

A Rapid Qualitative Appraisal of the Impact of COVID-19 on Long-term Care Communities in the United States: Perspectives from Area Aging Staff and Advocates

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The COVID-19 epidemic has hit residents and staff of congregate long-term care communities particularly hard. In North Carolina, the site of this research, over half of registered mortality has been associated with congregate living communities. This article reports on phase one of a rapid qualitative assessment of long-term care professionals and regional aging staff navigating care during this epidemic. Our purpose is twofold. We demonstrate both the value of rapid qualitative appraisals to capture the perspectives and concerns of COVID-19's long-term care workers and area aging staff, in this case, the staff and advocates that care for and protect the rights of long-term care community residents as well as present data collected in this phase. Key points raised focus on safety, including access and use of personal protective equipment, infection control, limited testing, and staffing issues. In addition, participants expressed concerns about the physical and mental health of residents because they have been isolated from family and friends since the executive order closed these communities to all non-essential people. We will utilize these data, in collaboration with staff and advocates, to inform policy and programming to better address the needs of both residents and staff of long-term care communities.

Key words: long-term care communities, COVID-19, rapid qualitative appraisal

Introduction

Life Care Center Nursing Home in Kirkland, Washington, was originally identified as the epicenter of the United States COVID-19 epidemic. It has since become apparent that there were numerous other cases and outbreaks throughout the United States, but the nursing home (NH) has received significant negative attention (Watkins et al. 2020). COVID-19 makes visible long-standing problems in long-term care (LTC) that advocates tie to widespread ageism in the United States. These include 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 (Kane 2001; Polivka 2020a, 2020b; Rosen et al. 2011). Sadruddin 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, accompa-

nied 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."

In most states, approximately one-third to one-half of all COVID-related deaths are attributed to residents and staff of congregate LTC communities. In North Carolina, the site of this research, the average weekly number of COVID deaths related to LTC communities in early June 2020 hovered higher, at around 60 percent (NCDHHS 2020). This research focuses on how LTC staff, advocates, ombudsmen, and surveyors¹ are adapting to unprecedented circumstances, with high rates of infection and death during this complex health emergency.

LTC providers are not traditionally considered "front-line" health care 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 hard hit 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. LTC communities are neither designed nor equipped to treat people with serious COVID-19 (Gardner, States, and Bagley 2020).

This paper reports on phase one of a rapid qualitative appraisal examining the impact COVID-19 has had on the

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provision of care for older adults in LTC communities in central North Carolina. In this phase, we conducted interviews with a sample of staff from a regional Area Agency on Aging (AAA) and a statewide non-government organization that advocates on behalf of LTC residents and their families. We examined the concerns they have about overseeing the care of residents during the outbreak and unanticipated issues they face in navigating their work. Questions focused on what resources they have made available, what needs are not being met, their concerns, and successes.

This paper has two purposes. First, we highlight the value of rapid qualitative appraisals during complex health emergencies by providing a tangible example during the COVID-19 epidemic. Surprisingly, there is limited use of rapid qualitative appraisals in complex health emergencies (Johnson and Vindrola-Padros 2017). A review article conducted by Johnson and Vindrola-Padros (2017) identified twenty-two such studies. In addition, qualitative work done during complex health emergencies privileges health care providers in hospital settings. The work presented here deviates from this and seeks to capture a broader range of “frontline” or direct care worker experiences in the communities hardest hit by COVID-19. To date, there have been no rapid qualitative appraisals studying long-term care for older adults in any country during a complex health emergency.

Second, we present findings from Phase 1 to both capture the experiences and perspectives of those working with LTC communities and to disseminate real-time data about the struggles and successes these communities and the organizations are facing to policymakers, advocates, and political decision makers. We expect that results from this project will inform policy and programming formation especially in anticipation of the continuation of the current COVID-19 outbreak or future complex health emergencies.

Rapid Qualitative Appraisals and Complex Health Emergencies

The Ebola virus outbreaks in West Africa (2013-2016) illuminate the increasing need for rapid qualitative work that values cultural and local perspectives, which had been relatively limited until this crisis (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 anthropologists to work on the mission (Abramowitz et al. 2015). Some consider this a “watershed” moment, whereby anthropologists using rapid qualitative methods had a “seat at the table” alongside transnational health-focused organizations in helping to guide programming and policymaking (Johnson and Vindrola-Padros 2017).

