaths. A critical situation in which what they knew of themselves as professionals and others as patients and colleagues was no longer on firm ground and often put to the test. The "other" had become a more fragmented unknown, a category about which very little could be presupposed, and so had the "we." This was especially true for those healthcare workers taking care of older adults, as the ones whose interviews are analyzed by Davis and Wolf. COVID-19 ravaged those older than sixty-five years old and went through nursing homes sparing few.

It is in this context, situated by and in the nine interviews referenced in this chapter and the narratives these elicited, that the fragmentation of the "we" and the "they" emerges as fundamental to the social identity co-construction of health service workers and how views about alterity had been significantly transformed by the perilous situation caused by COVID-19. The us/them dichotomy is present in all the interviews analyzed but not alluded to in a contentious manner, just to make sense of who both had become. The multiplicity of "they" is a reflection of how the "we" is in clear transition. Although there are different "theys," however, it is the "we" that is given more precedence, as "we" see ourselves as key to deal with the virus and restore the "other," and thus "we," to our previous selves, as much as feasible.

The analysis of "we/they," as deployed in the interviews under scrutiny, also points to the synergetic connection between the macro, the meso, and the micro level of social inquiry. Changing ideologies at the macro level tied to the COVID-19 pandemic and how these affected other/self perceptions of these workers, are mediated via the meso level, an interview, and instantiated at the micro (interactional) level by the use of distinct pronominal references, that reflect and also construct (affirming, questioning) those very macro-level ideologies. Hence, the need to carry out micro-level analysis but without forgetting to tie results to meso- and macro-level phenomena.

Now that, in many ways, the pandemic is behind us, it would certainly be interesting to see whether "we" and "they" are still fragmented similarly or have become gelled in ways that point to a different conceptualization of the social identity of long-term care service providers and those in their care.

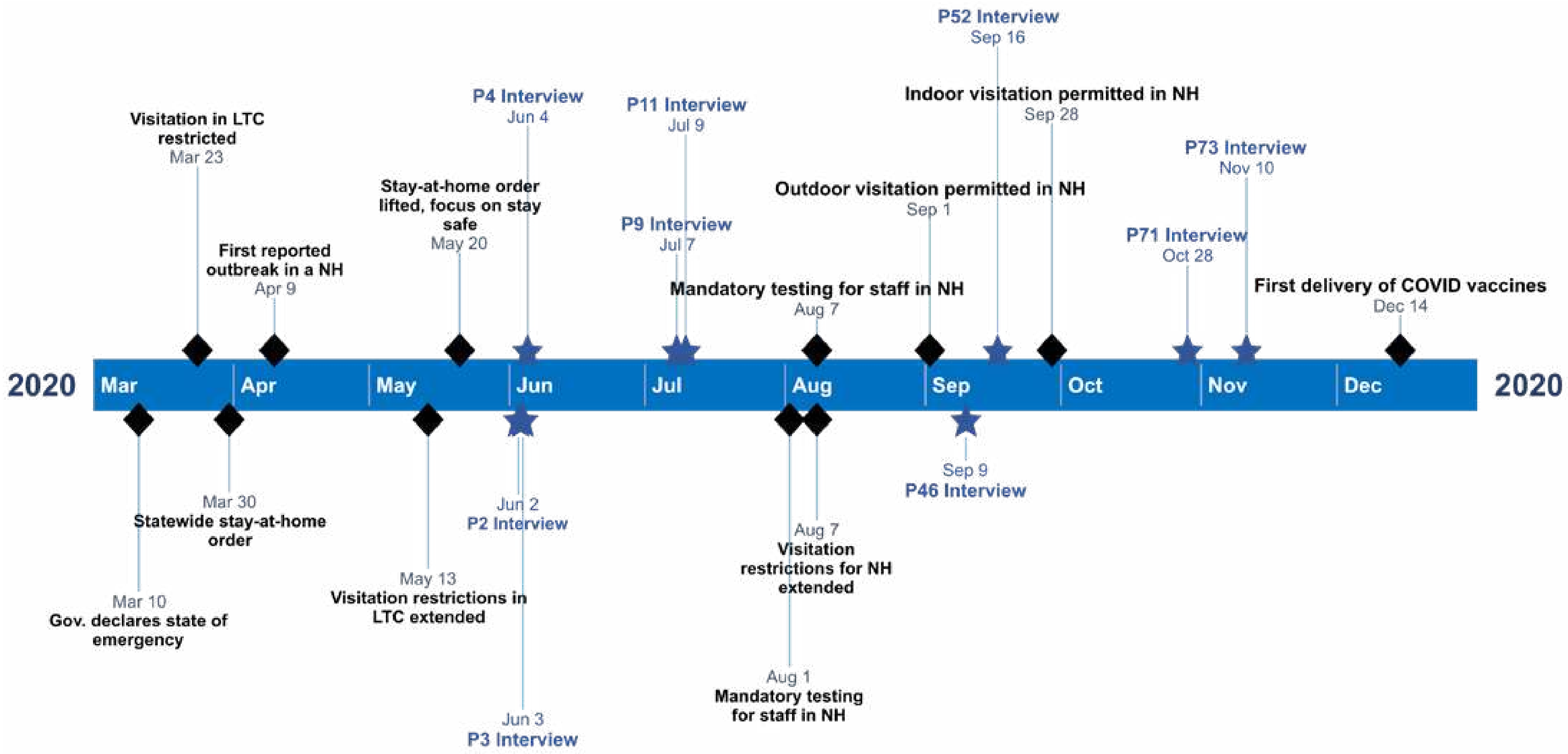

Figure 7.1. Timeline of Interviews Quoted in Chapter 7.

THIS CHAPTER IS A DEPARTURE from the others in the book as it provides a linguistic analysis by Dr. Boyd Davis with assistance from Christin Wolf. We focus on the language used in a subset of nine interviews selected by Shenk and Wolf to serve as representative of the three phases of the larger study. We used corpus-based analytic tools and techniques (*TextInspector.com* and *WMatrix.com*) to identify key discourse patterns as the interviewees talked about a situation that would not, and could not, stand still. In addition, our approach is from a sociopragmatic and interpersonal perspective to focus on language use in the discourse of the interviews themselves.

Three uses of language are of particular interest in our analysis, though these are in no order of preference. First is the use of interactive metadiscourse: words or phrases reflecting that the speaker or writer wants the hearer/reader to notice that they are using words to hedge and stall or to emphasize a particular word or phrase (we "might" . . . they "always"). Next is the use of quotative "like," often coupled with reported speech (and he's like "we should stop" . . . or they said that we should stop . . . instead of Geoff said "Stop!"). This combination is frequently used to justify or explain a choice of action or reaction (and they're like assuming that. . .). A third is the presence of multiple referents for the pronouns "we" and "they," whose range of senses helps us understand aspects of who the speakers are. We will focus most of our attention on this last usage.

As a preview of content, the subsample of participants from Phase 1 were confused and eager to understand the nature of the emerging pandemic and what its impact on their roles, rules and responsibilities might be. The residential long-term care community administrators and caregivers from Phase 2 spoke often of "knowing" in terms of what they knew they were doing for the older adults in their care while acknowledging that it wasn't enough. They were in the middle of a move from the unknown to dealing with the known as they faced the deaths of residents and personal losses associated with the ongoing nature of the pandemic. Phase 3 included caregivers working in senior centers, adult daycare programs, and home care agencies. They spoke of the little things they could do for clients and families even when they could not provide care in person because of closures and client isolation. Acknowledging the physical and mental decline—and even deaths—of the older, often cognitively impaired seniors they cared for, these caregivers continued to show up and do everything they could think of for those in their care.

Our discussion is keyed to transcripts of the selected interviews. All the interviewers and respondents in this subsample were female. Each interviewer began by asking the interviewee's role, title, and credentials, which in effect established the initial footings for the dyadic interactions: one person would ask questions focusing on the respondent's connection to older adult and dementia health care during the pandemic, and the other was, in the next turn, expected to answer. The turn of the respondent in the interaction could, and usually did, include several large chunks giving context for their response. This typically included both factual accounts or chronicles of events and some notion of perceptions and interpretation; respondents occasionally went beyond the opening and complications of their particular narrative or their chronicle to give some sort of evaluation. The respondent was positioned as an expert in their area of work and as being knowledgeable about expectations from supervisors for their particular role.

To some extent, the interaction in the interviews could easily be characterized and framed as organizational discourse: according to Fairhurst and Cooren (2018: 2), qualitative analysis of organizational discourse is frequently conducted from the perspectives of "ethnomethodology-informed conversation analysis," narratology, or critical discourse analysis. By "critical discourse analysis" we mean the combination of discourse and ideology; by "narratology" we mean the study of story; and while "conversation analysis" is what looks like a transparent term, when combined with ethnographic techniques for study, the researcher can look more closely at everyday interactional competence in the context of particular situations (Arminen 2012). Each of these allows an interpreter to isolate and discern issues of or related to power. We will focus on professional identity that presumes some aspect of organizational discourse from an allied but different stance, that of professional discourse. It is worthwhile, however, briefly discussing—and oversimplifying—some of the layers of power and positioning identifiable in narratives in these interactions. As Deppermann (2013: 67) reminds us, narratives are "particularly powerful resources for positioning." For positioning we cite the way it is explained by Bjerre, basing his discussion on Davies and Harré (1990: 46), "'the process by which people attribute to others or to themselves a set of characteristics', which 'affect future interactions' . . . and may be studied by focusing on central speech acts and the use of 'images, metaphors, storylines and concepts'" (Bjerre 2021: 250).

Although the respondents in the interviews can position themselves as having ownership over whether they will furnish information, they are nonetheless under the power of the interviewer. While the respondent has agency, the interviewer is ultimately dictating the direction of the interview because they ask the questions. These questions can threaten the persona of the respondent, which on the part of administrators early in the pandemic is actually likely. Respondents are under the authority of whoever directly supervises them on the job in the residential long-term care community, adult daycare, or other program or agency. Each of those locales are likely to be overseen by owners and/or advisory boards, monitored by local, state, and federal agencies. All, however, are currently under the power of a serious and mysterious illness about which none of the participants or their supervisors have confidence in their knowledge and all suffer some anxiety about a shared responsibility to care for others. Their individual, social, and professional identities have been shaken and their face—their standing as worthy in their own eyes, in the reflection from others, and in the eyes of the others—is threatened. If we were speaking of a master narrative that we apparently tell ourselves, it might be that staff at every level are plentiful, well trained, and take good care of older people in every kind of communities for pay or private homes; its counternarrative, which the pandemic exacerbated, revealed and extended the gaping crevasse in the system of care, in the sheltering buildings, and by extension the staff themselves (Hyvärinen, Hatavara, and Rautajoki 2021). We see both the master and the counternarrative in the answers, usually building to narratives or stories, by the respondents.

