RESPONSE TO COVID-19 IN LONG-TERM AND COMMUNITY-BASED CARE

FROM THE ALZHEIMER'S ASSOCIATION® DEMENTIA CARE PROVIDER ROUNDTABLE

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Response to COVID-19 in Long Term and Community Based Care from the Alzheimer's Association Dementia Care Provider Roundtable

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Abstract:

Mortality from COVID-19 has disproportionately affected persons over the age of 65, placing older Americans served by long-term and community based care—and the staff caring for them—at the forefront of the pandemic. The Alzheimer's Association Dementia Care Provider Roundtable (AADCPR) is a consortium of thought leaders from the dementia provider service continuum spanning assisted living, nursing homes, and home health and home care, whose mission is to promote the dissemination and adoption of evidence-based practice recommendations. Using the Alzheimer's Association's Emergency Preparedness Guidelines as a jumping off point, the AADCPR sought to provide insight into the creative ways in which their organizations have responded to the delivery of care during the pandemic, organized via the following five topics: caring for residents and families, caring for staff, seeking standardized guidance, the regulatory response, and preparing for ongoing and new challenges in a post-COVID-19-pandemic world. Lessons learned through COVID-19 will be essential for early and

effective future responses to emerging pathogens, and dementia care providers have much to add to these preparation and planning efforts.

Key Words: COVID-19, Nursing Home, Assisted Living, Home Health, Home Care, Dementia

In late January of 2020, a novel coronavirus, SARS-Cov-2, was identified as an international Public Health Emergency by the World Health Organization. Aided by significant percentages of asymptomatic carriers, it spread quickly around the world. Current estimates are that 83% of US COVID-19 deaths have occurred in persons over the age of 65, with most of these among people over the age of 85.[1] Millions of older Americans are served by long-term and community-based care, including estimates of 1.6 million in 15,600 nursing homes,[2] 825,000 in 30,200 assisted living facilities,[3] and 4.5 million receiving Medicare skilled home health care annually through 12,200 agencies,[4] and 13.9 million receiving home care.[5] While less than 1% of the US population lives in residential LTC, this population is more medically complex and at greater risk of complications due to COVID-19, factors no doubt contributing to fact that an estimated 35-40% of COVID-19 deaths are occurring within LTC settings.[6,7]

Despite the known disproportionate impact of COVID-19 on long-term and community-based care, facilities and organizations serving older adults have faced a patchwork of federal, state, and facility-level guidance, along with early and ongoing national setbacks relating to test and PPE availability. But while working with a high-risk, frail, and often-times cognitively impaired population while addressing COVID-19 has created special challenges, opportunities to advance care and awareness of long term and community-based care have arisen as well.

The Alzheimer's Association Dementia Care Provider Roundtable (AADCPR) is a consortium of thought leaders from the dementia provider service continuum spanning assisted living, nursing homes, and home health and home care. The mission of the AADCPR is to advance care and support services for people with Alzheimer's and related dementias (ADRD) and their care providers, both informal and formal, through the dissemination and adoption of evidence-based practice recommendations. In March of 2020, the Alzheimer's Association, in

collaboration with 36 long-term and community-based care organizations and associations, many of whom are AADCPR members, offered a set of emergency preparedness guidelines. Utilizing the Alzheimer's Association's Dementia Care Practice Recommendations (https://www.alz.org/professionals/professional-providers/dementia_care_practice_recommendations) as a foundation, the Coronavirus (COVID-19): Tips for Dementia Caregivers in Long-Term or Community-Based Settings (https://www.alz.org/professionals/professional-providers/coronavirus-covid-19-tips-for-dementia-caregivers0 offers a clearinghouse of CDC COVID-19 resources and provides specific recommendations and advice relating to six key areas of care provision during the pandemic when staffing shortages may occur, namely: illness prevention, maintaining the provision of person-centered care, keeping family and friends connected, assisting with eating and drinking, monitoring walking and unsafe wandering, and responding to dementia-related behaviors.

Using the emergency preparedness guidelines as a jumping off point, recent discussions of the AADCPR have included the creative ways in which their organizations have responded to the delivery of care in these areas, as well as ongoing and expected future challenges. The aim of this paper is to provide insight into the experience of being a LTC and community-based provider during the COVID-19 pandemic, which we present via the following five topic areas: caring for residents and families, caring for staff, seeking standardized guidance, the regulatory response, and preparing for ongoing and new challenges in a post-COVID-19-pandemic world.

