UMASS BOSTON
GERONTOLOGY INSTITUTE
MCCORMACK GRADUATE SCHOOL OF POLICY AND GLOBAL STUDIES
UNIVERSITY OF MASSACHUSETTS BOSTON

RESEARCH BRIEF • JANUARY 2022

# Provision of Skilled Nursing Care by Assisted Living Residences:

# Stakeholder Views on the COVID-19 Experience

LeadingAge LTSS CENTER @UMass Boston
*Research bridging policy and practice*

COLLECTIVE INSIGHT

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This research was supported by a grant from The Massachusetts Assisted Living Association (Mass-ALA). For more information, visit mass-ala.org.

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# Executive Summary

## Background

Governor Baker declared a state of emergency in response to the COVID-19 crisis that among other policy changes, enabled Assisted Living Residences (ALRs) for the first time to provide limited skilled services to residents. As a result, on April 2, 2020, the Department of Public Health issued an Executive Order allowing ALRs to provide limited skilled services during the state of emergency. The Executive Office of Elder Affairs certifies ALRs and maintained the role of assisted living regulator, including for these skilled services, throughout this Order.

To understand the impact of the Order, the Massachusetts Assisted Living Association (MASS-ALA) sought qualitative data from residents, family caregivers, and nurses about their experiences either receiving or providing care. MASS-ALA engaged Collective Insight, in partnership with the UMass Boston Gerontology Institute's LeadingAge LTSS Center @UMass Boston (LTSS Center), to independently conduct interviews in ALRs. To that end, 17 subjects—10 nurses, 5 family caregivers, and 2 residents—participated in interviews between October and November 2021. The purpose of this report is to summarize these experiences to better understand how the program affected these key stakeholders.

## Key Findings

**Individuals who have insulin-dependent diabetes are especially impacted by the Order.**

Individuals who have insulin-dependent diabetes are commonly excluded from assisted living if they cannot manage their diabetes on their own, with assistance from family, or with assistance from a paid outside agency. The Order provided residents the opportunity to access diabetes support directly from the ALR since family members were no longer able to enter the building. This option was reported to be a 'life changer' for many families. Not only was it more affordable, nurses and family caregivers pointed to improved health outcomes resulting from the consistency in which this care was provided by the ALR.

**ALRs are capable of providing "basic" skilled care, which can alleviate resident and family financial burden and delay Medicaid-funded nursing facility care.**

The interviewees agreed widely that ALRs are capable of providing "basic" skilled care and that making this care available was in the best interest of residents. Skilled care that nurses considered "basic" includes sugar sticks for blood sugar monitoring; insulin injections including using a sliding scale; other injections such as anticoagulants and B12 vitamins; simple wound care and tear dressings (e.g., 'stage one' wounds); routine blood pressure monitoring; and cream and eye drop applications.

From the interviewee perspective, the governor's Executive Order opened the door for residents to receive skilled care that was otherwise financially unsustainable for them. Family caregivers of residents in assisted living described the costs associated with skilled care, specifically the costs of diabetes sugar monitoring and insulin injections, as unsustainable. There was great concern that if ALRs cease to provide the basic skilled care once the Order sunsets, residents and family

members will incur the very high cost of diabetes management, which could force the resident to move into a nursing facility. Some residents and families reported that this transition would occur within a year. Residents and family members interviewed reported that their skilled care needs did not warrant a nursing facility and that they appreciated the independence and social opportunities afforded by ALRs.

### ALR provision of basic skilled care can improve communication and clinical outcomes.

Residents reportedly experienced no increased risk of hospital or facility admission after receiving skilled care from ALR nurses. ALR nursing staff instead discussed how their presence on site actually reduces risk for residents compared to the situation where external nursing staff are brought in to perform insulin care and wound care, particularly for residents receiving memory care. ALR nurses who provided basic skilled care improved the consistency of care, especially for residents with diabetes and wound care needs. ALR nurses pointed out that their knowledge of the residents played an important role in the quality of skilled care they provided (or could provide) to residents, supported timely assessment and monitoring of residents' needs, and enhanced communication with family members and medical providers.