Narratives by respondents in interviews are going to be full of fits and starts, memory glitches, and fishing for words, phrases, and chunks of suddenly remembered data or cascading with a sudden spillover of information and interpretation. Narratives typically fall into five categories, and their content—or at least a typical introduction and initial complication—will frequently be probed to continue along lines chosen by the interviewer. The five typical types of narrative are as follows.

1. Stories in which the conversation partner (here the interviewer) provides minimal prompts (Mm-hmm; Ahhh; I see). These can be previously told or new but connected stories instigated by interviewer prompt.
2. Small stories that sound like everyday events and are very short stories told "in passing" (e.g., studies and examples of small stories with full examples by Georgakopoulou 2007).
3. Shadow stories that remain "hidden" behind hints (de Medeiros 2015) unless the conversation partner probes.
4. Chunks of a story, usually a high point or evaluation, but without any discernible context.
5. Chronicles or accounts that have no narrative structure (Davis and Maclagan 2021, 6).

Any of these types will often include code-switching between professional talk and conversational register to indicate that the respondent has greater or lesser familiarity with an issue or situation. As Holmes and Marra indicate: "In different workplace contexts, and even at different points within the same interaction, participants emphasize particular facets of their social identities and different dimensions of social meaning—institutional or organizational affiliation, professional status, collegial solidarity, authority responsibilities, gender category, ethnic affiliation, and so on" (2005, 197).

Social Identity, Professional Identity, and Professional Discourse

Willetts and Clarke outline current discussions of "attributes" required of a profession such as nurses, which includes "a systematic body of theory . . . a regulative code of ethics . . . [and] professional bodies/associations that control and monitor conduct and performance within their profession" (2014: 165). Sarraf-Yazdi and colleagues review professional identity in medical students as "a multifactorial phenomenon, shaped by ways that clinical and non-clinical experiences, expectations and environmental factors merge with individual values, beliefs and obligations" (2021: 3511). Day (2020: 111) reviews distinctions in the UK between "professional occupations" such as doctors, and "associate professional and technical applications" such as medical technicians. De Fina reminds us that "situational identities may be seen as roles related to the specific context of interaction. . . . Who we are is often defined in terms of who we are not or who we are similar to" (2011: 270–71). She goes on to say that "social identity categories are related to situations, roles, characteristics, and ideologies that are often stereotypical, and that these associations become part of the shared knowledge and representations of groups which in turn feed into wider ideologies and beliefs" (278).

This explanation, keyed to categories (because identity is never singular) is congruent with Schiffrin's discussion of Gumperz, Goffman, and interactional sociolinguistics. "Both authors see language as indexical to the social world: Gumperz conceives of language as an index to the cultural background knowledge which provides information as to how to make inferences and what is meant through an utterance. Goffman views language as an index to the social identities and relationships which are constructed during interaction" (Schiffrin 2009, 87).

The work of each scholar helps disentangle the components of social identity that feed staff and caregiver affiliation with the rules, regulations, and responsibilities of the source of their original training for work in the governmental agency, community agency, care community, or homecare business to which they belong. Their original training, be it experience alone to advanced degrees or institutes, is designed to instill aspirations, expectations, and eventual affiliation. That affiliation in turn is consistently incorporated into each of the selected interviews that are professionally distinguished in table 7.1. We also include a summary of the focus for the participants in each of the three phases.

Table 7.1. Selected Interviews Analyzed in Chapter 7.

Phase 1: Regional agency staff or advocate	*Phase 2: Residential long-term care*	*Phase 3: Home and community-based services*
Bureaucratic repetitions from job-related materials	**Running a place and setting social distances**	**Hands-on with staff when the clients can't really be social**
#2 Nursing Home Ombudsman	#9 Nursing Home Administrator	#52 Senior Center Director
#3 Aging Program Coordinator (community-based programs)	#11 Memory Care Activities Director	# 71 RN working as CNA at Adult Day Healthcare
#4 Assisted Living Ombudsman	#46 Lead Housekeeper	#73 Home Care Agency Director

Focusing on #3, #9, and #73, all of whom held administrative positions, responsibilities are always on their minds. In the interview with the regional Aging Program Coordinator, "so" is typically used to explain a result and to hold the speaker's turn at the same time. Throughout the interaction, she continually quoted her agency or shared something from one of its reports:

> I could tell you, give me one second and I'll pull up last week's weekly report. So, we serve nine counties. . . Um, so, that's (name of county) is our biggest one and the surrounding eight counties, and I'll pull it up. Let's see here, and I can tell you too, it should have like how many, how many meals they've provided and then also how many people. . . . So, they're all set up a little differently. So, (name of) county, because they have such a large population, they always do frozen meals anyway. (P3)

On the other hand, the nursing home administrator focused on morale shifting when the residents could once again order food for themselves and their families could return to doing their laundry, presumably in accord with their personal preferences.

> Yeah, there was no delivery of any food for them. We got our food trucks delivered, like Cisco and US Foods and supplies, but they [administration] were not letting food come in from the community. So, when that was lifted, I noticed a huge uptick in the morale because the residents could order pizza if they're feeling bad. They could order Chinese, DoorDash, but we had to wait for CDC guidance and the state to tell us that was okay 'cause everything got shut down. And a lot of families do their own laundry. We had to start doing their laundry. . . . I mean, it was bad. So slowly but surely, we're getting

> back there. They can do laundry now, they can get deliveries, everything but homemade food, 'cause we can't control homemade sanitation. (P9)

Even when some residential long-term care communities and home and community-based programs could reopen, residents and clients were still confused about what to do. The home care agency director described:

> Again, specifically with the facility or a community, they shut down. So we couldn't go in. And we had a number. . . we had a couple of client families where they were trying to get us in as essential workers to try to come in and help, but again, not knowing what they knew, I do think they did the right thing, but that doesn't help. . . . An overworked staff at a community or a facility is not going to have. . . They're gonna have even less time for a client. . . . We had clients that didn't understand that they couldn't go out. (P73)

It was difficult for residents and day-services clients as well as caregivers to adjust to lockdowns and their relevance to the rising death toll for older and vulnerable people, especially those with dementia and other cognitive impairments. A glimpse can be seen in the small story remark by #73 in October 2020: "Initially, none of us could've thought (chuckle) that we'd be here, at, what? Eight months now. And I would say from, in those four weeks, in the first two weeks of March, in the last two weeks of March, really, I lost half my business. It wasn't so much clients, but it was also caregivers." This finding is echoed by #46, who is a housekeeper in a well-supported residential care community and is discussing losses of staff as well as the deaths of residents: "Oh, man. Ooh. I'm gonna say. . . Oh, gosh. Off the top of my head, I'm gonna say maybe fifty, maybe fifty. It may have been more than that, but we lost I think it was twenty-one to twenty-four residents."

Us vs. Them or We vs. They or Everyone vs. COVID

Kenneth Kong draws on a number of definitions to pin down professional discourse, which is, by and large, the discourse used in the interviews. He explains that "any profession or company represents a 'discourse system' (Scollon and Scollon 2001), which links members through a shared ideology, socialization, face systems and discourse forms" (2014: 2). Prominent in all nine of the interviews are the frequent uses of "we" and "they" which on the surface might appear to be a variation of the "Us/Them" distinction familiar in political discussions and rhetorical arguments of any kind.

In her dissertation about media interviews with Australian politicians, Bramley claims that "pronouns are used to construct politicians' multiple ‘selves’ and ‘others’ and . . . as they occur in sequence, the changing ‘selves’ of politicians and different ‘others’ are created” (2001: v). For example, Bramley’s “we” [us, our] is discussed as representing “‘institutional identity’ (Sacks 1992), ‘us and them’ dichotomy; ‘we’ as a means of co-implicating people; ‘we’ to indicate that it is not just the IE [interviewee] who is involved in the issue; and ‘we’ to invoke a general collective response” (2001: 86). Bramley adds that “they” can represent that which is oppositional, affiliative, neutral, or generic.

It is not just Australian politicians on social media who shift identities. Respondents in the North Carolina COVID-19 interviews do so as well, although they are not focused on the same identities as politicians and are seldom combative or oppositional. For a more detailed analysis, we focus on four women in a variety of positions. Table 7.2 displays the uses of “we” and “they” in the interviews with #3, #9, #73, and #46. There were a total of 251 “we” tokens and 181 “they” tokens, for a total of 432 tokens analyzed.

First, the “we” tokens. Only the nursing home administrator (P9) discusses a doctor’s visits to their residential long-term care community, and only two identify themselves as dealing with licensed and/or elected officials. In terms of self-identification as representing or belonging to a company, organization, or agency, the home care agency director (P73) mentions only her own. The aging program coordinator (P3) offers statements to quote and discuss from her supervisor and agency team of co-workers: her work links her with places where programs are offered, but there are many regulations to follow, particularly when she cannot actually see people receiving those services due to the lockdown. She punctuates a series of phrases with “so” to hold her turn while she thinks of the next part; after she has outlined what she was supposed to do, which is quite a lot, her answers smooth themselves and the “so” edges away:

> *So*, for example a program that we actually offer in house and deliver would be our evidence-based health programs. *So*, these are programs that we offer the community at no cost to older adults to help them manage chronic conditions, to help them prevent falls, to help them [take] care of themselves if they’re caregivers, all kinds of programs like that. *So*, that would be an example of a direct service. Um, some of the programs that I work with indirectly would be some of the in-home and community-based services like the senior nutrition program. *So*, that includes the congregate nutrition program. *So*, where people come together at one site to have meals and socialize. Also, the home delivered meal program, transportation programs, as well as senior centers. *So*, those would be the ones I work with most commonly. (P3)

The housekeeper, on the other hand, is eager to explain not only the inventive ways her well-endowed residential community has created to stem

Table 7.2. We/They Senses from Selected Interviewees.