Caring for Residents and Families

All congregate living situations create heightened risk of transmission and infection from COVID-19 due to population densities, indoor common use areas, and connections to the

"outside" community.[8] The RO for COVID-19 (the average number of people who will contract the virus from a single contagious person) is estimated to be 1.5-3.0, but this range rises to an RO of 5.0 to 14.0 in indoor spaces.[9,10] Viral particles spread readily from bodily secretions (e.g., saliva, nasal fluid, vomit, urine and stool), as well as soiled hands, talking, sneezing, and coughing[8]—all of which are nearly impossible to avoid when caring for older adults with varying levels of frailty, illness, and self-care ability.[11] A survey of a hospital room that housed a COVID-19 patient under quarantine found extensive contamination of the air and surfaces.[12] It is hardly surprising then that, in a study conducted in May of 2020, over 31% of a sample of 9,395 nursing homes had at least one documented case of COVID-19, with an average number of cases of 19.8 per facility and a range of 1 to 256.[13] Both larger facility size and urban location increased the likelihood of having a case.[13] A similar study also found more cases and deaths in facilities that were larger and had higher occupancy rates,[14] and a survey of home health care agencies found urban location was linked to having cared for a person with COVID-19.Shang [15]

Without sufficient testing, long-term and community-based organizations must work under the assumption that every person has COVID-19.[16] Residential care facilities have segregated COVID-19 positive residents as quickly as feasible from non-positive residents. Because few settings have airborne isolation rooms, some have erected barriers between residents in shared rooms.[11] Additional cleaning was instituted for common areas and surfaces more likely to carry fomites (sinks, toilets, etc.). Communal coffee and snack areas were reconfigured to offer single serving options. Residents dined alone in their rooms and their group activities were reduced or eliminated, though some facilities were able to create multiple smaller dining and activity areas. To minimize community-based transmission, visitors were tightly restricted, only the most essential contract workers were permitted inside (e.g. Hospice end-of-

life care), and telehealth was promoted as much as possible. Most communities conducted symptom screens and temperature checks on anyone entering the community, including staff and other healthcare providers. Staff members who tested positive or who were potentially exposed underwent a minimum two-week quarantine. Especially in home health care, workers often provide care to persons in more than one facility or type of setting. For example, staff at most home health care agencies (79%) provide care for persons living in assisted living communities, and around a third care for persons in nursing homes.[15] Some companies therefore tried to limit the number of facilities that any one worker could serve.[23]

As straightforward as the above measures may seem, they take on added practical, emotional, clinical, and ethical challenges when applied to long-term and community-based care. Persons with cognitive impairment do not adjust as readily to changes in their routines, from relatively simple ones like the need to wear a mask and avoid touching one's face, to more severe efforts like not being able to go shopping, leave their homes or rooms, have visitors, or share meals with friends. The emergency preparedness guidelines specifically address these issues, for example recommending that staff sit and talk with persons with dementia during mealtimes, in order to improve intake and help the person maintain strength.

Persons served by long-term and community-based care may not have access to, comprehend, or retain public health explanations or their necessity, leading to confusion, higher exposure risk for themselves and their care providers and, among persons with dementia, aggression, exit seeking, and agitation.[24] Even when careful guidance is provided, persons with dementia/cognitive impairment may have difficulty following through with the steps needed to employ that guidance in everyday life. In assisted living communities alone, more than 70% have some degree of cognitive impairment and 42% have moderate or severe dementia.[25]

The long-term and community-based care organizations that are a part of the AADCPR are dedicated to providing person centered care, in which care focuses on elders' emotional needs and care preferences and is relationship- rather than task-centered. In the context of COVID-19, this philosophy manifested in multiple ways, many of which are touched on in the emergency preparedness guidelines. Some of these: methods for more easily communicating resident preferences and ideas to direct care staff so that engagement could be increased as staff move in and out of the resident's room, providing residents with kits filled with activity resources to encourage independent activity in the room, increased use of in-house television programming to provide activity and engagement remotely, frequent contact with families through staff-facilitated virtual video visits, providing safe spaces for walking and regular exercise, and doubling down on the tools and strategies residential care settings had invested in over the years, such as life story, music and memory, Montessori-based activities, and behavioral support planning. Support provided to families and clients included creating COVID-19-dedicated webpages offering CDC and other guidance, and making educational videos about the virus and infection control.