Rapid ethnographic appraisals have characteristics that ensure the generation of valuable and timely information meant to directly inform interventions, policy, and programming. These include a condensed data collection timeline (ranging from weeks 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 data can be analyzed quickly and cross-checked (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 (see Pathmanathan et al. 2014).

Applied anthropology is well-suited to take the lead in these kinds of appraisals because of our practice of taking a holistic approach, valuing local knowledge and culture, being able to capture a diversity of narratives, emphasizing community engagement as well as being able to communicate across steep gradients of power. We are especially charged with demonstrating how our data can inform policy and programming. This can be accomplished by effectively using our tools, acknowledging our limitations, and providing transparency about our process and our goals (Johnson and Vindrola-Padros 2017; Vindrola-Padros and Vindrola-Padros 2017). This rapid qualitative appraisal takes up the call to action by collecting qualitative insights from direct care workers (DCW) and professionals working in long-term care about their experiences that can be used to inform the creation of new policy as well as amend existing policy from “the ground up” (Eisenberg 2011).

Previous Pandemics and Health Care Workers

COVID-19 is unique in its infectivity and high rates of morbidity and mortality impacting nearly all communities across the globe making it an unprecedented complex health emergency (Khachfe et al. 2020). Previous pandemics, including SARS, MERS, and Ebola, have provided lessons about how to care for patients during a time of emergency and also illuminate concerns among providers that treat infected and potentially infected patients (Khalid et al. 2016; Koh, Hegney, and Drury 2011; McMahon et al. 2016; Raven, Wurie, and Witter 2018).

Previously, health care workers’ main concerns during infectious disease outbreaks included risk of infection, lack of training, inability to properly treat patients, limited infection control, and not feeling supported by their governments as well as hospitals and communities (Khalid et al. 2016; Koh, Hegney, and Drury 2011). For example, McMahon et al. (2016) report that colleagues treating Ebola patients expressed distrust of each other centered around fears of infectivity that led to policing one another and the sentiment that it was “every man for himself.” Also, many of these “essential” workers considered quitting their jobs because of family pressure and stigma (McMahon et al. 2016; Raven, Wurie, and Witter 2018).

Particularly disconcerting are reports about the emotional impacts of providing care during an emergency. Health care providers, especially working with Ebola and acute respiratory infections, report mental health issues and psychosocial

distress, including feelings of depression, anxiety, fear, isolation, and stigmatization (McMahon et al. 2016; Raven, Wurie, and Witter 2018). In a qualitative study among providers during the Ebola crisis in Sierra Leone, respondents were particularly disheartened by their inability to bond and “suffer with patients” because of the required use of personal protective equipment (PPE) (McMahon et al. 2016). Similarly, Raven, Wurie, and Witter (2018) found health care workers faced trauma watching colleagues and community members die at high rates. In the United States, we have paid little attention to the psychosocial dimensions of what LTC workers face. Not properly documenting and addressing these stressors can lead to long-term mental health issues.

Conversely, there are studies that demonstrate how health care worker anxieties and stressors during an infectious disease outbreak can be mitigated. Koh, Hegney, and Drury’s (2011) review article demonstrates that health care workers accepted risk and were more likely to feel comfortable in their work if organizational measures were also in place, which included restricting visitors, making PPE available, instituting infection control trainings and temperature screenings, and requiring self-assessments of symptoms. These findings might resonate with LTC workers on the frontline of the United States COVID-19 epidemic.

Contemporary Challenges Providing LTC Pre-COVID-19

In the United States, we provide LTC for older adults within congregate living communities and through in-home and community-based care. Congregate communities include NH, continuing care retirement communities (CCRC), and residential care communities, also referred to as assisted living (AL) and family care homes. Special care for people with dementia is provided in dementia units within NH or AL communities, as well as free-standing memory care AL communities. CCRCs are communities with a range of levels of care available on a single campus. We also provide LTC through community-based programs and in-home services.