	P3	**P9**	**P73**	**P46**
	Aging Program Coordinator (Administrator)	**Nursing Home Administrator**	**Home Care Agency Director (Administrator)**	**Lead Housekeeper (Direct Care)**
We-doctors	0	2	0	0
We-officials	1	1	0	0
We-my organization/ agency/ies	30	20	1	30
We-our staff	35	16	18	13
We-me and my close peer staff at work	12	7	29	24
We-generic all healthcare	2	7	2	0
We-my family	0	0	0	1
Totals	**80**	**53**	**50**	**68**
They-residents	0	14	12	6
They-staff	5	5	16	20
They-official	8	11	1	0
They-peer staff with me	5	0	16	0
They-outside clients	15	5	4	0
They-other staff (outside agency)	5	4	2	0
They-outside community	7	7	2	0
They-all people	1	2	2	0
They-family members	1	1	4	0
Totals	**47**	**49**	**59**	**26**
Grand totals	**127**	**102**	**109**	**94**

the tide of infection, including moving rooms and even floors of people, but also its generosity to its hands-on and frontline care staff during lockdowns, giving them extra money and frozen and canned food to take home on a weekly basis:

> And since the pandemic started, I don't know about other companies out there, but they have helped us so much, so much, in any way that they can.

> Far as. . . When we was having problem with the tissue, they gave us. . . Man, they ordered so many cases of tissue. Thirty cases of tissue with ninety-six rolls in each box, to make sure that the residents and their staff will have tissue. They gave us food. They gave us food, they gave us chickens, they gave us pies, they gave us hamburgers, they gave us a lot of stuff, wipes, everything. (P46)

Throughout the interviews, staff as a topic falls into two categories. "Staff" can mean "other staff at our site" with whom I work closely, or else "staff" can be cited as a generic group in a residential long-term care community or program who perform care ("Oh, our staff will take care of that"). The way either category is discussed is keyed to the speaker's professional rank and job description that determines whether staff work under her or beside her.

The aging program coordinator (P3) most frequently mentions duties or responsibilities of "we staff-in-general," as there are a number of community-based programs (such as those mentioned in this chapter) that staff from her areawide agency must oversee in addition to nursing homes and assisted living communities, across nine counties. She works most closely with a set of peers who are staff as well; they each focus on one county. The administrator (P9) runs a nursing home: she mentions "we staff-in-general" in terms of the duties that change from day to day, although she has several peers and managers at her site with whom she shares ideas and comes up with solutions to the day's particular crises. The home care agency director (P73) works frequently with her closest staff; for her, "we staff-in-general" does not carry the load as much as the staff connected with caring for various clients in their own homes and residential long-term care communities. The housekeeper's (P46) emphasis is on expectations for general hands-on staff, and the daily shifting of duties for those peers who, like her, are working all over the building as COVID patients change rooms, wings, and floors. Everything changes all the time for a frontline worker during a pandemic. In general, people talk about what they would like to do, what makes them most afraid, and how essential their colleagues and peer workers are when they are on the job together. This is no doubt why health care as a topic for discussion has but a few mentions, primarily from the nursing home administrator who is quite naturally concerned with government pronouncements as she tries to keep the staff and residents safe. Personal family relationships are mentioned only by the housekeeper, who fears bringing disease home to the other five people (including a new baby) who live with her in her apartment.

"We" are much more important than "they," with only a few exceptions. Residents of residential long-term care communities are discussed by the nursing home administrator (P9) because she is concerned about keeping them COVID free; the home care agency director (P73) is worried about who in which agencies can handle "them," and the housekeeper (P46), who is the voice for the hands-on care, finds "them" to be problems to be solved as well as people to be helped, which is probably why she talks about staff in general and how they are being shifted around the building, just like her. The home care agency director (P73) is concerned for staff welfare as well as how her staff—individually and as a whole—can move to handle different assignments with clients here, there, and elsewhere. Visits from officials to monitor or investigate or chastise administrators are a concern, particularly to those who coordinate community programs or run a nursing home, but peer staff are especially helpful to the home care agency director as they move through programs, changing how they might be delivered. Clients at various programs are crucial to program coordinators, and staff and residential long-term care communities not normally supervised can have activities or actions that could be useful. Of interest, though it should not be surprising, is the lack of discussion of anybody or anywhere outside her current worksite for the housekeeper: while other staff at her site are an important "they" working with her, particularly as residents, rooms, and units are shuffled, nobody else is.

Discussion

The people whose discourse is the focus of this chapter were charged with reaching out and overseeing or providing services to older persons and educating their family members, or providing activities for them, or housing and feeding them and keeping them from harm. All but the direct care workers, the frontline, hands-on staff, had received advanced academic degrees as well as extensive training in the professions to which they now belonged. And they were afraid during 2020 and the first major surges of COVID-19—all the time. They even said it. Early in the pandemic, P9 commented:

> Nurses are very afraid to give morphine and they're just afraid, because the end goal is comfort, but sometimes it reduces your respiratory response so much that you just pass and they feel guilty. And so hospice nurses are over there pushing it, putting them on a drip. If they go, they go. (P9)

P2 remarked on why residential long-term care communities are afraid of baseline testing, although it could be useful if it were truly available: "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." Halfway through the data collection, the housekeeper, reported:

> My patients, they were afraid, and I was afraid for them, but for some reason, I would go in their rooms and stuff. . . . I cleaned, I kept things purified, I went over and beyond. I made their beds clean. I went in there and I was like, "No. This could be my mother, my sister, my. . ." I forgot about myself, and I lost myself in those people, and it meant everything to me because now that we have come out and we are looking on the other side, some of those people came out with me. (P46)

Toward the end of the data collection, once the initial surge had eased, P71 said about the adult day healthcare clients: "They're afraid to come back, their families are afraid for them to come back."

The interviewees were each afraid their roles were going to change even further and that they could not meet expectations or even regulations. They were afraid that they themselves would catch COVID-19 and that programs and residential long-term care communities would lose so many clients or residents that they would have to close, taking their jobs with them. Small wonder they took refuge in organizational discourse and their own professional ways of talking about their profession. And they were still nervous, even though they had developed ways to begin to handle and readjust and reframe every aspect of their work.

They were right to be afraid. On 5 July 2022, the National Institutes of Health reported that for people eighty-five and above, COVID-19 "was the second leading cause of death in 2020, but dropped to third in 2021, likely because of targeted vaccination efforts in this age group" (www.nih.gov/news-events/). In the United States, we have not yet, as in Singapore, resorted to commodification of potentially related products such as this thinly disguised advertisement, "Keep calm, stay safe, and drink bubble tea" (Starr, Go, and Pak 2022). In times of pandemic when we are all afraid, "we" has become more important than ever.

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8 CARING FOR OLDER ADULTS IN RESIDENTIAL LONG-TERM CARE DURING COVID-19 IN THE UNITED STATES AND SWITZERLAND

Balancing Protection and Social Isolation

Andrea Freidus, Dena Shenk, Megan Davies,
Christin Wolf, and Sandra Staudacher

Reflections on a Cross-Cultural Experience during the Pandemic, by Megan Davies

I had been living in Switzerland for just over a year when COVID-19 lockdown procedures were introduced. On 16 March 2020, I began a journal to try to make sense of what was happening. Reading my early entries brings it all back: "Day 1: . . . Just heard Switzerland is going into a partial lockdown—everything but supermarkets and pharmacies closed. I don't know what this all means. . . No lockdown in the UK yet. They don't seem to know what's going on."

Before moving to Switzerland, I worked as a nursing assistant on an older person's medical ward in the UK, so watching the UK from afar was really hard, particularly as things were getting stricter and feeling much more serious here in Switzerland. I became obsessed with reading global news while trying to focus on work, wondering why the UK wasn't reacting in the same way as some other countries. "Day 3: The UK still doesn't seem to be getting this. They are not in any sort of lockdown yet. I wish they would take this more seriously." The UK did not impose the same level of lockdown as other countries in Europe until almost a week after Switzerland on 23 March 2020. I was already being updated by a close friend who is also a registered GP in my hometown to try to understand the situation beyond news reports. On 15 March 2020, she contacted me about the hospital I had worked at: "one person is now confirmed . . . sorry to let you know." It became harder to be away, knowing that if I was in the UK I could help. On Day 9, I wrote: "I'm starting to feel guilty for being here and not in the UK where I could be working at the hospital." On 29 March 2020 (Day 14), an update from my friend included: "got a letter from the government asking to do more," which was sent to all NHS staff at this time. People were even being asked to come back early from maternity leave to boost staff numbers. The guilt of not being there to help was really hard to deal with.

In Switzerland, as the first wave ended, I began data collection in a care home. A week later, that care home had its first COVID-19 case among its residents. This rapidly went from bad to worse, but fortunately we were able to continue visiting the care home to observe and interview residents and staff. Different areas of the care home were sectioned off for isolation as cases spread. I began simultaneously researching global incidents of COVID-19 in care homes within my PhD work. I read about residents being abandoned, staff and residents catching COVID-19 one by one, and in the UK, care homes and the NHS functioning with skeleton staff who were working around the clock risking their health and sacrificing time with families to provide care. I could see firsthand in Switzerland how COVID-19 could rip through a care home and the impact it had on staff and residents. This care home had more staff than I was used to seeing in the UK and better resources, including PPE, which they had access to earlier in the pandemic. There were procedures in place to ensure staff would not take potentially contaminated items such as uniforms home with them. It was hard not to feel angry and upset about the situation in the UK. I felt like staff and residents were being let down. I felt like I was letting them down. While I spent my days in this care home observing residents and staff and interviewing with a research team to support me, the ward I used to work on was turned into a designated COVID ward, and my old colleagues were working tirelessly to provide care with little support.

As part of my PhD, I was originally due to begin comparative research in the UK in Autumn 2020, but this eventually began in August 2021, just after care homes in the UK had started allowing in-person visits again after more than a year of lockdown. The general population in the UK went in and out of lockdown throughout this time, but care homes were instructed to remain isolated for the duration. I didn't know what to expect going in. Part of me felt it couldn't be as bad as watching the devastation in a care home firsthand, but mostly I knew that it could be worse.

The UK care home itself had managed the last year amazingly with very little support. Unlike in Switzerland, staff in this care home had little PPE early on. Management had to source and buy what they could along with the rest of the general public. Where in Switzerland PPE while dealing with COVID cases consisted of goggles, FFP2[1] masks, shoe covers, gloves, and aprons covering the full uniform, in the UK they had small polyethylene aprons, gloves, and surgical masks, some needing to be reused. In Switzerland, staff could change out of their uniform before leaving the building, which was industrially cleaned for them. In the UK, staff took their uniforms home with them to wash themselves. I was provided more protection as an observer in the care home in Switzerland than staff had been provided while caring for residents with COVID-19 in the UK. Staff here were angry, and I was angry for them.

Observing this situation from a distance has been devastating, but comparatively easy. Knowing you can help but not being able to while others suffer is awful, but is nothing compared to what UK care staff went through. I am angry about the way things have been handled, but I'm in awe of the way care providers kept going. They deserve more, and this should not be forgotten.