Social distancing and isolation are some of the most difficult aspects of long-term and community-based care during the pandemic, as the essential roles of informal support networks and care staff in providing practical and emotional support are undermined.[26] In ordinary times, social activities are a large part of the services provided in residential care settings, and are also important to recipients of home health care and home care. Elders with cognitive impairment may not understand why their loved ones are no longer coming or can only be seen through electronic means or a window.[23,24] Restrictions on family visits may be hardest in settings such as assisted living communities, where families play such a vital role in monitoring resident well-

being and providing everyday care.[27,28] Persons utilizing assisted living, home health care, and home care faced restrictions in attending church and going on family outings or shopping.[27] Family members too are affected by the inability to touch and hug their loved ones, especially during a time of heightened anxiety over their loved one's health.[29] Telephone or video calls were used to help keep families and friends connected. Not all facilities or families have the resources in terms of equipment and training to rapidly upscale these options, and electronic communications may not be a good fit for all elders.[20] A survey of home health care agencies found that 17% had no telehealth capacity, and while 58% had increased their use of telehealth, these efforts were limited by clients with no or poor phone signal or Wi-Fi connection.[15] Many states provided grants to facilitate the purchase of ipads and other technologies to support virtual visits.

Difficulties related to telehealth are not the only issues that have complicated the clinical care of persons with cognitive impairment or dementia during the COVID-19 pandemic. Even amongst cognitively intact persons, the initial symptoms of COVID-19 can be subtle and difficult to distinguish from the common cold, seasonal flu, sinus infection, or even a simple case of pink eye. The added difficulties for persons with cognitive impairment are only heightened when formal and informal caregivers have less interpersonal access to them. A reduced ability to report symptoms may partially explain why persons with dementia have higher rates of hospitalization even after controlling for morbidities.[30]

Compounding this barrier to care further is the frequency with which older frail persons may evince nontraditional COVID-19 symptoms. Recent case studies suggests that, in older COVID-19 positive patients with cognitive decline, a sudden change in mental status (rigidity, alogia, abulia, etc.) may belie critical disease progression in the absence of significant respiratory

markers,[31] potentially linked to hypoxia.[32] Referring to this as COVID-19 delirium, the authors suggest that mental status change be added to the list of testing criteria. In the meantime, hospital doctors and triage nurses may not be aware of the importance of neuropsychiatric findings in the population. According to some of the AADCPR members, when LTC staff would recognize these changes and bring the person to the ER, they received "blank stares." The person was deemed asymptomatic according to existing symptom lists and sent back to their facility, to decline rapidly and in some cases, die the following day or days of COVID-19.

These considerations raise difficult ethical conundrums in evaluating the benefits and risks of policies instated in response to COVID-19. As Barnett and Grabowski (2020) point out, long-term and community-based care are fundamentally different from hospitals in that the care and services are being provided in the place the care recipient calls home.[20] The emotional and physical consequences resulting from prolonged distancing and isolation from staff, family, fellow residents, neighbors, church friends, and treasured activities are not known, but must realistically be seen as a trade-off for the immediate increased safety of lower COVID-19 risk. Loneliness and social isolation are critical issues for older Americans even without the added social isolation required for COVID infection control.[33] On a person-to-person basis, there are ethical implications for care resulting from residents being unable to see families, experiencing declines in function due to inactivity, and living their days with diminished meaning, joy, and satisfaction. This is particularly true for those with dementia who cannot understand why their lives are so altered. The effects of stress caused by isolation and disruption of routine could even increase vulnerability to infection. Furthermore, these effects are cumulative; the longer the precautions remain in place, the greater the incidence and severity of the changes in mood, function, and overall health and well-being.

