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COVID-19 in Assisted Living: Protecting a Critical Long-Term Care Resource

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A B S T R A C T

The COVID-19 pandemic had a big impact on assisted living (AL), a vital setting in long-term care (LTC). Understanding the strengths and opportunities for improvement through practice, policy, and research are essential for AL to be prepared for the next pandemic and other challenges. AL communities experienced the pandemic in unique ways, because of varying regulatory environments, differences in familiarity with using and procuring personal protective equipment not typically used in AL (such as N95 masks), loss of family involvement, the homelike environment, and lower levels of licensed clinical staff. Being state rather than federally regulated, much less national data are available about the COVID-19 experience in AL. This article reviews what is known about cases and deaths, infection control, and the impact on residents and staff. For each, we suggest actions that could be taken and link them to the Assisted Living Workgroup Report (ALW) recommendations. Using the Center for Excellence in Assisted Living (CEAL) 15-year ALW report, we also review which of these recommendations have and have not been implemented by states in the preceding decade and half, and how their presence or absence may have affected AL pandemic preparedness. Finally, we provide suggestions for policy, practice, and research moving forward, including improving state-level reporting, staff vaccine requirements, staff training and work-life, levels of research-provider partnerships, dissemination of research, and uptake of a holistic model of care for AL.

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SARS-CoV-2 (COVID-19) is attributed to more than 1,000,000 US deaths, of which 75% were among persons aged 65 years and older.[1] Estimates are that assisted living (AL) saw nearly 30,000 resident COVID-19 deaths between January 2020 and March 2021.[2] AL is a vital part of long-term care (LTC) in the United States and serves 918,700 residents in 31,400 AL communities.[3] AL began decades ago with the idea of person-centered care (PCC) and with a population much healthier than today's AL residents.[4] The medical complexity, frailty, cognitive, and functional status of this population places them at high COVID-19 risk.

Understanding the full impact of the pandemic on AL is important but challenging. AL is regulated by state laws and must follow state infection control prevention guidelines, which vary in terms of data reporting, protective restrictions, oversight, and assistance. Nevertheless, it is essential that the AL COVID-19 experience be understood to prepare for future emergencies.

Examinations of COVID-19 in AL must take into account the unique features of AL communities.[5] Approximately 40% of older adults in residential LTC choose AL communities,[3] which range widely in size, staffing, case mix, services offered, and policies.[6] Between 2007 and 2017, there were 4700 new AL communities, making AL the fastest-growing sector of LTC.[7] AL has become popular because of the

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emphasis on individualism, choice, and social engagement opportunities through a care model that integrates social and medical components. AL residents require assistance with activities of daily living, such as medication management, using the bathroom (49%), dressing (62%), bathing (77%), walking (69%), eating (26%), and transferring (51%).[8] More than 60% of AL residents require assistance with 3 or more activities of daily living and 27% need assistance with 2 or more activities of daily living. More than 70% are cognitively impaired, and 42% have moderate or severe dementia.[9] Almost 50% of residents have 2 or 3 chronic conditions, including 55% with hypertension and almost a third with depression.[8]

The Center for Excellence in Assisted Living (CEAL) is a diverse collaborative of national organizations working together to promote excellence in AL. CEAL was created in 2003 by the Assisted Living Workgroup (ALW), a national initiative of nearly 50 organizations tasked by the US Senate Special Committee on Aging to develop AL consensus recommendations. The resulting 110 ALW recommendations encompass (1) accountability and oversight, (2) direct care services, (3) medication management, (4) operations, (5) resident rights, (6) staffing, and (7) affordability. In 2018, CEAL revisited 90 of the 110 recommendations, determining which had been implemented by states.[10] Although developed well before COVID-19, many of the recommendations could have influenced the ability of states and ALs to respond to the pandemic in a more timely and effective manner. This article describes what is known so far about case and death rates, infection control, and impacts on residents and staff in AL during the COVID pandemic. For each, we present recommendations based on the ALW guidelines and the 15-year CEAL report, with the hope of better preparing states and the AL sector for future emergencies (see Table 1).