Introduction

Across the globe, COVID-19 has disproportionately impacted the older population in terms of morbidity and mortality, particularly those living in residential long-term care.[2] Over 40 percent of COVID-19 related deaths globally have occurred in residential long-term care, with figures as high as 80 percent in some higher-income countries according to the World Health Organization (2020). In the United States, residential long-term care residents account for 41 percent of overall mortality. In Switzerland, over 50 percent of COVID-19-related deaths have been linked to residential long-term care residents since the start of the pandemic, with actual figures varying from canton to canton (equivalent of state to state). To date, the Swiss population aged over eighty years has been most vulnerable, accounting for the highest number of deaths countrywide. As a result, concerns for resident safety led to extensive isolation of people living in residential long-term care since the beginning of the COVID-19 pandemic (Chu et al. 2021). In the United States, residential long-term care communities were locked down in the early days of the pandemic and reopened slowly to families, friends, and other caregivers. Switzerland took a more liberal approach and, except for an initial six-week visitation ban, have allowed family and friends to visit, reinforcing stricter rules only during an outbreak. Both approaches have costs and benefits. In this chapter, we present perspectives of residential long-term care staff in the US and Switzerland in addressing the overwhelming challenges faced during the pandemic. A primary focus is staff perception of social isolation and the tension between physical protec-

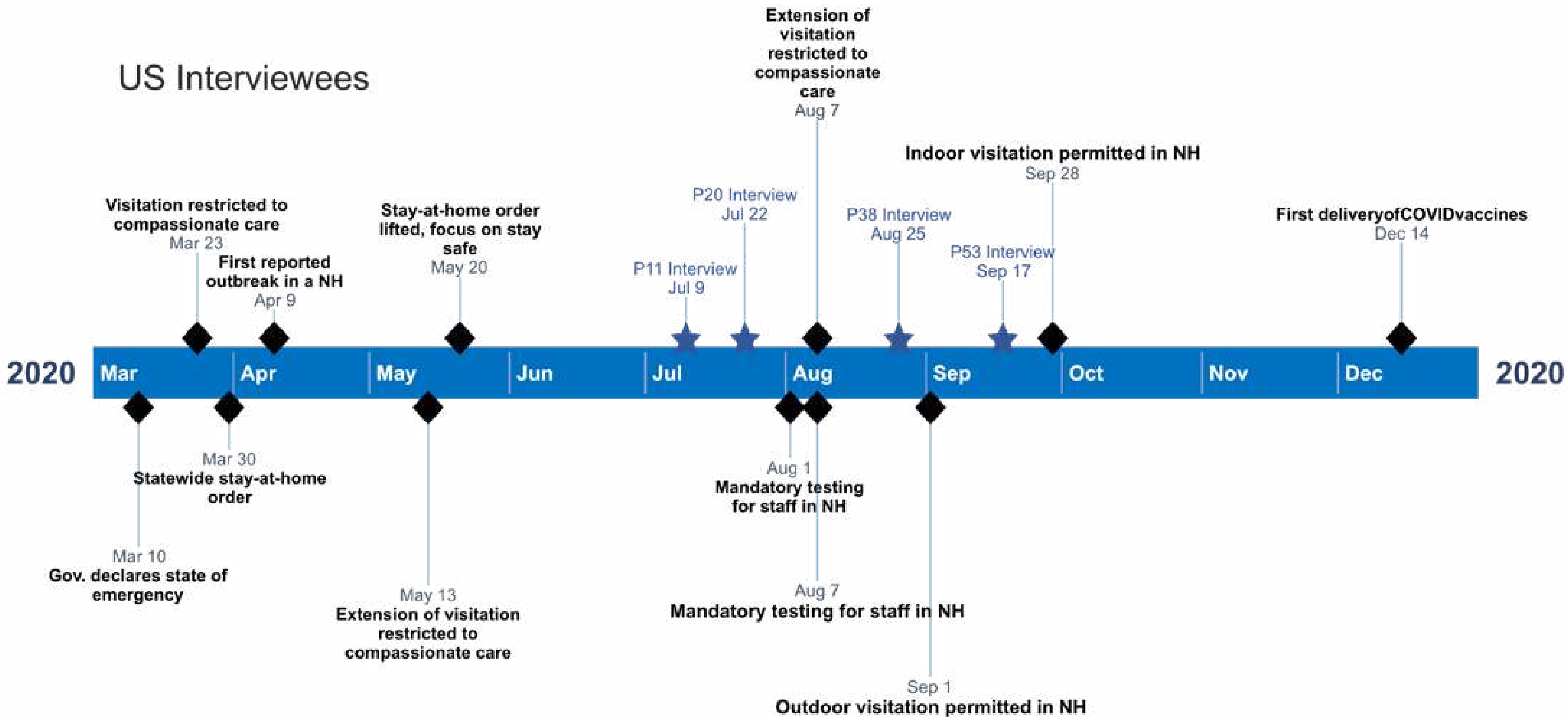

Figure 8.1. Timeline of US Interviews Quoted in Chapter 8.

tion and quality of life of residential long-term care residents. In their daily care of residents, staff had to balance safety measures and infection control with preserving the quality of life of a social group considered high risk.

A Swiss team and our team working in the US conducted independent qualitative appraisals of frontline workers in residential long-term care during COVID-19. In the following section, we focus on the perceptions of residential long-term care staff who navigated caring for residents in these different settings. We report on our findings, drawing on interviews with frontline residential long-term care workers, which illuminate the ongoing tensions between the need to physically protect residents while also providing adequate quality of life, which is defined as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (Peel, Bartlett, and Marshall 2007). We examine staff perceptions and experiences including 1) their fear and anxiety in relation to the risk of COVID-19 infection; 2) navigating provision of care during the pandemic; 3) implementing limited and evolving policies and guidelines; and 4) supporting engagement and quality of life for residents amid ongoing isolation.

Models of Residential Long-Term Care: Between Medicalization and Person-Centered Care

Due to the nature of the medical emergency and the differential mortality of older adults, in the US the focus has been predominantly on protection rather than quality of life. In Switzerland there has been a similar culture change in residential long-term care, with a shift in focus from a medical to a social model, which intends to provide a home environment rather than focusing solely on physical care. This updated concept of care focuses more on a person-centered approach, emphasizing overall well-being and quality of life for residents (Nolan 2001). Person-centered care has led to a change in care planning and decision-making in residential long-term care in Switzerland, with more involvement from relatives and residential long-term care residents themselves in the decision-making process. It is difficult to say whether all residential long-term care in Switzerland has succeeded in implementing full person-centered care, but it is clear that the aim is to provide a home with accessible care, taking into account the individual preferences of the resident moving in, rather than a place of care with a bed (McCance, McCormack, and Dewing 2011).

During the COVID-19 pandemic, even in Switzerland, the level of person-centered care provided was restricted by protection guidelines and difficult decisions made by management teams. The need to protect residents, particularly during an outbreak, caused residential long-term care staff to move further and further from their usual person-centered care approach. The increased need for care and infection control procedures led to a shift back toward a medical model of care to accommodate higher care demands and lower resources.

Impact of Social Isolation and Increasing Loneliness

It is already known that well-meaning policies and decisions intending to protect residential long-term care residents from COVID-19 have inadvertently caused social isolation (Chu et al. 2021). As discussed in chapter 4, social isolation is a significant risk factor for loneliness, which is a subjective feeling or desire for greater contact with social partners (Xie et al. 2020). Although social isolation and loneliness do not always co-occur (e.g., one can feel "alone in a crowd"), both are significant risk factors for negative health outcomes (Cacioppo and Cacioppo 2014; Courtin and Knapp 2017; Hayashi et al. 2020; National Academies of Sciences, Engineering, and Medicine 2020). Care staff were faced with taking on extra responsibilities and trying to respond to the social isolation of residents while dealing with an already heavy workload increased further by COVID.

In the US, loneliness and social isolation became volatile topics in terms of the ways in which federal, state, and local policies, as well as individual residential long-term care communities, restricted visitation to prevent exposure to the virus (Freidus and Shenk 2021). The primary focus was on the physical health of older Americans, which illuminates the failures of a medical model to address the social needs of residential long-term care residents. The medical model focuses on physical care and safety in the context of a complex health emergency and does not recognize residents as having agency to determine particular levels of risk in an effort to maintain their quality of life.

In Switzerland, contact with relatives and friends is encouraged following a move to residential long-term care. For example, some homes encourage relatives to stay for the first meal following a move to make the transition smoother for the resident. In addition, activity coordinators and frontline staff facilitate interactions between residents with similar interests. This is a key element in providing a person-centered approach and contributes to resident quality of life. This continuity is particularly important for people living with dementia. Restrictions imposed during the COVID-19 pandemic caused group activities to be halted and at times full social isolation to be implemented, due either to local lockdowns or residents exhibiting symptoms or testing positively for the virus. The lack of contact with specific people and a reduced wider network caused by this can create "emotional loneliness," which increases risk of morbidity and "all-cause mortality" in older adults (Gordon et al. 2020). Residential long-term care staff were forced to provide care in an environment described in the media as "prisonlike," while disputing decisions and practices that could increase social isolation (Peduzzi and Staudacher 2020).

Implementing Protection Measures

In order to slow the spread of COVID-19 to vulnerable older adults in the US, the federal Centers for Medicare & Medicaid Services (CMS), which sets the standards for nursing homes, issued strict guidelines shuttering the homes to everyone besides essential staff and residents on 13 March 2020 (Centers for Medicare & Medicaid Services 2020). CMS standards followed Centers for Disease Control and Prevention (CDC) guidelines and were then implemented at the state and local levels and followed for assisted living communities as well. The North Carolina governor restricted visitation of all visitors and nonessential healthcare personnel in residential long-term care communities (see Figure 0.3 in Introduction). An exception was made for specific compassionate care situations—for example, those involving end-of-life care (Executive Order 120 2020) (see chapter 2 for discussion of compassionate care guidelines). The state Department of Health and Human Services (NCDHHS) promptly canceled all communal activities in residential long-term care, including group meals, with any infractions subjected to state and federal regulatory processes. (NCDHHS 2020).