### ALR basic skilled care does not replace skilled care agencies.

Reportedly, the Executive Order has allowed ALR nurses to address skilled care gaps because ALR nurses are most familiar with residents and are consistently present on site. Many nurses indicated they are comfortable with simple stage 1 wound care, which is especially important if a resident needs immediate re-dressing of a wound and a skilled nursing agency may not be able to get there until the next day. Nurses reported that more serious wounds would likely require specialists who are better suited to perform this care.

### ALRs must remain social, home-like settings.

The consensus across interviewees was that providing basic skilled care in ALRs would be appropriate as long as it does not diminish the social or community feel of assisted living. Those interviewed discussed the importance of ALRs focusing on residents' quality of life, not the provision of skilled care. Although many of the nurses pointed to the benefits of providing skilled care to residents, some were concerned that dementia can make skilled care more difficult and could take nursing staff time away from other necessary tasks.

### ALR training practices must account for new types of care.

Because ALR-based skilled care provision in the residence is relatively new, some ALR nurses felt isolated from the opportunities to practice skills and equipment use that more clinical settings offer. As a result, they felt that more staff training and oversight would be important to provide skilled care in-house. Such training could include COVID-19 specific measures (e.g., vitals and nose swabs) as well as resident-specific needs (e.g., diabetes management and wound care) and refreshers on wound care and dressings, vitals, blood sugar monitoring, and injections.

# Research Purpose and Methods

The Massachusetts Department of Public Health issued an Executive Order on April 2, 2020, which allowed assisted living residences (ALRs) to provide skilled nursing care as part of the COVID-19 emergency response. To understand the impact of this Order, the Massachusetts Assisted Living Association (MASS-ALA) sought to collect qualitative data from residents, family caregivers, and nurses about their experiences during this period. MASS-ALA engaged Collective Insight, in partnership with the LeadingAge LTSS Center @UMass Boston, to conduct interviews in ALRs. In preparation for these interviews, the research team implemented a workgroup to inform the research questions and focus areas, which provided the foundational basis for the work reported here. Workgroup participants met three times in August 2021 and included nurse managers and administrators of Massachusetts ALRs who were familiar with the resident, family caregiver, and staff populations.

All ALRs that were members of MASS-ALA received a flyer sharing the purpose of the study and including a link to learn more and to sign up to participate as a research site. This information was also shared in the MASS-ALA newsletter. The research team contacted potential research sites to 1) share an overview of the project, 2) share a project information document, and 3) answer any questions about this research. All ALRs interested in participating in this study were included in this research and assisted the research team in identifying nurses, family caregivers, and residents to interview. Three separate ALR providers assumed the role of sites for this research, including one that chose not to provide skilled care during the pandemic. These ALRs varied in size, with some having multiple residences across the Commonwealth. A total of 17 subjects participated in interviews between October and November of 2021. Of these 17, 10 were nurses, 5 were family caregivers, and 2 were residents. The number of residents interviewed for this study was less than originally planned since much of the skilled care that that took place occurred in memory care settings with residents who faced significant cognitive limitations.

The research team included one interviewer and one note taker. The interviews were conducted in person or over video conference, per the request of each participant. Fourteen sources (with multiple people occasionally participating as one source) were recorded and transcribed. Transcripts were coded using NVivo, a qualitative data analysis tool, by a research team member with supplemental coding provided by a second research team member to assess interrater reliability of codes and themes. A total of 564 data elements were coded into themes across all interviews, and a total of 14 codes (themes) and 24 sub-codes were identified. Using calculations in NVivo, we determined a Cohen's Kappa coefficient value for each variable. We found that the coding categories had agreement that ranged from very good (64%) to perfect (100%), relatively high scores. This report details the findings from these interviews.