One pervasive challenge in LTC communities involves staffing. Issues that staff, often minority women, face are not new but are exacerbated by the epidemic. These include high job turnover, low wages and meager benefits (Harahan 2010; Rosen et al. 2011), limited job satisfaction (Karantzas et al. 2012; Rosen et al. 2011), emotional burnout (Karantzas et al. 2012), lack of institutional and societal support (Jakobsen and Sorlie 2010), and limited autonomy (Shenk 2009). COVID-19 makes apparent many of the failings that characterize congregate care for older Americans, as it presents unprecedented challenges to the staff of LTC 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 re-emerges.

The perspectives of health care workers on the frontlines are regularly captured, but LTC workers have not been

given the same attention. This work seeks to fill this gap using a rapid qualitative appraisal that captures the narratives of all LTC providers as an essential step in understanding what obstacles they face and what resources and strategies are needed to avoid “sacrificing” themselves and the older Americans they serve.

Methods: Case Study from North Carolina

This article is based on the first phase of a three phase developing case study conducted in central North Carolina. Phase one focuses on administrative and non-governmental advocacy groups that work with LTC communities including residents, families, and the direct care providers within these homes. We interviewed individuals who have an intimate understanding of resident needs, family concerns, and DCW challenges. Phase two includes a sample of administrators of LTC communities as well as the DCW providing hands-on care. Phase three focuses on community and home-based care workers that provide services and assistance to older adults living in the community. Similar questions are posed in each phase. We ask these workers about the overall impact of the epidemic on their provision of care as well as their key concerns.

We used a purposive sample, common in rapid qualitative appraisals (Vindrola-Padros and Vindrola-Padros 2017), that drew on Shenk’s professional network to recruit participants in a range of positions related to oversight of LTC communities and programs. We targeted higher-level regional administrators as well as aging specialists and advocates who typically have hands-on experience with residents, residents’ families, and staff. The themes generated from interviews are meant to capture how COVID-19 is affecting a specific sub-population, workers overseeing the provision of care for people living in congregate living communities, in one catchment area. While results may not be generalizable, they are expected to produce valid insights likely reflective of what is occurring in similar sites across the state and country.

We conducted in-depth, semi-structured web-based video interviews with eight participants, including two interviews with two participants (See Table 1). Six participants worked for an AAA. These included ombudsmen,² the director, the assistant director, and aging program coordinators. Federal funding allocated through the Older Americans Act (OAA) is filtered through the states to the regional Area Agencies on Aging, which oversee OAA funded programming. The other two participants were the executive director and volunteer board chair of a statewide advocacy group.

Collaboration and communication with stakeholders have proven essential when conducting rapid appraisals to ensure the data make its way to those able to direct policy and programming (Vindrola-Padros and Vindrola-Padros 2017). Therefore, we had staff members of the AAA as well as the advocacy organization review our interview protocols. The purpose of this was to ensure we were collecting useful data that could bolster their influence when negotiating policy, programming, and funding in relation to COVID-19.

Table 1. Participant Information

Participant #	Age	Credentials	Years of 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

Interviews were recorded, transcribed, and then coded using NVivo software. Coding went through three phases. The team used a grounded approach that avoided the use of pre-existing codes in order to ensure the narratives were driving the analysis. This is important when conducting research on a complex emergency with a population that has not been previously studied. Shenk reviewed all interviews and generated a master list of themes. This allowed for an inductive process driven by the narratives to capture participants’ unique perspectives (Bernard 2006). After Shenk generated initial codes, the other authors independently coded the transcripts in NVivo. We then compared these data for accuracy. There was near 100 percent agreement on data analysis. In an effort to maintain a rapid timeframe, data collection, analysis, and write-up have occurred simultaneously.

These data are sensitive because of the differential mortality and morbidity LTC communities face alongside the stigma associated with having an outbreak. In addition, the communities within which interviewees work are tightknit. Therefore, we do not provide potential identifiers of participants when presenting data, such as their position or title, to ensure anonymity and confidentiality. This research has IRB approval. Finally, limitations include the fact that we were not able to “get into” the buildings since they are still in lockdown, and we draw upon a small sample size.