Many residential long-term care residents rely on family care for social support and to maintain health, well-being, and safety, and therefore need to stay connected to their families (Hado and Feinberg 2020). As the toll on residents increased due to lack of visits and communal activities, staff implemented creative visitation solutions, including the use of window visits and outdoor visits utilizing plexiglass dividers. The task of deciphering and implementing guidelines from federal, state, and county agencies was left to individual residential long-term care corporations and communities. With the pandemic ongoing after a year, compassionate care situations were expanded to include residents who were grieving after a friend or family member recently passed away, those experiencing weight loss or dehydration, or those experiencing emotional distress, seldom speaking, or crying more frequently. Overworked staff were directed to use a person-centered approach to identify the need for compassionate care visits.

In Switzerland, the Federal Office of Public Health recommended restricting residential long-term care visits from 16 March 2020 and introduced social distancing of two meters within residential long-term care. At the beginning of April, a full visitation ban was imposed; however, these were guidelines rather than law (Federal Office of Public Health 2020). Legally, each Swiss canton was responsible for deciding how residential long-term care visits should be regulated, although in practice, responsibility of how to handle visits was mostly delegated to individual residential long-term care homes. During this time, all external activity groups were prohibited, and internal activity groups were restricted by individual residential long-term care homes. Additional care, such as physiotherapy (physical therapy), was stopped in line with federal guidance on 16 March. The strict lockdown protocol early in the pandemic created a period of isolation for residential long-term care residents (Gordon et al. 2020). By the end of April, many residential long-term care homes in Switzerland installed plexiglass panels to enable safe visits in accordance with national rules; however, in-person visits and contact remained prohibited. On 6 June 2020, the Swiss visitation ban was lifted across many cantons, including Basel-Landschaft, where this research was conducted. Individual residential long-term care homes were left to decide how to proceed with minimal guidance, yet had to submit a protection concept and have it approved by the cantonal health authorities.

Methods

The US case study was conducted by our three-member research team. We interviewed a purposive sample of thirty-one staff caring for residents in fifteen congregate care sites in central North Carolina between June and October 2020 (female: n=25, male: n=6) as discussed in chapter 2. They included workers in continuing care retirement communities (CCRC), nursing homes, assisted living communities, adult care homes, and memory care for people living with dementia. Participants included dining staff, housekeepers, chaplains, marketing staff, certified nursing assistants (CNAs), medical technicians (med techs), activities staff, nurses, nurse practitioners, and administrators. In addition, follow-up focus groups were held in February and March 2021, along with media and policy analysis.

Interviews were video recorded using a web-based platform and were transcribed verbatim. Semi-structured interviews ranged from twenty-three minutes to two and a half hours, for a total of twenty-seven hours. We asked these workers about the overall impact of the pandemic on their daily provision of care as well as their key concerns and experiences. The team implemented a grounded approach that avoided the use of preexisting codes (Freidus, Shenk, and Wolf 2020a, 2020b).

The Swiss case study "Tri-National Ethnographic Multi-Case Study on Quality of Life in Long-Term Residential Care," which aims to look at the concept of person-centered care and resident quality of life in long-term care took place in a purposefully selected long-term care home that purports to use person-centered care, in Basel-Landschaft, Switzerland. The site was selected in conjunction with CURAVIVA Schweiz, a care association working with long-term care communities to provide innovative care in Switzerland.

Ethnographic interviews, observations, and informal conversations were conducted by a four-member research team. Twenty-one healthcare staff (female: n=18, male: n=3)—including nursing staff, activity coordinators, physiotherapists, physicians, cleaning staff, catering staff, administrative and management team members, and hairdressers—were included in the study. Data collection took place from October 2020 to March 2021, during the peak of the second wave of COVID-19 as it affected this long-term care community. Data collection took place while the long-term care home coped with risk and uncertainties during the COVID-19 pandemic, allowing us to observe the situation firsthand and interview staff during and after the most challenging times of the second wave. Interviews were audio recorded and transcribed verbatim, and fieldnotes were made throughout. During the data collection period, we also shadowed staff members during daily tasks and while they coped with and recovered from outbreaks of COVID-19 in the residential long-term care home.

Collectively, both the US and Swiss teams generated a master list of themes. This allowed for an inductive process driven by the narratives of the participants to capture their unique perspectives. Both studies received individual Institutional Review Board (IRB) approval.

Findings

Fear and Anxiety While Navigating Risk of COVID-19 Infection

Residential long-term care staff in both the US and Switzerland recounted extensive fear and anxiety in their efforts to care for residents and keep them safe. This fear took on many forms, especially during the early days of the pandemic, when little was known about the virus, transmission, and how to prevent its spread. Staff expressed concerns about becoming infected themselves, infecting residents, as well as potentially infecting their own families. This was especially true for staff also caring for older relatives in their home or with small children. For example, Grace, the US participant that we met in the introductory chapter, who works at a CCRC that suffered a major outbreak leading to the deaths of several residents explained: "I didn't sleep well that first month, maybe six weeks . . . , because every night I would lay in bed and think, 'Oh my gosh, have I brought this virus home to my mom?' 'Cause my husband's working from home, and my mom was at home and we did have some caregivers coming into the house, but it was me that was out among the people." (P38)

Similarly, in Switzerland, care staff were scared of becoming infected while working in residential long-term care, or that they would unknowingly bring the virus into residential long-term care from outside. Some used strategies to deal with this fear, including isolating themselves from others in their household, sleeping in separate rooms from their family, and making use of regular free testing provided by the residential long-term care home. Many staff members spoke of their ambivalent feelings toward WhatsApp and social media groups established within the facility; on one hand, they were glad to be informed about what was going on, but they also found it challenging to be constantly confronted with new positive cases, uncertainty, and their colleagues' fears.

News media in the US, as well as in Switzerland, often placed blame for residential long-term care outbreaks on care staff. Residential long-term care staff carried this additional burden of anxiety about being "vectors" introducing the virus into residential long-term care, which threatened the lives of residents. This fear and anxiety created more stress and pressure on already overwhelmed staff, who were being asked to provide additional services while also putting their own lives and the lives of their loved ones at risk. In an effort to cope in this environment, one participant explained: "How I actually made it through is I just shut down. . . . I disconnected. I was like, 'This is what doctors have to do, this is what people have to do.' To do your job every day, you have to just. . . You can't feel anymore" (P23).

This situation became increasingly difficult with "chronic" overburden, as highlighted by a senior team member in the Swiss case study, who explained: "They are minimally staffed at the moment, . . . Then there are also employees, who have now been burdened for a very long time, who want to go on holiday, or want some time off, . . . everyone is prepared to work for a certain time above average . . . but then when it becomes chronic, it becomes difficult. . . . There has to be a change, a relief." A Swiss care team member echoed this sentiment during an informal conversation, explaining that staff felt contracting COVID-19 would "at least mean they get to rest."

Findings from both the US and Switzerland suggest that residential long-term care staff struggled to maintain their own physical, mental, and emotional well-being during the COVID-19 pandemic, while also being responsible for maintaining the physical, mental, and emotional well-being of their residents. This pressure was exacerbated by older adults being identified as a group with the highest risk of both morbidity and mortality, as well as knowing the rapid physical and mental deterioration that can impact older adults in isolation.

Providing Care during Isolation

Residential long-term care staff in both countries reported facing many challenges in ensuring all resident needs were being met during the COVID-19 pandemic. Staff had to take on additional tasks that family and friends visiting their loved ones had previously assisted with. This included helping with feeding, laundry, and socializing with residents. Respondents discussed the challenges of increased labor on an already stretched and stressed team. A nurse in the Swiss case study explained how she became an intermediary between residents and relatives, also reassuring some anxious relatives during the isolation phase: "I experience telephone calls from outside, from relatives. . . . Question time has increased in the morning, e.g.: 'Have the biscuits/chocolates/photos arrived?'; 'My mother became a great-grandmother, for the ninth time'; '—and then you start looking and at the end of the service [shift] you try to call everybody to say 'I found it/ It's there/She was happy.'"

Staff in both the US and Switzerland also explained the need to constantly adjust their planning, which not only caused additional work but also required them to be prepared for anything that could occur. For example, a Swiss nursing team member described: "Sometimes I come to work in the morning and I already have to reschedule because someone is not here, or I have to send someone home if they have a sore throat, fever. Just these symptoms—that's quite new. . . yes. I have to go and measure temperature for all the residents. I have to notice and feel everything."

In some residential long-term care homes in the US, meals were still being served individually to the residents' rooms eleven months into the pandemic. Some communities were able to establish split meal schedules or otherwise serve residents sitting at physically distanced individual tables. This depended on the size and layout of the specific residential long-term care community, but arrangements had been made particularly for those who require assistance with eating. These arrangements all required adaptation and increased the workload of the staff, as summarized by a CCRC Campus Director of Culinary and Nutrition Services: "Once we made the call [in March] that we were shutting down dining services, we opened the next day with a full delivery program [to residents' rooms]. And that delivery program was for every single resident on campus twice a day. And we're putting everything into this styrofoam takeout container" (P53).

Similarly, in Switzerland, no overall rules regarding mealtimes were enforced. During the time of the study, residents were mostly permitted to dine together in a communal restaurant designed for residents from all floors to meet, while maintaining physical distance. However, when residents tested positively for COVID-19, specific floors had to be isolated. During this time, isolated floors were restricted to dining either in the "café" area on the floor (only residents who tested negatively) or in their room (residents testing positively). Residents required to quarantine due to direct contact with a confirmed COVID-19 case or testing positively were isolated in their room for a minimum of ten days, and the remainder of that floor became isolated. For care staff on isolated floors, this meant mealtimes became an additional daily task when ordinarily catering staff would serve and clear resident meals. In addition, to enter an isolated room, full PPE was required and all PPE had to be disinfected or discarded afterward. The additional protective measures added a minimum of fifteen minutes per room on each entry. Staff had additional concerns because during non-pandemic times, many residents dined with relatives and would therefore desire more staff interaction than usual.

In the US, care staff pivoted to scheduling and facilitating family "visits" through phone calls, FaceTime and Zoom, window visits, and porch visits. These visits had to be monitored to ensure proper infection control protocols were being followed because many family, friends, and residents were tempted to touch, hug, and physically console each other. One staff member explained that these visits were emotionally difficult to witness:

> We have set up a window visit area and made it really special for them to be able to come through one of our gates into the playground courtyard, and then we have the residents come to the window for them to be able to visit with them. We have our cellphone in place, we have headsets in place for them to use. . . . And we, of course, we monitor, we stay there with them. . . . It has been a challenge, and when we first started that, yeah, it was really hard, really hard." (P11)

In the Swiss case, having to monitor visits was equally challenging while visitation was restricted.