# ALRs' Executive Order Response

## Differences in Response

ALRs responded differently to the option of being able to provide skilled care to their residents. Some ALRs at the height of the pandemic provided skilled care to a limited number of residents who required this care when family caregivers and external skilled care agencies were not allowed to enter the ALR. Other ALRs, even during the height of the pandemic, allowed skilled care agencies into their residence. Because of this, they chose not to have their own nurses provide skilled care. We found three circumstances under which an ALR had its own nurses provide skilled care: (1) when skilled care support from family caregivers was not available; (2) when residents who had been successfully managing their own skilled care could no longer do so; and (3) when residents acquired a skilled care need during the pandemic and could only have their need met by the nurse on the premises.

## Skilled Care Provided

**Range of Skilled Care Provided.** Interviewees indicated that the types of skilled care provided under the Executive Order included blood sugar testing, provision of sliding scale insulin injections, minor wound care, routine blood pressure checks, and application of eye drops. The majority of those we interviewed discussed how the Executive Order expanded opportunities to provide blood sugar monitoring and insulin injections for residents with diabetes (11 sources, 60 references[1]). From their perspective, the Executive Order opened the door for residents to be able to receive skilled care that was otherwise financially unsustainable for them.

**Concept of "Basic" Skilled Care.** Nurses consistently discussed the benefits of ALR nurses providing some "basic" skilled care for residents within their community (11, 73). Skilled care that nurses considered "basic" included blood testing for sugar monitoring; insulin injections, including using a sliding scale; other injections, such as anticoagulants and B12 vitamins; simple wound care and tear dressings (e.g., 'level one' wounds); routine blood pressure monitoring; and cream and eye drop applications. Some nurses pointed to examples in which residents with these care needs, specifically blood sugar monitoring and routine injections, were often not accepted into ALRs because there was no support for these needs.

Nurses consistently pointed out that ALR nurses should not provide all categories of skilled care. In fact, there were specific skilled care interventions such as intravenous fluids and urinary catheter care that many believed skilled care specialists should perform to ensure appropriate care and infection control. As one nurse put it:

> "I think there are wonderful things that could come out of [ALR basic skilled nursing care]... for example, checking the blood sugar on site, being able to administer that insulin, and residents and families aren't waiting around. I think that's great; however, if we started doing G-tubes and IVs and things like that, I think that some of the kickback from nurses would be, 'It's not what I

[1]Figures in parentheses indicate the total number of interviews and individual responses provided by theme. The first figure represents the number of interview sources of coded data for the given category out of a possible 14 interviews. The second figure represents the total number of times each theme or subtheme was mentioned across all interviews.

> **"There's a lot of basic things that [ALR] nurses can do. For example, dressing changes and finger sticks and stuff like that, insulin administration—for me, I feel like those are basic. I didn't see any[thing] wrong [with]… doing it in assisted living…."**
>
> **— ASSISTED LIVING RESIDENCE NURSE**

signed up for, and it's not what I want to do. If I wanted to work in that environment, I would. I'd go to the hospital. I'd do home care. I'd do a nursing home.' "

Some nurses discussed the collaborative relationship between the nurses in the assisted living residences and the external nurses. They emphasized the fact that together they were better able to meet the needs of residents in a timely manner, especially when it comes to wound care. According to one nurse:

> "There's still a specific benefit of using a [skilled care agency] for wounds… However, in conjunction with that, if someone's… dressing comes undone, or they sustain… a new skin tear, or something of that nature, in between the [skilled care agency] visits, our nurses have filled that gap… the [skilled care agency] might leave us extra supplies that they're using… so that we're able to reapply something. Or, if it gets soiled, we can reapply [the dressing]. Which, before, we weren't able to do."

## Characteristics of Residents Who Received Skilled Care

**Most had cognitive impairments.** The individuals described as receiving skilled care from ALRs ranged in functional and cognitive needs, with some residents being independent with personal care tasks and others requiring significant daily help with toileting, bathing, and dressing. We found that the majority of residents who received skilled care had some form of cognitive impairment and most of those were receiving memory care support within dedicated memory care floors or wings (10, 25). Many of the residents who received skilled care were at one point in a skilled care setting, but reportedly no longer required that level of care and chose to move to assisted living for a "home-like setting." According to one family member, "he wasn't happy over there [at the nursing facility]."

