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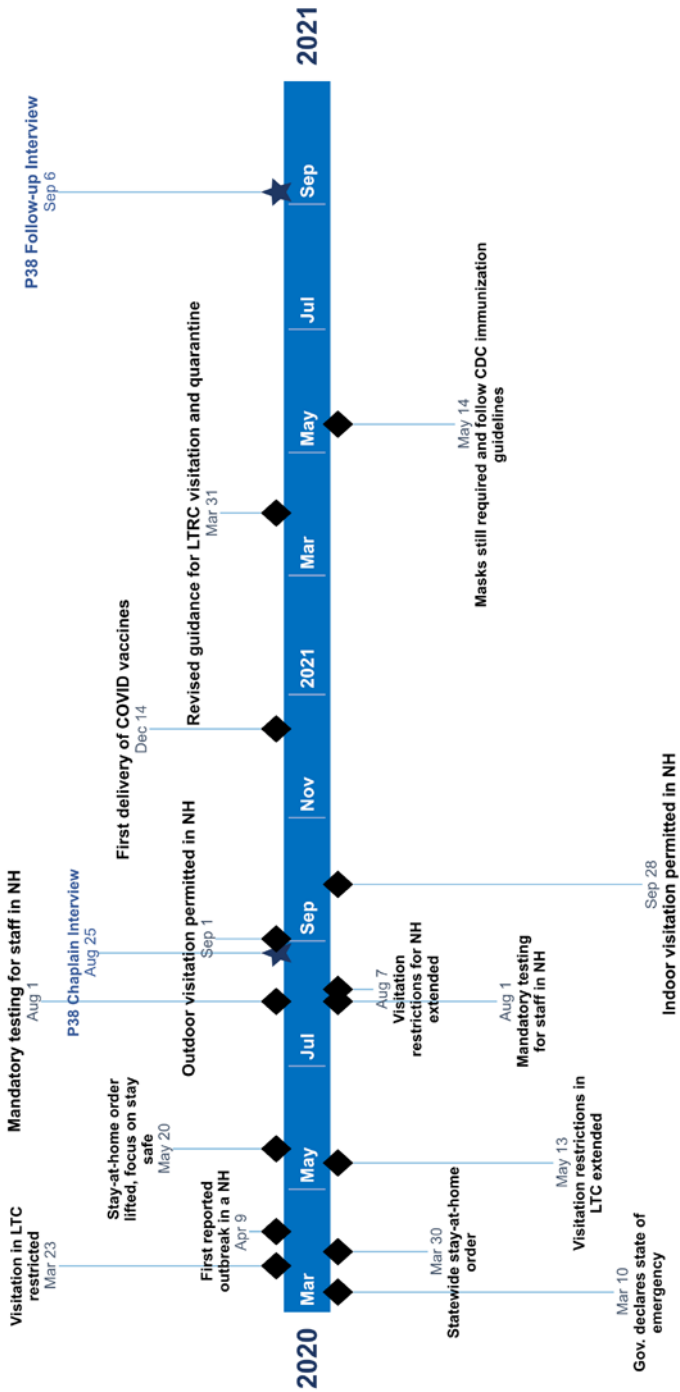
Figure 0.1. Timeline of Early Response to COVID-19 in North Carolina.

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), rele-

vant 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.
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> 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 profession-
> ally, 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 be-
come 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 ap-
proaches to ever-expanding ranges of daily living activities, processes, and
states of being including aging and disability (Zola 2009). Aging Amer-
icans have historically been defined and managed by their physical and
biological needs and limitations. As a result, models of care for this popu-
lation have focused almost exclusively on the physical self and quantity of
life, with less attention paid to the whole self, overall quality of life, varia-
tions 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 com-
munities 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 res-

idents, who in these settings have reported feeling bored, lonely, and help-less (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 human-istic approach to care (Junxin and Porock 2014). Culture change requires a reorientation of institutional values, attitudes, and practices of the indi-vidual 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 psy-chosocial needs in addition to their physical requirements. There has been less attention paid to identifying local cultural features to preserve or re-configure 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 pan-demic 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
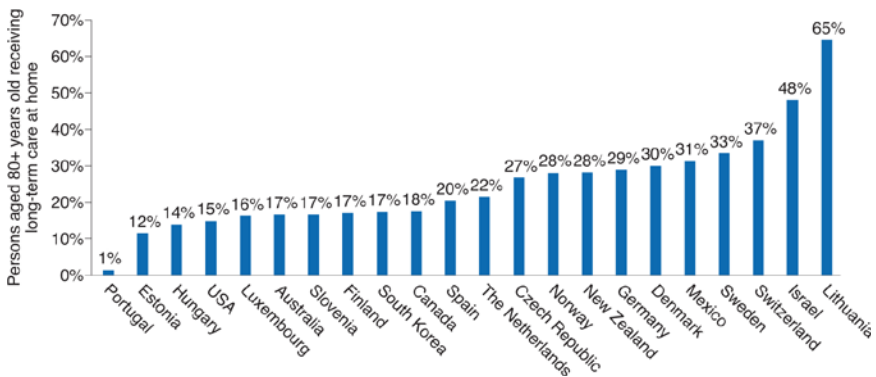

Figure 0.2. Proportion of Older Adults Receiving Long-Term Care at Home in Various Countries.[2]
All data are from 2018 except Canada, Mexico, and the US, which are from 2016, and the Netherlands and Slovenia, which are from 2017. Data obtained from OECD.Stat (2020).

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

NC DEPARTMENT OF
**HEALTH AND
HUMAN SERVICES**

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

SEPTEMBER 22, 2020

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

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

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 re-

ferrals, 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 coordi-

nated 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, co-authored 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.