Findings

At the time of these interviews in early June 2020, fifteen out of thirty NH in the catchment area reported COVID-19 positive residents, and four out of fifty-three AL communities had positive patients (Interviewee, 06/03/2020). In the state at this time, there were sixty-one outbreaks and ninety-nine deaths in residential care communities, which include AL and family care homes, and 108 outbreaks, and 605 deaths in NH (NCDHHS 2020). Not surprisingly, the data presented below demonstrate that safety of staff and residents was a key issue for nearly all interviewees. Participants were concerned about the lack of PPE and testing as well as inadequate staffing. In addition, these data point to concerns about 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 LTC communities were shuttered by the governor’s executive order on March 18, 2020.

Key Concern: The Unknown

It was common to hear AAA staff as well as NGO advocates express frustration and anxiety about not having a full picture of what was actually happening within LTC communities. One interviewee stated this 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.” Not letting family in is cited as problematic because family often provide an essential, if informal, level of oversight. Residents’ families are often advocates and actively involved in the caregiving of their loved ones.

Another interviewee also expressed frustration because they are now reliant on administrators and staff to update them on what is happening within the LTC communities they are tasked with overseeing. Some LTC administrators can be less than forthcoming, which can be related to fear of negative publicity. There may also be communication issues, as everyone trying to oversee and provide care during such a deadly epidemic are concerned first with the immediate need to ensure the health and safety of their residents and staff. Communicating with agency staff, families, and others can take a back seat. One participant 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?

Today, both facilities and NCDHHS are required to provide detailed reporting of COVID-19 cases and deaths within LTC communities. While advocates and the AAA staff considered this a positive outcome, they voiced concerns about the way cases were counted and the potential underreporting that was occurring, suggesting they are still struggling to know what is happening in congregate communities. One interviewee explained:

I'm still a little intrigued how they're [NCDHHS] getting the numbers. Anyway, I'm going to be really honest. So if you pull up the state list from DHHS, for COVID outbreaks, yea, 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.

To date, it is unclear how individual facilities and hospitals navigate counting COVID-19 cases. What is known, regardless of these documentation issues, is that safety in these communities is of concern, especially as the prevalence and incidence of COVID-19 cases continue to rise. Overall, there is 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 findings presented here focus on safety, including issues related to accessing PPE and infection control, testing which is alluded to above, and long-standing issues of staffing that have been exacerbated by the risk associated with care in congregate communities.

Safety: Testing

When asked whether AL communities or NH were being harder hit, one respondent explained that NH were reporting more outbreaks but acknowledged that there was still limited testing, especially in AL communities. At the time of this interview in early June, the epidemic had been spreading for three months, but testing was still a problem. This participant 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, 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....

They go 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.

Five of eight participants expressed frustration about the lack of availability of testing and pointed to the state having not made baseline testing mandatory in all LTC communities, although this changed in late June. When one participant was asked about what they knew 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 interviewee reiterated access to testing being an issue, in part, because the state has pushed for facilities to be responsible, not the government. They explained that while state officials claim testing is statewide, that's not the reality:

What we hear on the street is that 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.

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

Universal testing practices did change when Vice President Pence told governors on May 11 that all nursing home residents and staff should be tested for the coronavirus in the following two weeks (Brosseau 2020). On June 11, North Carolina ordered universal testing of all nursing home residents and staff. On June 25, it was reported that still hadn't happened (Brosseau 2020). By early August, universal testing began, but a backlog led to long delays (sometimes up to eight to ten days) to get test results and ALs and other congregate care communities are not yet included in this program.

Safety: PPE and Infection Control Strategies

PPE includes, but is not limited to, face masks, hand sanitizers, scrubs and booties, and face shields. Since the inception of the epidemic, PPE has been in high demand and short supply. While nursing homes are included on the priority list of institutions that should have access to PPE, they too suffered shortfalls. ALs were not included as priority communities, and home health care aides continue to have trouble procuring the necessary amount of 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 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, whether it was masks or gloves.

Interviewees suggest there is a connection between the lack of access to PPE and issues related to staffing. For front-line 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." LTC communities are not mandated by law to provide or stockpile PPE, and there has never been such a need in the past.