Cases and Deaths

The exact number of COVID-19 cases and deaths within AL will likely never be known. As of October 2020, only 39 states were publicly reporting limited COVID-19 AL resident data.[11] Although ALs were required to report staff cases and deaths to the Occupational, Safety, and Health Administration (OSHA),[12] very few states were publicly reporting staff rates.[11] Based on CMS claims data, the AL all-cause mortality rate during the pandemic increased by 17% overall and by 24% in the 10 states with the highest community spread. These rates are comparable to those seen in NHs.[13] Knowing cases and numbers in real time means that states and the Centers for Disease Control and Prevention (CDC) were quickly made aware of hot spots and could respond accordingly. The National Center for Health Statistics (NCHS) estimates that between January 2020 and March 2021, there were 169,074 cases, 40,100 hospitalizations, and 29,736 deaths due to COVID-19 in AL, whereas estimates for AL staff include 147,363 cases, 3,753 hospitalizations, and 591 deaths.[1]

Future Steps and the ALW Recommendations

The ALW recommendation *A0.11—Measure of Resident Outcomes* is especially important to understanding cases, deaths, hospitalizations, and other important resident outcomes during a pandemic and beyond. For infectious diseases like COVID-19 or influenza, states can facilitate data collection by using measures from the CDC's health care–associated infection tracking system, the National Healthcare Safety Network (NHSN). Reporting should be efficient and nonduplicative, and cost assistance should be considered. Future state data collection initiatives can learn from states that have implemented programs to collect AL data and use measures already in use or endorsed by the National Quality Forum (NQF).[14]

Infection Control and Preparedness

AL COVID-19 infection control and preparedness was hampered by inadequate state and federal support, low staffing levels (because of prepandemic workforce shortages and the pandemic), and limited staff clinical expertise and medical oversight. AL faced ongoing challenges obtaining sufficient personal protective equipment (PPE) and testing supplies while trying to implement conflicting regulations and guidance from OSHA, CDC, and local and state health departments. States were not aligned in their requirements for testing in AL, creating difficulties for providers operating in more than 1 state. Larger AL organizations had the ability to create their own protocols, centralized PPE supplies, and targeted response teams,[15] but more than 60% of ALs have 25 or fewer beds, giving them much less PPE purchasing power and storage capacity.[3] NCHS reported that 40% of ALs had PPE shortages, including N95 respirators.[2]

Over time, NHs received billions in federal assistance for testing, PPE, and staff shortages, but initially assistance to AL was limited to those ALs serving residents that accept the Medicaid waiver, which includes roughly 16% of AL residents.[16-18] Without additional resources and supports, many ALs did not have the staff or resources to respond to the practically overnight need to maintain and monitor PPE supply and use, identify cases through regular testing, make up for staff absences because of quarantine, illness, and child care or family obligations, assist with telehealth appointments or virtual family and friend visits, and complete tasks usually done by family and friends who were no longer permitted to visit.[19]

Lack of medical oversight likely exacerbated these pandemic challenges. Not all ALs have medical directors and, depending on the regulations of each state, registered nurse clinical oversight may not be required either. Older persons with multiple chronic conditions often demonstrate uncommon and more difficult to identify COVID-19 symptoms, including a sudden change in cognitive or mental status, now referred to as COVID-19 delirium.[20]

The greater use of single rooms and apartments in AL made isolating cases easier, likely slowing spread,[21] but AL workers often provide care to persons in more than 1 community or type of setting,[22] increasing the risk of spread between high-risk sites.[23] To combat this, some AL communities tried to limit the number of communities served by any 1 worker, although this likely increased strain on staffing levels.[24]

The inclusion of AL in the CDC's Federal Pharmacy Partnership for Long-Term Care ensured priority vaccine access to AL residents and staff. The CDC worked closely with stakeholders providing education, support, and information to LTC settings to ensure the program's success. This early access to vaccines allowed many ALs to resume family visits and other "normal" activities.