As these competing risks are weighed, the relative risks to different groups of people must also be taken into account. For example, having a greater percentage of African American residents in a nursing home has been found in two studies to relate to higher rates of infection,[13] even after controlling for such factors as facility size, ownership, and years of operation.[14] Wilson (2020) describes the trade-offs occurring as a result of lockdowns in residential care settings as a disability human rights issue, and argues that any restrictions applied should be as "narrow and limited as possible," known to actually make persons with mental and cognitive impairments safer, and sufficiently flexible to accommodate individual needs and abilities in complying.[17]

Caring for Staff

Millions of Americans work in long-term and community-based care. In residential care settings alone, care is provided to 2.16 million persons by 1.24 million staff.[18] Anything that impacts staffing levels or morale will therefore impact the care that these older, frail persons and their families depend on.

Even prior to the pandemic, large daily staffing fluctuations, high staff turnover, low weekend staffing, and low staffing levels in general characterize the long-term and community-based care industry.[19-21] Staffing issues during the pandemic varied depending upon the setting and facility, with some facing staffing shortages and others having to turn to furloughs. Some staff left due to fears of contracting the virus themselves, or giving it to a loved one. In response, some long-term care communities arranged for temporary housing near the worksite .[34] Insufficient testing and PPE early in the pandemic increased these fears and frustrations, including the fact that non-reusable PPE were deemed re-usable by the CDC.[15] Long-term and community-based care organizations have had to put extra resources toward tracking PPE

inventory, training staff on their effective use and handling, and negotiating with suppliers and public health officials for scarce equipment that tended to be prioritized for acute care hospitals.[11] Frequent changes in the types of PPE that were available necessitated extra training.[22] A survey of home health care agencies found that most had put new procedures in place for PPE use.[15] Shortages were so significant that some facilities had to enlist volunteers to hand sew gowns and masks for them.[15] National and local-level testing shortages also created stress. In one survey, only 12% of home health care agencies reported that they had the capacity to test clients, despite 61% having already cared for a person with suspected or confirmed COVID-19.[15] Of course, staffing levels were further affected by COVID-19-related sick leave, quarantining, childcare needs when schools went on lockdown, and the difficulty of attracting new hires in the midst of a pandemic to jobs already known for their low salaries and demanding work environment.[26]

For some, staff furloughs have been more common than shortages. A recent survey of home health care found that most (69%) had experienced a decrease in clients, primarily due to hospitals placing limits on surgeries, and families being reluctant to seek outside services due to fear of the virus.[15] There are indications that settings in urban areas saw more staff shortages, while those in less urban areas experienced more furloughs, but more information is needed on this pattern.[15] Work hours were also shifted in creative ways. For example, as medical offices saw reduced patient loads, staff with jobs at both a medical office and a long-term and community-based setting were able to increase their hours for the latter.[15] Nursing homes may also have hired away assisted living community personal care attendants, as they make on average two dollars less an hour than certified nursing assistants.[35]

But while staff morale and anxiety had major impacts on retaining staff, they also affected the well-being of the staff who stayed. Fear of the virus for themselves and their loved ones, grief at the loss of residents/clients and staff to COVID-19, anxiety that they could be the one to bring COVID to their workplace, continuous turmoil at work due to changes in personnel and infection control procedures, and the national and local level uncertainties of the virus's effects on hospital access and economic devastation combined to create a situation of unparalleled anxiety for persons working in LTC. A recent meta-analysis of thirteen studies found concerning levels of depression, anxiety, and insomnia among health care workers dealing with the pandemic, with higher levels among frontline workers and women.[36] But while hospital workers were being recognized worldwide as heroes, including nightly rounds of applause in some cities, staff doing equally demanding and risky work in long-term and community-based care felt invisible, ignored, and at times even blamed for being infection hotspots.

Efforts to support staff well-being have been central to the COVID-19 response in long-term and community-based care. An important initial tool was education to dispel myths and provide knowledge and tools to minimize theirs and others' risk.[15,26] This included publicly accessible websites for families and staff providing curated resources specific to the care of older adults. As the pandemic and its emotional impacts progressed, organizations responded more directly to these needs. For example, a large multinational home care organization set up a 24-hour support line staff by mental health professionals to help with the emotional impact. Employee assistance programs created in-house portals with information and encouragement to engage in self-care and stress management. Support groups and one-on-one mental health first aid services were also offered. Finally, organizations sought ways to recognize the heroic efforts of staff through appreciation pay, sick pay, food support programs and free meals. All the

members of AADCPR were keenly aware that care providers cannot provide high quality care when they themselves are stressed out beyond their own capacity, and that health staff are the foundation of good person-centered care.