**Most believed funding, not skilled care needs, would drive a future move to facility care.** Residents, nurses, and family caregivers alike commonly cited the characteristics of ALRs—specifically the activities, individual rooms or apartments, and opportunities to build relationships—as important to the residents' quality of life, even in the presence of a need for skilled care support. However, there was a consistent view among interviewees that residents needing blood sugar monitoring and injections would eventually be forced to move to a nursing facility care primarily because of a lack of funding to pay for private skilled care (10, 27), and not because of an inability to address the skilled need. As one nurse reported: "There's a lot of people that have been turned away from assisted living because they're diabetics, because we [don't] manage the insulin."

## Why Not Basic Skilled Care? Family Frustrations Pre-COVID-19

Throughout the interviews, nurses emphasized how easy it would be to provide basic skilled care and how much it would benefit residents (7, 24). As one nurse puts it, "I don't see any challenges with it, it just went smoothly." Another nurse reported, "You know, you're a nurse and that's just a part of us that is what we do." Even so, nurses pointed to the challenges they faced with family members of residents who were confused or frustrated with the ALR nurses because they were not

allowed to provide basic skilled care pre-COVID. As noted by one nurse:

> "Well, for me as a nurse, as long what we're doing is under our nursing scope of practice, I don't think there should be a limit... It's different than a nursing home, group home, and hospital. There's a lot of basic things that nurses can do. [For] example, dressing changes and finger sticks and stuff like that, insulin administration—for me I feel like those are basic. I didn't see any wrong of doing it in the assisted living... when the family member call[s] you and ask[s] you just a basic question, basic thing... to do for the resident and then you have to say, 'Oh, I'm sorry. Due to the assisted living rules policy, we can't do this.' ... They ask you a lot of questions. 'How come you can't do this? How come you can't do that? You're a nurse.' Even [when] you try to explain... it's not easy to convince them in that way."

## Perceptions of Risk

We asked those we interviewed about the risks of residents receiving skilled care from ALR nurses, and few were noted. In fact, residents reportedly experienced no change in risk of hospital or facility admission after receiving skilled care from ALR nurses (4, 15). As one nurse reported: "[Residents] were able to get what they needed then. I don't think they [even] discovered the [skilled care agencies] were [previously] coming. I think the gap was well filled in."

There was at least one circumstance where a nurse reported that their ability to provide skilled care allowed for timely assessment and intervention, which may have prevented hospital admission. As this nurse reported:

> "We've had incidents where a blood sugar did drop. Not so drastically that they had to go to the hospital, but where we did have to intervene and give, you know, protein and milk or orange juice, whatever... to stabilize the resident. But, again, it's hard because, prior to our ability to do this, we couldn't even check that person's blood sugar to know if they were low. You know, we couldn't even follow up on what was going on."

ALR nursing staff also discussed how their presence on site actually reduces risk for residents, compared to the situation where external nursing staff are brought in to perform insulin care, particularly for residents receiving memory care (4, 5). According to one nurse, the concern for this risk was what led to them performing skilled care during the pandemic:

> "Memory care's high risk. You're bringing in two or three different outside people just for that one resident to manage their-their insulin during the day. So, by allowing our nurses here to do it, we're able to—you know, we have our nurses testing on a regular basis. It's more controlled...and it was safer for our community and our residents."

**"My [loved one is] now in an assisted living facility, seven weeks in, and the quality of his life is so much better [than the nursing facility] because the focus of his days are interaction and support. It's like walking around home, a comfortable home, not a hospital unit. And for [his] quality of life and his day-to-day, that's really important. So that's why we chose, after four months of planning, with [him] demonstrating stability over a year... that's why [we] chose to move to an assisted living facility."**

**— RESIDENT FAMILY CAREGIVER**

# Perceived Benefits and Opportunities

## Informed, Person-Centered Care

ALR nurses pointed to knowing the residents they serve as playing an important role in the quality of skilled care they provided (or could provide), particularly for diabetes care. One nurse said, "I'm here with the resident so I know they're waking. I know what time they are up in the morning. What time they have the mealtime...I check [their blood sugar] before going downstairs for breakfast. I know I'll be on time for this... Coming in later, of course, after breakfast, the blood sugars are going be higher than if you check it before breakfast. By doing that [an outside agency coming in later].. you get a higher reading than if you take it before breakfast. That can increase the amount of the insulin given."