Future Steps and the ALW Recommendations

AL is no stranger to infectious disease and outbreaks from foodborne illness, norovirus, seasonal flu, and other pathogens. By 2018, 44 states had emergency and disaster preparedness plan requirements (Operations 0.04). Although 31 states had AL infection control policies in 2020, only 10 included language relating to epidemics and only 6 described resident isolation practices.[25] Infection control and emergency preparedness plans therefore need to be revisited to cover all possible emergencies and disasters. Revised plans should include complete infection control practices, PPE use training for all staff, access to supplies, dealing with staffing shortages, stronger partnerships with local health departments, the temporary relaxation of administrative requirements,[26] conducting surveillance, and even staff transportation and temporary adjacent housing.[11] Likewise, state

Table 1
Summary of Future Steps and Recommendations

Topic	Assisted Living Workgroup (ALW) Recommendations	Future Steps
Cases and Deaths	Accountability and Oversight AO.11: Measure of resident outcomes	1. States could facilitate data collection by using already existing tracking like the CDC's National Healthcare Safety Network (NHSN) 2. Reporting outcomes or other information should not be duplicative 3. Cost assistance should be considered to relieve any monetary burden on AL for collecting or reporting data 4. If possible, measures should already be in use or endorsed by the National Quality Forum (NQF)
Infection Control and Preparedness	Operations O.04: Emergency and disaster preparedness plans	1. All states should have infection control policies in place for AL 2. Individual ALs should have internal policies that can expand on these topics related to the individual AL 3. All policies should include the following: a. Language related to epidemics b. All policies should describe resident isolation practices c. PPE use and training for all staff d. Access to supplies e. Dealing with staffing shortages f. How to form and strengthen partnerships with local health departments g. Temporary relaxation of administrative requirements h. Conducting surveillance i. Staff transportation j. Temporary adjacent housing for staff 4. State, local, and federal organizations overseeing emergency preparedness need to be educating about AL including types of residents served and how best to communicate with AL communities during crises
	Staffing S.09: Vaccinations	1. ALs should consider a clinician (MD, DO, NP, or PA) on the care team or a medical director (this does not mean a full-time staff member, it could be a few hours a week and should be based on acuity and needs of residents) 2. All staff and volunteers be tested for and vaccinated against communicable diseases
Effect on Residents	Resident Rights R.11: Resident rights and provider responsibilities	1. Essential Caregiver programs should be in every state and include AL (eg, Rhode Island's program) 2. Essential caregivers should add onto care and not replace staff 3. Essential Caregivers should follow the same vaccination and PPE requirements of paid staff.
	Operations O.09: Activities, and O.10: Activities for special care residents	1. Creative ideas for activities that were successful during social distancing should be included in emergency preparedness plans for AL and at the state level
Effect on Staff	Staffing S.10: Discussion of job descriptions with potential employees, and S.13: Recruitment and retention	1. States should provide guidelines for enhancing staff training 2. States should provide guidance valuing staff
	Staffing S.12: Staff Recruitment and retention: management practices	1. States should provide guidance and ALs should work on implementing or providing the following to staff: a. High-quality leadership b. A respectful organizational culture c. Improved human resource policies (wages, benefits, flexibility, training, career ladders, scheduling, etc) d. Motivational work organizations and care practices e. Adequate staffing ratios based on resident acuity

and local organizations overseeing emergency preparedness need to be educated about what AL is, who they serve, and how best to interact with AL communities during crises.

Access to clinical staff is vital for AL, especially for infection control. All ALs should consider having a medical doctor, doctor of osteopathy, nurse practitioner, or physician assistant on their care team, and should assess their need for a medical director to support clinical decisions. This need will vary greatly by resident acuity and availability of clinical staff in the area. Some ALs may need a full-time clinical staff whereas others may only need to contract for a limited number of hours each month. Residents should still have a choice in their primary care physician and if they prefer going out of the building for care. Ongoing infection control education is important for all staff. The ALW recommendation (staffing) S.09 recommends all staff and volunteers be tested for and vaccinated against communicable diseases (consistent with current CDC and OSHA requirements), and the CEAL Board continues to support this recommendation. Despite significant efforts to reduce misinformation-related vaccine hesitancy around COVID-19, this remains a major problem in LTC, including staff leaving their jobs rather than be vaccinated. Providers report that incentives have not always worked; thus, research is needed on effective methods to address hesitancy.