In the US, end-of-life care proved particularly difficult. There were times when care staff were the only available physical and emotional support for residents because family and friends were too fearful to visit or were not able to get to their loved ones in time. One CNA explained how difficult this was as they sat with a resident dying of COVID-19: "Like I said, it was just a very hard thing to be with people that didn't have their loved ones there holding their hand or putting the washcloth on their forehead, that sort of thing. That's the worst part of everything that was, I don't ever want to do that again" (P20).

These frontline workers demonstrated great resilience in confronting the monumental tasks of physically protecting residents as well as providing them emotional and social support. For example, US activities coordinators and dining staff were able to quickly pivot to serve the needs of residents. Staff developed such creative activities as in-room bingo, hallway bowling, water balloons and water guns outdoors, and family car parades to celebrate residents' birthdays.

In Switzerland, staff credited their ability to adapt during times of restrictions to a sense of camaraderie that enabled staff to empathize with each other. Staff on isolated floors became a unit, and together with the residents a family. In discussions following the reopening of isolated floors, several nursing staff highlighted the unity felt over the negative experiences with a sense of pride. They were not only proud of surviving the experiences during isolation, but of uniting as an interdisciplinary team from assistant personnel to the leadership team and many others between. The care team described interactions with the leadership team as being able to "let off steam for a short time" or "bitch and moan" (*auskotzen*) while they tried to stay strong for their coworkers.

Frontline workers in the US who were the focus in chapter 2, who experienced a major nursing home outbreak and volunteered to work on a sealed COVID unit, expressed similar feelings of closeness to other members of the team, but talked about feeling ostracized by other staff outside the unit.

Implementing Evolving Policies and Guidelines

The uncertainty surrounding the novel coronavirus was particularly evident in the ways policies and guidelines were ever changing as new information about COVID-19 emerged. Additionally, the unforeseen length of the pandemic led to the evolution of policy and programming as new concerns arose. This created a difficult terrain for governments at all levels as well as individual residential long-term care homes to navigate in their efforts to both protect and provide appropriate care for residents.

Switzerland and the US experienced the creation and implementation of policy in varied ways that can be tied to the different conceptualizations of care that emerged in response to the pandemic. US government policy emerged alongside policy focused on healthcare facilities to quickly shut their doors to all but the most essential staff needed to care for residents. As the pandemic progressed, residential long-term care communities were given some leeway in terms of what kinds of access was allowed to family members. This was the case more so in Switzerland where, aside from an initial "full lockdown" period, the residential long-term care home made their own decisions on lockdown procedures, taking into account resident needs as well as cantonal guidelines. This required care staff to juggle both the implementation of changing policy and programming coming from government policies as well as administration and corporate offices, in addition to acting as conduits of information to anxious families concerned about their loved ones. One participant explained:

> In the beginning, based on the things that I've observed, and some of the family members that I've spoken with, they were glad that the administrator put into place immediately, no visitors, which includes family members. Again, we try to stay in tune and communicate with our family members, and have residents communicate with their family members. . . and making sure that they know their family member's in the best hands, that they are safe, still. (P16)

This additional labor was draining on care staff. Many participants reported exhaustion and fatigue associated with navigating their work under constantly changing conditions as well as uncertainty that decisions being made and implemented were the correct ones. This created a tenuous work environment as staff were aware that repercussions of ill-informed policy could be devastating to both workers and the residents in their care. Remember Grace who expressed: "You make a decision and it's the right thing, and then you make the decision and it's the wrong thing. And it's just been building the plane while you're flying it" (P38). Staff regularly talked about rules changing daily: "So every day is different. . . Literally every day, there's a new policy, a new procedure, and we're just. . . That's sort of a joke, our ongoing joke, like, 'What could possibly go wrong today?' And just figuring it out" (P13).

In the Swiss case, the long-term care home, which had to make most decisions, developed constant feedback loops between the "crisis team" who met daily and all other staff members. They were in constant contact by phone, email, and WhatsApp groups. This meant information from the leadership team could be communicated more quickly and clearly. At the same time, the "crisis team" learned from new instances and staff uncertainty. Several staff members explained that despite the uncertainty and constant new situations, they did not feel alone as they could ask for help from the leadership team or other senior staff at any time, day or night: "I just come to work and take it forward. . . because. . . how I have to act, I am guided. I can read that at home, [the information] from the crisis team. . . . I'm already prepared. . . with all this knowledge of how I have to act. If

I'm unsure, I can already sit at the computer. . . at 7 a.m. and write 'I'm unsure.'"

The US experience varied between different residential long-term care communities and also compared to that of Switzerland. In the US, administrators and managers met frequently to respond to executive orders and guidelines at the state, local, and corporate levels. Some nonmanagerial staff felt they had little to no voice in decision-making regarding how to handle the pandemic as well as the needs of residents and were responding to constantly changing rules. They were also faced with negative reactions in the community and pushback from families, due in part to negative media reports. In this context, many direct care workers felt anger, frustration, and helplessness.

Meanwhile, Swiss long-term care homes were largely given freedom to decide how to balance protecting residents while maintaining access to family and friends, and included staff and in some cases relatives in the decision-making process. During the peak of the second wave, when cases were at their highest, the Swiss long-term care home was still able to lockdown on a floor-by-floor basis. Floors with positive cases went into isolation, but residents and staff on floors with zero cases were able to move freely around non-isolated areas of the home while wearing masks. In addition, visitors were allowed in designated communal areas throughout this time, and in-room visits were permitted under special circumstances, which were decided on a case-by-case basis and permitted on compassionate grounds. During this time, residents could not go offsite but had as much contact with family and friends as the "crisis team," who at this point were in daily contact with the cantonal GP, felt safe. This site evolved between the first and second waves of the COVID-19 pandemic, gradually learning how to function effectively to protect resident quality of life, while negotiating guidelines from cantonal authorities to keep residents safe.

Balancing Isolation with Quality of Life

Throughout the evolution of the ongoing pandemic, staff struggled with balancing protecting the residents from COVID-19 and the negative effects of social isolation. One US administrator expressed:

> I want them to be able to have these experiences and not be secluded, so the best thing for the resident is for families to be in here, and so I want that. If I had to pick one or the other. What I have been told is I've been the most aggressive with the outdoor visitation compared to the other administrators in our region, and I actually, I was told to back it off just a little bit. . . the last thing I wanna do is have another outbreak, so you're. . . I'm torn between the two. (P56)

The long-term care home observed in the Swiss case study is perceived in Switzerland as having strict protection measures. However, the leadership team constantly strived to provide a level of resident freedom alongside restrictive safety measures. Resident quality of life was factored into decisions surrounding isolation, as this staff explanation demonstrates:

> What we do in here actually should have the same effect as when we close completely. . . . We no longer do room visits, we stopped that two or three weeks ago. . . . In the end you can ask yourself, if someone dies because of COVID, or because of “grief” or “wasting away” or “being alone” or simply no longer have the will to live . . . then I have to ask myself, or we just ask ourselves, “What has been gained?” . . . These are such ethical questions, or, there is no right and wrong. I maintain that if we and everyone stick to the protection concepts we have, it would work. But it doesn’t work because not everyone sticks to it. . . . And then there is always the question: Do we punish everyone now?, and it is perceived as punishment [when they are not allowed to have visitors].

In the US, the majority of participants acknowledged that the social isolation was profoundly affecting residents, both physically and emotionally. At the same time, they expressed fear and anxiety about allowing families into the residences. Recognizing the cost to some residents, they questioned the wholesale shuttering of communities and were concerned that residents and families were not given any agency in this process. One administrator observed: “I have residents every day who say, ‘It’s not worth living like this.’ So it’s a fine line trying to decide what is right. And honestly, just because I feel depressed and wanna see my family, is it worth exposing the whole facility to that? It’s really about what’s best for the group. So, I’m really torn.” Another staff member shared that residents were “in a pit of sadness” and that was too high a price to pay for the protection provided by the lockdown. They were supportive of the expansion of compassionate care visits. They went on to say that after the residents’ families were allowed to visit, “It was amazing. And they [residents] would cry and cry afterwards and saying how that just felt like years to them, they haven’t seen their family” (P31).

Discussion

Care staff found themselves navigating the physical risk of COVID-19 to their residents, self, and families while also being responsible for the quality of life of their residents who were experiencing isolation. Some of their responses related to fear of the disease and the potential repercussions. The fear and anxiety experienced are responses to challenges faced in caring for isolated residents, such as enforcing infection control policies, providing emotional support while families are absent, and dealing with PTSD after watching residents suffer. These experiences and perceptions shape care staff's ideas about how to address further isolation while balancing quality of life. Caring for residents who have tested positively for COVID-19 increased the chance of staff experiencing anxiety and PTSD. Throughout this period, uncertainty in relation to the overall impact and duration of the pandemic prevailed for staff. In addition to increased levels of care required during such a period of uncertainty, staff had to cope with members of their own team contracting COVID-19, often without knowing how the infection had spread. This, in peak times of crisis, also led to staff shortages adding to caregiver burden. Staff numbers were also impacted by staff who were themselves considered vulnerable and unable to work in isolated areas. There were obvious concerns with using external agency staff to supplement staffing or having staff work in multiple locations.

The narrative in the media portrayed a very negative view of residential long-term care, with much blame being attributed to staff. There were of course problematic elements, as with any industry during the pandemic, such as a lack of PPE, but successes were overlooked and the focus fell on the negatives. This was even the case when negative factors were beyond the control of residential long-term care staff due to shortages of resources or lack of external support. Staff in both countries compared experiences during instances of high COVID-19 cases as being in a war zone or a wildfire—constantly fighting to get ahead in times of extreme exhaustion and uncertainty. In the Swiss case study, where floors were isolated on a case-by-case basis, shifts on non-isolated floors were observed to be running relatively "business as usual" beyond the required masks and additional infection control procedures. Meanwhile, neighboring floors were in crisis, with the majority of residents having tested positive for COVID-19. In non-isolated areas, aside from signage, disinfectant hand gel and masks ever present, it was easy to forget just how arduous the situation was for staff working in isolated areas. However, despite this, teams in isolated areas became stronger than ever, and staff adapted to go above and beyond for the residents in their care.