Participants 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 LTC communities as are being recorded. They relayed that even state surveyors expressed that these outbreaks were 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.” Later in the interview, this respondent discussed infection control in tandem with staffing because these issues are largely interdependent. Staff members are tasked with understanding and implementing infection control, which is not always a priority for underappreciated and underpaid staff:

...[M]aybe because of some of the highlights of COVID, I think they 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.

Safety: Staffing Issues

Staffing issues in LTC are deep-seated and were extensively documented prior to the epidemic. Research into this high turnover has pointed to low wages, limited benefits, the 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 interviewee stated:

...[I]n 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?

Interviewees are well versed in the lack of commitment to LTC work associated with the meager compensation structure.

At the same time, many LTC 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 has to work even if they are not feeling well. This can be problematic when confronting a virus with high infectivity rates. Workers that test positive for COVID-19 are required to take at least two weeks of leave, and most of it is unpaid. One respondent relayed:

Therefore, when we have the epidemic 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.”

This participant did not believe these workers had malice but rather were forced to make an impossible choice. They 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.”

Many providers also have multiple jobs to make ends meet. One participant explained:

...[B]ecause 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 care-give for people. So, there's so much, I wanna say, potential cross-contamination, even unknowing, that it's happening.

Beyond compensation, additional institutional challenges are exacerbated by the epidemic, at times putting DCW and residents at increased risk. For example, many congregate communities designate areas as “COVID floors” once an outbreak has been identified to quarantine residents. Under ideal conditions, staff attending to these designated areas would not rotate onto non-COVID floors. However, because of a shortage of staff, interviewees expressed concerns that some communities do not have that luxury. Similarly, in ALs that also house memory care units for people with dementia, it would be beneficial to segregate staff into units and not reassign them to different areas daily. One respondent explained:

And then you know how, 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 staying 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.

Memory care comes with its own unique concerns. Memory care units refer to stand-alone AL communities for people with dementia or units housed within ALs or nursing homes. 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 recommendation to social distance. All interviewees were particularly concerned about safety for these residents. One 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.

Another interviewee that works primarily with ALs, which includes the majority of memory care units, expressed the same concern:

They've [nursing homes] 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, they just say we're doing our best to keep them apart.

Two interviewees expressed 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 ALs making it unclear if the memory care units are more susceptible. The dearth of detailed data about those impacted are of concern to advocates and agency staff.

Meeting Physical Needs of Residents

All interviewees expressed concern about how COVID-19 has impacted the ability of workers to meet both the physical and social needs, including mental health, of residents. The data presented above suggest that this is already a strained workforce, and the epidemic is compounding that stress. How this translates into the care of residents is of concern to LTC advocates and career AAA staff. One interviewee explained the greatest challenges as:

...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 (epidemic). 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.

Of particular concern is how stress levels compounded by an epidemic might lead to residents not getting adequate care. The interviewee quoted above explains it as an already "volatile situation" that is going to potentially get much worse, and the residents will suffer. They further expressed, "Labor is short, everywhere.... What I think is that you end up with a very stressed workforce...and the additional stress and all of that rolls down to the resident." Another concern was the disruption that occurred when they relocated residents onto or off COVID-19 floors and even moved them to different communities. This posed a 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. ...I know 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.

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." Moving residents into and out of their "homes" affects their physical and mental health. In addition, it makes it difficult for families to connect with their loved ones and track what is happening.

Meeting Social and Mental Health Needs of Residents

A major concern expressed by every interviewee was social isolation. 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. By mid-June, there was not a plan in place to open these facilities. One interviewee explained:

Those individuals 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.

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

People living with dementia experience increased quality of life when they are provided with routine and engagement with loved ones and those familiar to them (Alonzo 2017). The loss of these connections is troublesome, as one interviewee explained:

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 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.

Three interviewees said that residents in memory care find it difficult to interact with workers who wear masks because they can't see their face, read their lips, or follow their expressions. One advocate explained that this can be disorienting and even lead to non-COVID, yet COVID-related death as a result of agitation, depression, and loss of appetite (see Shenk and Freidus 2020). They 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."