## Timely Assessment and Monitoring

Interviewees pointed to an additional benefit of having ALR nurses provide basic skilled care, namely that it allows for timely assessment and monitoring of residents' needs (5, 18). As one nurse put it, "there are days when [the resident is] just not feeling good and you're wondering if it's her sugar. Not being able to monitor it, you don't know exactly is it diabetic-related or if it's something else. In a way, it is good for us to be able to have a little more skill to better assess a resident, especially with diabetes than if you don't have you don't know. You then need to rely on family coming in to check, and even in those times, the family doesn't always report it to the nursing staff." A nurse also pointed to the fact that when families provide or support skilled care, it creates its own quality monitoring challenges. According to this nurse, "the spouse that we had doing it, she had dexterity issues. So she was having trouble getting... the blood glucose. So sometimes she was just giving the insulin not knowing the blood sugar level... You have zero control of the situation, and then we have, like, a high-risk resident... in our community..."

> **"We [ALR nurses] all have the training to work with the residents and know them and go with that flow with the residents. We can tell if they are having a good or bad day...[When] we have an outside agency person, there is more opportunity with something missing, lack of understanding of baseline, things fall through the cracks, lack of communication with family members, don't talk to nurses, [and] residents have extra level of anxiety or confusion [if] they don't know the person."**
>
> —ASSISTED LIVING RESIDENCE NURSE

## Consistent Care

Many of those we interviewed discussed how allowing ALR nurses to provide basic skilled care improves the consistency of care

provided to residents (5, 18). They provided concrete examples in both diabetes management and wound care. Nurses also pointed to their role in skilled care and their knowledge of the resident as creating opportunities to identify any additional interventions that could be beneficial for the resident (5, 11). For example, when discussing a resident with diabetes and dementia, the ALR nurse reported, "When we saw her or we assessed her, we were able to say, 'okay, this is her baseline,' meaning her level of confusion. [Also,] we knew if we gave [the resident] any type of patient education, we know [the resident] enough to say…we'll have to follow up with her because she might not follow through with this education piece that we're providing for her whether that be the diet or just anything—her choices for water intake versus soda, whatever the case may be. Just knowing her, we were able to provide more consistent care, I think."

When discussing wound care, one nurse reported, "We see changes, and sometimes maybe [outside skilled care agencies] have their own schedule. Maybe they'll come after two days. Sometimes we feel something needs to be done before two days. We may call, and maybe there's nobody available to come in a third time."

A family member linked this timely and consistent care to his/her loved one's quality of life. According to this family member, "…my [loved one's] goal is to be comfortable. So keeping my [loved one] out of … [kidney] failure, keeps [him/her] comfortable…. And that's [his/her] desire. And, compliance with [his/her] meds is what helps my [loved one] be able to breathe and to be comfortable. And, so if [he/she] doesn't have a therapeutic relationship with the nursing staff, who are responsible for [his/her] … day-to-day administration of meds… [he/she] is not going to be comfortable. And, that's a big problem. And, I think consistent nursing staff who are skilled, who know the residents, their patients, is critically important [to his/her quality of life]."

## Delayed Expenses and Facility Care

Those interviewed consistently emphasized that the skilled care provided by ALR nurses was less costly than that provided by nurses from outside hiring agencies, and that it was therefore financially beneficial to residents and their families (10, 27). Interviewees also believed this likely delayed institutionalization. As one nurse noted, "I think they're [residents and family] appreciative, and they're grateful. For them, it's an expense they don't have to take on, that they may not be able to afford to take on. In that respect, for sure they're grateful." A family member reiterated this point when they stated, "She really wanted to be in a facility like this. The location is perfect. It just couldn't have been any better. The people seemed very, very nice. I was very impressed with the staff…. I have made it clear to her, and I think she understands, that ultimately the money will run out."