Effect on Residents

Unlike other LTC settings, families assume a major role in care for residents in AL.[27,28] When asked to describe their social networks, 99% of AL residents included at least 1 family member, 66% of the network was family, and the strongest predictor of resident well-being was the proportion of family in one's network.[29] In addition to socialization, families contribute to monitoring, medical supplies, communicating with staff, and assisting with hands-on care. Residents benefit from engagement within the AL via personal care assistants, dietary staff, housekeeping, maintenance and transportation staff, volunteers, and other residents, whereas external engagement comes from hairdressers, manicurists, music and pet therapists, and family and friends.[30] COVID required the banning of most of these key engagement partners, leading to a "second pandemic" of anxiety, loneliness, depression, isolation, and hastening declines.[31,32]

Most persons living with cognitive impairment or dementia do not adjust readily to changes in routines, such as mask wearing, room lockdowns, and missing group activities, as well as visits and mealtimes with friends and family.[33] They also often have greater difficulty comprehending and retaining explanations for these changes, leading to confusion, "noncompliance," and agitation.[33] In a March 2020 case

study of an AL setting, staff noted more forgetfulness, less basic hygiene, disrupted sleep, more napping, mood changes, cognitive declines, and marked declines in food intake.[34] Isolation affected family members too, especially during a time of such heightened anxiety. Remote communications helped, but required additional time and resources, and not all families and residents had access to or were a good fit for these options.[35]

In ordinary and extraordinary times, the features of AL exerting the greatest impact on residents' satisfaction include the quality of their daily life, their relationships, their level of control, and the degree to which they feel at home, all of which are foundational to PCC.[36] In interviews with ALs practicing PCC prior to the COVID-19 crisis, PCC was one of the primary practices "guiding and sustaining them through the crisis," in part because staff were better prepared to fill the roles of family when visitation was prohibited, reducing boredom and loneliness.[37] Knowing each resident well also helped when a greater focus had to be placed on individual over group activities. This has caused professionals to rethink what constitutes quality activities and life enrichment driven by individual interests and preferences.

Future Steps and the ALW Recommendations

There are ethical trade-offs when, in the name of protection, residents experience decline in function and live their potentially few remaining days with diminished meaning, joy, and connection.[38] Infection control policies in AL should and did vary over time as risk levels changed, but questions relating to the risks and benefits of lockdowns and other procedures require further investigation as a disability human rights issue.[38] Similarly, to the extent that AL is built around uncompensated family labor, families are not visitors but essential care partners integral to AL's existence.[39] During COVID, some states enacted Essential Caregiver laws or programs, allowing 1 or 2 family members or close friends to visit even during restricted visitation. Essential Caregiver programs promote residents' rights and well-being (as per R.11 Resident Rights and Provider Responsibilities), but families need early and clear communication about such programs. These programs must be created in such a way that Essential Care adds onto, rather than replaces, staff care. Essential caregivers should also be required to follow the same vaccine and PPE requirements as staff. All staff should recognize that every interaction with a resident presents an opportunity for resident socialization and connection.[39] The ALW recommendations O.09 Activities, and O.10 Activities for Special Care Residents, both of which many states had implemented, still required modifications that enable social distancing. Creative ideas for activities that were successful during the pandemic should be included in emergency preparedness plans.

Effect on Staff

Throughout the pandemic, LTC staff took heroic measures to care for residents. Many isolated from their own families, filled in extra shifts, and found creative ways to keep residents socially and cognitively engaged. Providers went to great lengths to protect staff, including purchasing PPE despite increased costs and finding PPE replacements when proper supplies were unavailable (eg, ponchos). Some staff left or retired early from LTC because of the stress of the pandemic. Those who remain are forever impacted by the experience. All of LTC suffers historically from large daily staffing fluctuations, high staff turnover, and low weekend staffing.[40] A staggering 96% of ALs are short-staffed.[41] Within the LTC direct care workforce, turnover rates fall between 40% and 60%.[7] During the pandemic, some ALs furloughed staff whereas others faced severe shortages because of staff quarantines, staff illness, staff burnout, family responsibilities (eg, remote schooling), fear of getting the virus and becoming a vector (heightened by insufficient PPE), and the difficulty of hiring during a pandemic. Restaurants and other businesses can shorten hours or limit services in response to short staffing, but AL cannot.