Seeking Standardized Guidance and Support

Long-term and community-based care organizations are no strangers to infectious disease and even outbreaks, for example from foodborne illness, norovirus, seasonal flu, and other pathogens, but the size and scope of the international COVID-19 pandemic, combined with the special susceptibility of these settings, required new levels of guidance and coordination, much of which was and remains lacking. The CDC has changed PPE and other guidance recommendations throughout the pandemic based on need and supplies. The first formal CDC guidelines for nursing homes were released in late April of 2020, and they have been updated frequently since.

For the most part, organizations were left to respond to a patchwork of changing and sometimes contradictory state and local level guidelines. Larger organizations created their own protocols and targeted response teams (e.g., centralized PPE supply, telecommunications, infection control), which smaller agencies did not have the resource expertise, or manpower to put together. Confusion with respect to these guidelines was matched by the confusion families felt, especially when families from out-of-state assumed that the guidelines in the state where their loved one resided would align with their own state. Long-term and community-based providers also have differing levels of expertise on-hand in order to decipher, synthesize, and apply existing guidelines. For example, nursing homes are required to have a medical director, but relatively few assisted living communities even have RNs.[19,37] Even at the state level, infection control guidance and support for nursing homes varies widely. Though most (92%)

include mention of nursing homes in their healthcare-associated infection (HAI) control plans, only a little over half (57%) of plans offer nursing home relevant training materials on HAI reduction, and the most common of those pertained to antibiotic stewardship.[21] The illness prevention, resource links, and other components of the emergency preparedness guidelines were offered as resources to help fill these gaps.

The Regulatory Response

Although we recognize that regulatory agencies were themselves responding to a rapidly evolving situation, more flexibility and support from these sectors could have reduced stress while directing existing energies and resources in more targeted ways. For example, fines were levied for nursing homes, when using directed plans of correction and directed in-services, including sending experts to collaborate on specific issues, would have gone further in supporting those on the absolute front lines of COVID-19. This seems all the more appropriate given that traditional quality metrics, such as a nursing home's star rating on Nursing Home Compare or whether they had had a prior infection infraction, were found to be unrelated to whether a facility had a case or the size of its outbreak.[13] In a study with a smaller sample of nursing homes, those with 5-star ratings were less likely to have had COVID-19 cases and deaths, but there were no differences between those with ratings of 1 to 4.[14] Of course, assisted living is not routinely regulated by the federal government, which gives the state fewer tools to encourage assisted living communities to meet the needs of residents, families, and staff during a pandemic. A review of state regulation of assisted living communities found that only 13 states (26%) had an infection control program, a lack of focus that may have had important impacts on PPE stockpiles and other components of high quality infection control.[11,27]

Preparing for Ongoing and New Challenges in a Post-COVID-19-Pandemic World

Nursing homes, assisted living communities, home health care, and home care tend not to be the first options that jump to mind in discussions regarding health care, but as Barnett and Grabowski (2020) state, "they are a critical safety net for frail older adults and part of the fabric of our society."[20] Statistics indicate that, eventually, 44% of men and 58% of women will use the services of a nursing home.[38] Disasters and pandemics will also continue to occur, and so we must find a way to increase the resilience of these settings to future unexpected events.[39] To the degree that large residential care communities are more vulnerable to pathogen spread, a greater number of smaller settings might be preferable, as might a higher proportion of single rooms.[40] The Green House small home model[41] is an evidence-based approach that has documented the positive effects of smaller care settings on factors such as social engagement,[42] and studies also demonstrate resident preference for single rooms.[43] Placing limits on the number of settings that a given care provider can service might also lower the risk of spread, as might dedicating nursing homes to long-stay residents while creating separate nursing homes focused on post-acute care. This would require a restructuring of payment systems, but it would alleviate the current situation in which nursing homes are facing bankruptcy due to decreased Medicare revenue at the same time as they face higher costs of care for their long-stay residents and lower Medicaid reimbursement levels.[16]