> **"… for wound care, at least, the nurse here can monitor it more regularly and change it regularly and maybe prevent it from getting worse…. The nurse might be able to be more mindful and monitor it better in-house than just waiting twice or three times a week for someone to come and check on it."** — ASSISTED LIVING RESIDENCE NURSE

## Enhanced, Not Replaced Role of Skilled Care Agencies

There was general agreement among interviewees, and in particular the nurses, that while ALR nurses should be able to provide some basic skilled care to residents, this should not replace the role of skilled care agencies that frequently enter the community to provide more complicated and demanding skilled care (8, 46). For instance, when it comes to wound care, many nurses indicated a comfort with doing simple wound care (e.g., stage 1). More serious wounds would likely require wound care specialists who are better suited to perform this care. Reportedly, the Executive Order has allowed ALR nurses to provide skilled care that fills gaps in care because the ALR nurses are most familiar with residents and are consistently present onsite. As one ALR nurse put it, "what we've done through the pandemic is... a hybrid approach where we work in conjunction with a [skilled care agency]. ...[these skilled care agencies]... [are] specialized wound care nurses ... that we do not have at our community." This is especially important because a resident may need immediate wound re-dressing and a skilled nursing agency may not be able to get there until the next day.

Some nurses discussed the collaborative relationship between the nurses in the assisted living residences and the external nurses. They emphasized the fact that together they were better able to meet the timely needs of residents, especially when it comes to wound care. According to one nurse:

> "There's still a specific benefit of using a [skilled care agency] for wounds... However, in conjunction with that, if someone's... dressing comes undone, or they sustain...a new skin tear, or something of that nature, in between the [skilled care agency] visits, our nurses have filled that gap... The [skilled care agency] might leave us extra supplies that they're using...so that we're able to reapply something. Or, if it gets soiled, we can reapply [the dressing]. Which, before, we weren't able to do."

**"A lot of our residents move to [a] nursing home. Not because of skills or because of their condition, but it's because of financial reasons. That's usually what I see here."**

**—ASSISTED LIVING RESIDENCE NURSE**

# Impact on Family Caregivers

## Families' Role Prior to COVID-19

Many of the family caregivers we interviewed had a range of experiences providing care and support for their loved ones prior to the pandemic, including providing hands-on care before the resident moved into assisted living. Even within the ALR setting, family members described everything from coordinating medical care and advocating for the residents' needs when the resident was in assisted living to providing skilled care like sugar monitoring and insulin injections (5, 27). Interviewees indicated that the majority of the residents had dementia or diabetes (or a combination of both). Many of them also had a history of falls and urinary tract infections.

**Interviewer: "What was your [daughter] doing before you lived here?"**

**Resident: "Everything."**

One family caregiver discussed what it was like supporting the resident full time prior to the resident's move to assisted living. According to this family caregiver, "Oh, at home it was a madhouse. I couldn't go out. I had to get food. When I would come back, I'd open the door and yell his name and didn't know if he'd be on the floor or what. It was very hard." According to another, "Well, his brother came to see him. His sister came to see him. He was downstairs. After a while, I wanted to just keep him downstairs. I thought I'd put a bed downstairs. The stair lifter helped, but then he had the problem on the platform. It just was one thing after another. I was feeding him and not feeding myself and it just was very hard, very hard."