Discussion: Rapid Qualitative Appraisals and Impacting Policy and Guidelines

The purposes of this paper are to demonstrate the value of rapid qualitative assessments undertaken by applied anthropologists during complex health emergencies, as well as present important findings from a case study using this methodology with communities hard hit by COVID-19 in the United States. To summarize our data, we found that communication and transparency are crucial to ensure the health and well-being of both DCW and the residents in their care. When the executive order was enacted and the doors to these communities were shuttered, the ability for AAA staff, advocacy groups, surveyors, and family members and friends to access their residents was halted. While an important step in terms of infectious control, there was nothing in place 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 participants voiced concerns about both the physical and mental health of residents. Social isolation and the ways in which mental health causes physical deterioration were identified as needing immediate attention.

This project also demonstrates the utility of using rapid qualitative appraisals during a complex health emergency beyond the confines of the hospital. In particular, we demonstrate how the focus of methodological undertakings that arose during previous complex health emergencies can be modified or expanded based on the nature of the epidemic, the communities hardest hit, and the providers that are tasked with ensuring the safety and well-being of the vulnerable. Previous rapid qualitative appraisals proved essential in ending 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; Pathmanathan et al. 2014). COVID-19 has expanded the definition of "frontline" workers to include those working with older adults in congregate living communities because they have been so hard hit.

The purpose of this work is to report on the initial findings from such a project that will ensure the safety and quality of life of those living and working in congregate care. We can only accomplish this through partnerships and collaborations with aging service providers that include advocacy groups, AAA staff, DCW, and facility management. While this is only the initial phase, we are disseminating these data to a variety of stakeholders through various forms. For example, we presented initial findings to a non-profit group of aging service providers. In addition, we will share the data generated from all phases of this project as reports, presentations, published articles, and blogposts for use in policy development, as well as to inform guidelines for future disaster preparedness. One participant with substantial policy experience suggested that there was real opportunity to direct policy, especially after the initial outbreak and its insufficient response:

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?

Looking ahead to the near and more distant future, interviewees indicated the need not just for guidelines that may be implemented inconsistently but 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 health and well-being.

These data also provide knowledge about the policies that need immediate attention and suggest access to residents by families as well as regulatory staff and advocates is an essential first step. Advocates are currently working with the state DHHS to develop a plan for phased re-opening beginning with safe visitation. There is consensus that the social isolation of long-term closures has 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, is essential. In addition, the "unknown" reported on in this paper suggests the need for mandatory reporting and communication systems, or an "emergency outreach communication plan," that ensures the utmost transparency between AAA staff, advocacy groups, families and friends, with administrators and DCW in congregate living communities, especially in light of these long-term closures.

In addition, infection control protocols need to be reviewed and enforced in light of this particular outbreak. LTC communities must maintain a minimum sufficient stockpile of PPE in the event of a sustained outbreak, re-emergence, or new infectious disease outbreak. Many of these communities

have the resources to stockpile supplies but did not have them readily available when COVID-19 emerged. This 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 DCW 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. Paid sick leave should be mandatory.

We are dedicated to working with advocates and staff to shape and influence policy and improve the provision of LTC in the “new normal” as well as any future emergency, as we finalize data collection. To most effectively impact policy and programming, we hope to create a more robust, holistic understanding of the impact COVID-19 has had by drawing on a wider range of narratives in the on-going phases. The preliminary suggestions proposed thus far are meant to bolster the care and protection of older Americans living in LTC communities. The COVID-19 epidemic and the data generated here have helped to make visible long-standing fissures in older adult congregate care and provides a seminal moment to rethink how we value aging and what kinds of resources are needed to secure the well-being and dignity of this vulnerable population.

Acknowledgements

The authors would like to thank the area agency and long-term care staff, administrators, and advocates that so generously shared their time and insights with us during an ongoing epidemic. The authors would also like to thank the reviewers who provided helpful feedback in such a timely fashion, also during an ongoing epidemic.

Notes

¹Surveyors employed by the North Carolina Division of Health Service Regulation (NC DHSR) conduct regular inspections and investigate complaints against NH.

²Under 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 LTC communities. In our region, the ombudsmen are housed within the AAA.

³Federal CARES money enhances Medicaid payments, but it is restricted to NH and does not include AL unless they house Medicaid recipients. At the state level, they enhanced Medicaid and Medicare payments and provided direct appropriations.

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