Clearly, PPE, test availability, infection control guidance, and staffing levels for long-term and community-based settings should be top priority in the continued response and future response to any novel virus that appears to create a special burden for older adults.[20] This includes delineating symptom profiles for different ages, and recognizing that the care providers working with older adult and cognitively impaired persons are likely to be the most expert in

detecting subtle changes that might indicate the existence of a serious disease process. State and federal agencies should review existing required infection control and prevention training, especially for assisted living communities, home health care, and home care, where less overall training is required.[21,27] As Pillemer et al (2020) put it, COVID-19 in long-term and community-based care should be considered, and continue to be treated, as a critical sub-outbreak within the broader expanse of the pandemic.[34] Only by discerning the unique rates and patterns of disease and transmission occurring within these highest-risk settings can the community-wide infection be controlled.

The courage of persons who return to work day after day to care for the frailest in our society, knowing they may be infected with a novel virus and may transmit it to a loved one, should never again go unappreciated. Many of these workers have underlying health conditions themselves, and we are learning more daily how death is not the only negative health outcome of COVID-19. Hazard pay for first responders and hospital workers should extend to long-term and community-based care nursing and staff,[23] as should short-term programs to quickly supplement the workforce where it is needed.[16]

Of course, accurate data is needed to support and refine each of the recommendations made here. In the case of COVID-19, this may present a problem because, since the beginning of the pandemic, there has been wide variation in disease reporting formats, case definitions, and update frequencies.[44] Some states report only cases once they meet a certain minimum threshold, or only in settings of a certain size. Even under the more recent federal reporting requirements, residential care communities are not required to report cases and deaths that took place before May—the critical early months of the outbreak in the US.[44] There is understandable concern that a swiss cheese of data collection may present a barrier to future longitudinal and national

analyses. As Smith et al. (2020) write, we must ensure "the accuracy and integrity of statistical data collection and analysis to provide the raw material for clinical decision making and policy making not adulterated by political or financial agendas."[45]

Conclusion

At the time of this writing, rates of COVID-19 continue to increase across the nation, but hopes for a vaccine in the near future are also high. As such, it is appropriate to recognize areas of continuing, real-time concern while also considering areas of opportunity and growth. For example, the immense toll COVID-19 has taken and continues to take on frail elders, their families, and the care providers who serve them, is still increasing, not diminishing. Ethical decisions weighing the risks and benefits of continued isolation to prevent spread versus opening up in order to prevent the myriad negative effects that isolation creates are happening daily across the country and will no doubt be part of an ongoing conversation for providers, families, and society. As the COVID threat persists and precautions remain in place, we must grapple with whether or not we help or hurt through the limitations we place on the lives of elders to keep them safe. Similarly, the effects on staff now and in the future must be recognized. Even as we figure out how to better safeguard staff health and safety, we must put more resources into supporting mental health due to the chronic stress staff experience while working at the epicenter of COVID-19 disease and death impact.

Areas of potential growth have also opened as a consequence of the coronavirus pandemic. While long-term and community-based care providers have always seen themselves as a part of the healthcare continuum, the health care system and society generally have not always done so. COVID-19 has helped to shine a light on the importance of long-term and community-based care in the health and well-being of older adults and those with cognitive

impairment. As is true for broader sectors of society as well, elder care providers have a new appreciation for the value of communication technologies for video conferencing, telehealth, and connecting clients with distant family and friends. We expect these approaches not only to continue, but to evolve in ways that make them simpler for older persons and persons with physical and cognitive deficits to benefit from. Issues around regulatory oversight, public funding, infection control guidance and local support for long-term and community-based providers have come to the fore with a rapidity and relevance that only a crisis of the magnitude of COVID-19 could have engendered. As one example, a national provider association dedicated to advancing policies, practices and research to support healthy aging, recently held a legislative action day based on a platform of requests from long-term care providers. The AADCPR welcomes the opportunity to engage in and contribute to these discussions and solutions. Finally, as deadly as COVID-19 is, a future pandemic could be more deadly still. The ongoing experiences and lessons learned through COVID-19 will be essential for early and effective future responses to emerging pathogens. Long-term and community-based care providers have much to add to these preparation and planning efforts.

Conflict of Interest: The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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