The ongoing situation caused residential long-term care to revert back to more of a medical care model in many cases, even in Switzerland and in US residential long-term care communities where a culture shift had previously seen a move away from this approach to care. This resulted from time constraints, staff shortages, and the need for extensive protective measures in a time when resident safety was the main priority. Overburdened staff in isolated areas focused on keeping residents testing positive for COVID-19 alive and comfortable during a time when they were told to expect few survivors. At the same time, staff became more than just carers during times of isolation and were still expected to provide key elements of a person-centered care approach. They became the main source of interaction and both intermediaries and (in some cases) replacements for relatives. Care staff provided the additional care and emotional support usually given by family and friends when visiting a resident. In extreme cases, this included additional palliative support, making sure no resident was left alone or without contact at the end of life. This was the case in both the US, where a medical model of care still largely prevailed prior to the COVID-19 pandemic, and in Switzerland, where the research site was known for providing a person-centered approach to care. While the US continued extreme restrictions on long-term care throughout the pandemic, the situation in Switzerland enabled long-term care communities to respond to specific situations and open for more visitation, rather than continuing with a total shutdown. This more nuanced approach was equally challenging for staff but was positive in terms of the lower level of isolation and loneliness experienced by the residents they care for. In the Swiss case, protective measures were more effectively balanced with an effort to provide adequate quality of life.

In both the US and Switzerland, the COVID-19 pandemic continues to impact residential long-term care homes, whether they currently have positive cases or are dealing with the aftermath. With the duration of the pandemic and the severe shortage of workers in long-term care currently, it is impossible to say when residential long-term care staff will get significant relief. It is clear from the interviews and observations undertaken during the height of the pandemic that this level of expectation on staff is unsustainable in the long term. It is important that lessons are learned from this pandemic, and that strategies are designed for the future based on staff experiences.

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Notes

1. FFP stands for "Filtering Face Piece," with the number corresponding to the level of protection the piece provides: 1 being the lowest level of protection and 3 being the highest.
2. Adapted from Freidus et al. (2022).

CONCLUSION

LESSONS LEARNED AND APPLICATIONS AS WE LOOK TO THE FUTURE

As the pandemic progressed, our research team met daily and talked about what we were hearing from the participants. Shenk, in particular, began following the struggles of family members and other informal but essential caregivers who were frustrated by the ongoing lockdowns and their inability to visit their loved ones. These reports appeared on social media from family members and activist groups, along with frightening accounts in the media. We began following the Facebook groups of "North Carolina Caregivers for Compromise—because isolation kills too!" and "Long-Term Care Nursing," as well as the national movement for long-term care visitation started by Mary Daniel. She took a job as a dishwasher in the kitchen of the memory care community in Florida where her husband is a resident in order to be able to visit with him after her shifts. She has continued to fight for visitation rights, along with other family members of long-term care residents and advocates nationally. Compassionate care visits were arranged for families to visit residents who were dying of COVID, but as we discussed in chapter 2, people were dying alone or with a CNA or housekeeper holding their hand. Family members who helped care for their loved ones when they visited regularly before the pandemic began sought the designation of "essential caregiver" and visitation rights following the guidelines being enforced for any staff entering a long-term care community.

Along with hospitals, long-term care communities set pandemic restrictions on visitors to protect patients, residents, and staff from infection. These concerns for safety led to extensive isolation and decline of residents and exacerbated the demands on overworked staff. New laws have since been developed, and supporters of these new laws say they want to ease the restrictions because the rules harmed patients and residents. In terms of visitation in long-term care, at least nine states have passed "No Patient Left Alone" acts and several others have bills under consideration. Other states including Arkansas, North Carolina, and Oklahoma passed similar

"No Patient Left Alone" acts that also guarantee visitor access to patients in hospitals. Some laws, like those passed in New York and Texas, are specific to long-term care communities. They allow residents to designate essential caregivers, also known as compassionate caregivers, who are allowed to visit regardless of whether there is a health crisis. In January 2022, the Texas Health and Human Services published a "reminder" that all long-term care facilities must allow all visitation and essential caregiver and end-of-life visits must be allowed for all residents with any COVID-19 status. A facility or agency may be cited if visitation is not allowed.

While we were interviewing participants back in 2020–2021, we were frustrated by the tension between the anguished narratives we were hearing from the long-term care providers who were endangering themselves and their families in order to care for residents and clients, and those who were highlighting the outbreaks and "dangers of nursing home care." The research participants expressed their dedication to the residents and clients in their care, while the "outside world" chastised them for isolating those in need of care and being part of the problem leading to the high number of deaths among this population.

In August 2022, Shenk was invited to a meeting of OPENDOORS, the group started by Black and brown residents at Coler Rehabilitation and Nursing Center, on Roosevelt Island, New York City, which is spotlighted in the essay in chapter 2. At that Zoom meeting, we talked about this book as well as their ongoing efforts through Nursing Home Lives Matter and the impact campaign for the documentary then in production, *Fire through Dry Grass*. I met the founder of the national Essential Caregivers Coalition and offered my support in their efforts to reform long-term care. This online group is continuing to work to pass legislation at both the national and state levels to designate essential caregivers for residents in long-term care, as discussed previously. As described on their website: "This is a national advocacy group dedicated to the establishment of an Essential Caregiver designation in order to prevent long-term care residents from suffering due to the effects of social isolation when faced with measures meant to secure public safety" (Essential Caregivers Coalition n.d.).

We have come to realize that mistakes were made, especially during the early days of the pandemic when little was known about COVID-19 and how to control this rampaging virus. As discussed in chapter 8, the prolonged lockdown of residential long-term care communities and the isolation it caused led to irreversible decline of some older adults and deaths that might have been avoided with a more nuanced approach to protecting residents. This crisis has exacerbated the ongoing problems in long-term care and made very visible the problems in our system for those in need of support and care. This is a moment ripe for change. As it tore through long-term care communities and the deaths were shouted in the media, the COVID-19 pandemic has laid bare the inadequacies of the long-term care system in the United States.

The 2022 report from the National Academies of Sciences, Engineering, and Medicine on the national imperative to improve nursing home quality places its recommendations in this context: "despite making up less than one-half of 1 percent of the US population, as of October 2021, nursing home residents accounted for approximately 19 percent of all COVID-19 deaths" (2). Another 2022 report, keyed to interviews with CNAs in metropolitan New York, echoed its call for increasing stability and addressing growing staff shortages (Franzosa et al. 2022). A brief from the ASPE (Assistant Secretary for Planning and Evaluation) Office of Health Policy (2022) also emphasized worker shortages across the healthcare workforce, "increased health care worker burnout, exhaustion, and trauma" (3) and disparities in geographic distribution of hospitals (10). Reinhard, Flinn, and Amero (2022: 4) reported that older people and persons living with dementia at home lost services and socialization, as some states restricted provision of home health care. The COVID-19 pandemic called—and continues to call—attention to many problems across the entire healthcare system in multiple countries and, in the US, across a range of states. Emphasis has grown across the world to focus on how we care for aging people and persons living with dementia in environments including nursing homes, memory care homes, other long-term care communities, and in homes in the community.

Especially during the first few months of the pandemic, there was an emphasis on "the important role of long-term care staff at the frontlines of fighting the virus and preserving the lives of older adults. As a society, it is our duty to ensure the status and benefits associated with direct paid eldercare work are improved so that staff are adequately trained and rewarded for their work" (Ayalon et al. 2020). While these workers were deemed "essential workers," they were not accorded the status and benefits that should come with that designation. Dire headlines notwithstanding, at the time of this writing we are in much better shape than we were at the start of the pandemic. We've discovered a lot more information about how COVID-19 works and now have effective masks, vaccines, boosters, treatments, and rapid tests. We've also learned that having to hunker down comes at a real cost to the mental health and well-being of both the caregiving staff and older adults they care for. The cost of a strict lockdown may have been deemed worthwhile in 2020, but by and large that's not what US experts advise now. A key variable that needs to be examined is the movement of staff in and out and within residential long-term care environments. Early in the pandemic most homes and programs limited staff to working in a single building or unit or serving a small number of clients in their homes. The staff were moving in and out of the long-term care environments, however, and were likely the source of at least some of the spread of the virus. Other challenges in preventing outbreaks were residents and clients going out to medical appointments or to visit family. As we saw in chapter 6, one assisted living community that had no known COVID cases throughout 2020 had an outbreak in January 2021, shortly after residents were able to go home for the holidays in December.

Our comparison of the responses of staff caring for older adults in residential and community-based long-term care suggests that home and community-based service providers were generally better able to respond quickly and effectively as they pivoted during the pandemic. While there will always be a need for nursing homes for some people who require skilled nursing care, and a range of long-term care options, most people prefer to stay in their homes as their care needs increase. Home and community-based care is also more cost effective and works better physically, mentally, and socially for older Americans. The pandemic also highlighted the value of agency, which was more easily afforded to those who provided and received care in their homes.

The future of long-term care requires investment in both residential and home-based services. As Grabowski (2021) explains, if there is a silver lining to COVID-19 in terms of long-term care, the pandemic will hopefully accelerate the decades-long push toward expanding home and community-based programs while also causing a reconceptualization of nursing home care. These are not competing goals but rather complementary ones. The goal should not be to abolish nursing homes, but rather to abolish the institutional models and the underfunding of home and community-based programs that have plagued long-term care for far too long (Grabowski 2021).

We agree that following the pandemic, countries like the US should increase their overall government spending on long-term care, and the bulk of that additional spending should go to home and community-based models. The median for countries in the Organization for Economic Cooperation and Development (OECD) is to spend roughly 15 percent of their healthcare budget on long-term care services. In countries that allocate a small percentage of healthcare spending to long-term care, such as Australia (2 percent) and the US (5 percent), dollars could be taken from general healthcare spending and reallocated to home and community-based services (Tikkanen 2017). This increased spending on home and community-based care would benefit not only the care for recipients but also their family members, who often must take time away from their jobs and risk their own health to provide this care (Grabowski 2021).

Along with an increase in funding for home and community-based services, measures are needed to assure the quality of these programs. We are encouraged by the recent adoption of the first ever home and community-based quality data set by CMS to promote consistent quality measurement within and across state Medicaid home and community-based programs (Gerontological Society of America 2022). "CMS strongly encourages [but does not require] states to use this information to assess and improve the quality and outcomes of their home and community-based programs. CMS expects to update the measure set in the future, including adding newly developed measures to address gaps, as the field of home and community-based measure development advances" (9). This is just a start and would need to be expanded beyond Medicaid-funded programs.

For those who need residential-based care, the goal should be to provide a range of environments where well-educated and well-compensated staff provide effective care in a small homelike setting such as the Green House model. We agree with Polivka that "existing large facilities should be reserved for short term, convalescent and rehabilitative care, which nursing homes are already providing on an expanding basis" (2020b). Small home models like the Green House model have been found to provide higher quality care relative to traditional nursing homes (Afendulis et al. 2016). Early reports during the pandemic indicated that residents in Green House communities, for example, were one-fifth as likely to get COVID-19 compared to those who live in typical nursing homes, and one-twentieth as likely to die from COVID-19 (Tan 2020). Small home models are also able to provide care that affords a higher quality of life and avoids social isolation that were particularly crucial concerns during the pandemic.