For remaining staff, emotional trauma was significant, especially the high rates of illness and death of residents and colleagues. A recent meta-analysis found high levels of depression, anxiety, and insomnia among direct care workers facing the pandemic.[42] Although hospital-based staff received well-deserved accolades, LTC staff doing equally demanding and risky work did not receive the same level of recognition.

During the pandemic, as reported to one of the authors, an AL had the space to let the children of staff participate in onsite virtual school, potentially reducing staff shortages, but state regulators denied the special request. This was unfortunate as even postpandemic, onsite day care creates reliable child care while encouraging children to engage with older adults, possibly fostering a passion to work in LTC.

Future Steps and the ALW Recommendations

These workforce challenges are multifaceted and require multiple and creative solutions, including job training, higher pay and benefits, child care and transportation options, greater job flexibility, and stronger support at the federal, state, and local levels. The ALW recommendations S.10 Discussion of Job Descriptions with Potential Employees and S.13 Recruitment and Retention: Human Resource Practice provide guidelines for enhancing the training and valuing of these roles, many of which recommendations have not been implemented by states.[10]

Training increases job satisfaction, commitment, performance, knowledge, and job retention.[43,44] Although all but 3 US states require some form of entry-level CNA training, only 17 states and DC stipulate minimum training hours (ranging from 1 to 90), and only 38 require continuing education.[45] Flexibility around training regulations may be needed in emergent and pandemic situations, allowing shortened duration and/or delaying state testing. Finally, S.12 Staff Recruitment and Retention: Management Practices, which no state currently has in place, includes high-quality leadership, a respectful organizational culture, improved human resource policies (eg, wages, benefits, flexibility, training, career ladders, and scheduling), motivational work organization and care practices, and adequate staffing ratios.

It is long past time for direct care workforce jobs to be seen as desirable. For this to happen, the sector must focus on providing benefits like high-quality insurance, paid sick days, better pay, career advancement, and respect.[46] The workforce needs to be and feel respected, researchers, policy makers, providers, press, and others tend to use language like "unskilled," which is not helpful, especially because great skill is needed to do these jobs well.

Implications for Practice, Policy, and Research

Good policy is based on sound research and evidence-based practice. During the pandemic, research published quickly (but without compromising validity or integrity) helped both practice and policy makers trying to address financial, PPE, and other needs of AL to keep both residents and staff safe. Going forward, researchers should work with policy makers, providers, staff, residents and families to ensure their research is relevant and timely, and to devise effective methods of dissemination. Good examples have been grant opportunities through PCORI, AHRQ, and NIA that require community partner participation. Providers should work with researchers and encourage their staff and residents to participate in research. Having research-provider partnerships in place *before* a pandemic vastly speeds the research process in times of crises.

Future research should examine the relationship outcomes and the following indicators—staff clinical training, infrastructure to handle a pandemic in AL, and infection control protocols. Infrastructure and

processes should be improved (if available) or developed around communication between providers. AL providers, government agencies and others involved in responding to emergencies should review strengths and opportunities for improvement of processes and implementation of rapid training, acquiring supplies, supporting staff and residents, communicating with families, and streamlining vaccination efforts. Implementing a plan for improvement that includes review and updates will help to ensure success in the face of crisis.

Lastly, the pandemic has shown that AL is a vital part of long-term care and the entire health care continuum. CEAL advocates strongly for the holistic, PCC model of care that is the hallmark of AL. Research is needed to document the importance of this model of care, including the preservation of resident and staff well-being in the face of a deadly disease that targeted this demographic. Policy is needed to support care that melds social and medical needs, both because it creates the highest quality of care and quality of life for residents and because it best prepares these communities to face crises, lowering risks of infection for everyone.

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