While care providers in long-term care were considered essential workers during the height of the pandemic and were expected to show up and provide the necessary care, they are not always treated as valued workers. That leads to another major set of recommendations related to the structure of eldercare work and the way elder care is staffed. Staffing issues include adequate pay, appropriate benefits, and effective career paths. As Picard (2021) outlines from Canada:

> More than anything, the pandemic exposed how important frontline workers are, especially to frail elders; chronic labor shortages are as deadly as viruses. COVID-19 also graphically underscored that the conditions of work are the conditions of care. Improving eldercare begins with fixing the work environment for nurses, PSWs [Personal Support Workers] and others. Staff need resources, structures, support and time to deliver quality care. (164)

Our findings suggest several major staffing issues highlighted by the pandemic that need to be addressed. First, in terms of the inadequate pay for those providing care, workers require a living wage so that they don't have to work multiple jobs in order to earn enough to live on. This should include appropriate compensation as well as benefits such as paid sick leave and health insurance. Second, there needs to be clear career paths and professionalization for CNAs and home health workers, in particular. Third, the pandemic demonstrated the need for a specialized wellness coordinator to track testing, symptoms, and quarantining protocols as knowledge and guidelines evolved. Fourth is the need for extensive cross-training of staff, as discussed by the administrators in chapter 6 and highlighted in the essay in chapter 6. Fifth, the resilience that is required of staff requires the support of supervisors in addition to that of family or friends.

It is important to recognize the integral role played by caregivers with established relationships with the older adults for whom they provide care. In chapter 3 we focused on Kellin, the bus driver who took on new responsibilities during the lockdown. Because he knew his clients well, he was able to check in on them and determine whether they were okay. This emphasizes the policy implications of assuring that workers receive appropriate wages, sick pay, and leave, rather than resorting to using temporary workers who do not have established relationships or understanding of the residents' or clients' needs. Full-time staff regularly express the challenges of working short-staffed or with "agency staff" who are generally paid more than residential community staff.

While many of the research participants discussed the importance of the support they received from their informal support networks throughout the pandemic, those who felt supported by their supervisors and coworkers spoke about a sense of agency that enabled them to remain effective in providing care. As demonstrated in the narratives, the staff working to provide care for older adults requiring their expertise stepped up and did the work that needed to be done even when it endangered them and their families. We owe it to both the workers and the residents and clients who require care to assure that well-trained, well-supported, fairly compensated staff are available to provide care.

A major finding of a recent report on nursing home care is that the public view "caring" as an innate characteristic rather than a learned skill (Aasar and Volmert 2022). Their recommendations related to improving the skills of the caregiving workforce based on this finding include: 1) an emphasis on the learned skills required for good caregiving that can be taught and improved; 2) the rigorous training necessary to achieve the necessary expertise and its importance in the day-to-day responsibilities of all levels of staff; 3) the need for detailed understanding of how training, better wages, and improved working conditions impact the quality of care in nursing homes; and 4) contextualizing nursing home work within

Illustration 9.1. Faces of Caring signs made by director of nursing (PowerPoint slide 106). Photo credit: Attic Angel Assisted Living and Memory Care

broader narratives and conversations about racial and gender justice and linking efforts to reframe care work with the larger movement for a just and equitable society (13).

It is clear from our findings that the long lockdown that began in March 2020 was difficult for the caregiving staff and also detrimental to the health and well-being of many long-term care residents. Looking at the way this was handled in some other countries suggests that a more nuanced approach would have been more successful at protecting the residents from COVID while providing the necessary care alongside adequate socialization. As discussed in chapter 8, the US continued extreme restrictions in residential long-term care, while Switzerland enabled residential long-term care communities to respond to specific situations and open for more visitation rather than continuing with a total shutdown. This more nuanced approach was equally challenging for staff but was positive in terms of the level of isolation and loneliness experienced by the residents they care for. In the Swiss case, they more effectively balanced protective measures with an effort to provide adequate quality of life. Tailored infection control guidelines would have helped assure that better care for residents was provided, incorporating more appropriate interaction and socialization during what turned out to be an extensive period of time. This could have partly been accommodated by increasing the use of compassionate care visits and establishing a more effective system for allowing residents to deem select individuals as "essential caregivers" and allowing them to visit utilizing the same restrictions that were in place for staff.

The major themes of resilience of staff, importance of valuing human infrastructure, and communication are highlighted in each chapter, and we have discussed recommendations in terms of the organization of the long-term care system and staffing. We will now go on to address key recommendations related to communication. During the pandemic, the need for effective communication at various levels was paramount and had to be expanded. This includes communication about evolving policies and guidelines to staff, as well as regular updates to residents/clients and their families. Those residential long-term care and home and community-based programs that had strong relationships among staff, with residents and family members, were able to utilize these trust-based relationships to foster effective communication and care as the pandemic progressed. We came to recognize the importance of effective communication that incorporates flexibility as key to navigating the challenging situations facing staff, residents/clients, and families.

The role of strong, sensitive leadership has been crucial throughout the trajectory of the pandemic. The managers and administrators who were particularly successful in guiding their staff and programs through the evolving pandemic demonstrated these skills. Structured leadership within each congregate care community and community-based program was essential to responding effectively and pivoting rapidly to continue to meet the needs of staff, clients, and residents. Effective leaders had the respect of their staff, residents/clients, and family members. A key element of effective leadership during the pandemic was assuring adequate avenues of communication. The staff of residential long-term care communities and community-based programs faced huge challenges in assuring adequate communication with their residents or clients and their own coworkers. A particular challenge was communicating effectively with family and enabling them to keep up to date on their loved one's situation and engage with them.

What did not emerge consistently, even when guidance and direction were needed early on, was an adequate way of communicating across individual long-term care communities and community-based programs to share ideas, experiences, and innovations to address the impacts of social isolation. Professional organizations including the NAAP (National Association of Activities Professionals) and NCCAP (National Certification Council for Activity Professionals) hosted open meetings in the early months of the pandemic. Some staff utilized social media and personal and professional networks to commiserate and share information, but there didn't seem to be sufficient safe spaces within which professionals could share thoughts and express their emotions. For example, during the focus groups we held on 30 October 2020, 25 January 2021, and 8 March 2021, with administrators and activities staff who had never met, we noted how they quickly supported each other as they discussed their experiences, and shared successes and failures. The participants all agreed that having connections with other communities, programs, and agencies made it easier to respond effectively to the needs of staff and to pivot quickly to effectively meet the needs of the older adults they care for.

One of the most dramatic changes we observed during the pandemic was the vastly expanded use of technology in many different forms, including communicating with residents/clients and family members. We saw an expanded use of FaceTime and Zoom in addition to telehealth platforms, some of which can be continued beyond the pandemic. All residential long-term care and home and community-based programs should have adequate technology to enable social interaction, because those who did not have it were at a disadvantage during the height of the pandemic. While virtual platforms were used on an expanded basis to foster communication between residents/clients and families during the lockdown, those resources can continue to be used effectively to gather families who are in different locations. The serious issues related to engagement, and avoiding isolation and loneliness, suggest the need to strengthen and keep our in-person programs and services strong with an increased use of technology and telehealth as we move into the future.

Positive Outcomes to Build on and Lessons Learned

While the pandemic was a horrific experience for most workers caring for older adults in long-term care, we were able to identify a set of positive outcomes and creative approaches, as well as recommendations that can be incorporated and built on to improve care. Below we list some examples of how long-term care providers were able to meet the evolving needs of older adults during the pandemic. These operational flexibilities, creative approaches, and positive outcomes can be useful in efforts to restructure and improve long-term care moving forward. An overarching theme from these data is that individuals and communities drew on available resources in creative ways to meet the needs of residents and clients and their families. The resilience and creativity shown by the staff were remarkable in light of the difficult and restrictive circumstances.

- Telehealth—We know that telehealth does not work for everyone and certainly not for all medical situations, but it has been integrated into more healthcare practices; it will continue to be used in certain situations as part of the system of long-term care, as an effective means of communicating with providers, patients, residents, clients, and their families.
- Collaborative relationships between agencies and programs—Programs that were most effective in pivoting quickly to address the needs of their residents and clients drew on long-standing relationships with other community partners that had different kinds of resources available to them.
- Relationships within teams—A key finding from this study suggests that the environments that were able to provide the most effective care were those where team members felt supported, protected, and informed. In particular, when staff felt they had agency within their workplace and their supervisors were attentive to their input and concerns, they were best able to provide quality care throughout the pandemic.
- Share best practices, mistakes, resources, and strategies—Staff have to be willing to not only share best practices and effective strategies but also admit weaknesses or mistakes made during the evolving pandemic. There needs to be a willingness to share across different organizations and programs.
- Videos of long-term care environments during lockdown—During our interviews, a couple of research participants walked us through their community while on Zoom in order to let us see how things were functioning. Some staff created and shared videos of activities that showed family members what was going on and reassured them about the situation and precautions that were being taken.

We hope that by sharing these examples of positive outcomes and techniques, we can help other providers recognize possibilities to implement in their own communities and programs in the future.

Recommendations

- It is essential to maintain effective mandatory reporting and communication systems, or implement an “emergency outreach communication plan” that allows the utmost transparency between all levels of workers and clients/residents/families.

- There needs to be adequate attention to infection control. Programs and communities need to maintain a sufficient stockpile of resources including PPE to ensure proper infection control. A specific position is needed in residential long-term care environments to monitor and ensure that infection control protocols are enforced.
- Staff, especially in residential long-term care, need to be cross-trained in the event they need to step into new or additional roles to ensure the safety and health of their residents.
- Recognition of the importance of and improved utilization of existing networks is necessary across various models of long-term care to share information and strategies regarding evolving needs of staff and those in their care.
- In terms of persons living with dementia, particular care needs to be taken to prioritize a person-centered care approach provided by a well-trained staff.
- Innovations like the distribution of animatronic pets should be expanded because they will always provide important interaction and support in the best as well as the most challenging of times.

Conclusion

Our overriding sense as we complete this book, three years after we all weathered the initial brunt of the COVID-19 pandemic, is the disappointingly ineffective and inadequately funded approaches to providing care for older adults and support for those who provide that care. Our system of long-term care in the United States is not well funded. It is not well regulated, and we do not listen and respond to the voices of those extending or receiving care. As we look to the future, we need to do better for our elders and those who care for them. If not now, when?

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