## Families' Role in Skilled Care Prior to COVID-19

Families were investing a great deal of time supporting general care and skilled care, especially when they couldn't afford agency assistance. As one loved one stated, "I probably spend... [a] minimum... five, six hours a week. Just I mean, if I'm talking on the phone and all the planning and stuff that needs to be scheduled... We have somebody [from the family] there visiting twice a week. Saturdays and Sundays are the busy time. That's an average of three hours a day, Saturday and Sunday." This same family member discussed the investment of time required to provide the resident diabetes management support. "The insulin only takes anywhere [from] five to ten minutes to do. I mean, it's a very simple task, but we're all a minimum of an hour away. It takes up the better part of three to four hours each time we come up there, both between travel and the care time." Some families could manage the provision of diabetes care even though it was time consuming. Other families were more challenged. Some older spouses were unable to read a sliding scale properly, some were unsteady when injecting insulin, and others did not document or share the blood sugar or insulin measures with ALR nurses or the resident's medical team to assure better coordination of care.

## ALR Skilled Care Gave Peace of Mind, Improved Quality of Life

Residents' loved ones who were previously responsible for the residents' skilled care talked about the peace of mind this new care provided and how this influenced their own quality of life. One family member reported, "The one place my parents are at right now is extraordinary. And that team being able to provide that level of care gives me great peace of mind. So that's really positively impacted my quality of life and my brother's because we feel like they are both in a place where they've been cared for by the skilled nursing and the aides. And, they're being loved and that's what you can do for your parents, right? And, so it's given us great peace of mind."

# The Diabetes Dilemma

Before COVID-19, individuals who have insulin-dependent diabetes were (and still are) reportedly often excluded from assisted living if they could not manage their diabetes on their own, with assistance from family, or without assistance from a paid outside agency. For one family, the inability to afford private skilled care meant working with medical professionals to switch from insulin to medication at the time of the move to assisted living with the hope that the resident's diabetes could be appropriately managed in this manner.

## The Pandemic Opportunity

The Executive Order provided some residents the opportunity to access diabetes support directly from the ALR when family members were no longer able to enter the building. This option was reported to be a 'life changer' for many families. Nurses and family caregivers pointed to improved health outcomes resulting from the consistency in which this care was provided by the ALR. According to one nurse:

> "I think they're [family caregivers] happy that we're able to help and do it. One, they don't have to come in and do it, but two, they know their mom or dad is being checked and looked and assessed and things like that. They trust us and so they trust our judgement in helping out with the skills that the resident needs. Every family's different, but the reason why they're coming in is because we're not able to do it. That's why family has to come and do it. I'm sure they're happy if the nurse[s] actually are able to do it... and be able to assess it better and contact the doctor and have a better judgement on what the resident needs when we do help with the skills."

## Improved Diabetic Outcomes

One family caregiver discussed the transition of diabetes management to ALR nurses at the height of the pandemic and the outcomes of this transition. According to this family caregiver, "They actually jumped right in the middle of it and took over immediately. His health improved and his numbers improved immediately. I would say within two weeks to a month, he was consistent at the numbers that we would expect to see him...numbers that actually he hadn't seen in two years." When asked the difference, the family caregiver reported, "Consistency." The ability to administer the sugar daily and at the proper time—which is always before a meal—and not have to worry about whether it was administered within an hour of breakfast was critically important. Then dinner, having given it to him just prior to dinner or within a half hour after returning from dinner, as opposed to at 8 or 8:30 at night when he went to bed, if he remembered."

This caregiver highlighted the importance of the link between the timely monitoring of blood sugar and previous falls. "He'd been in rehab a couple of times for falls.... Actually, what we and his doctors have determined is...every time his blood sugar would go out of whack, his balance would deteriorate. His legs were weak. He wouldn't notice it, but he became a little bit loopy to speak with as well. Once his sugars were back in line, everything balanced out and he was back to his normal self."

## The Cost of Privately Paid Diabetes Care

Family caregivers of residents in assisted living described the costs associated with skilled care, specifically the costs of diabetes sugar monitoring and insulin injections, as unsustainable. For that reason, there was great concern that if the new assistance available in ALRs ceases, residents and family members will have to then incur the very high cost of diabetes management, which could force the resident to move to a nursing facility. When a family caregiver was asked how long they thought their loved one could afford this care, the family caregiver reported, "Well he'd be out... less than a year." When asked what would be next, the family caregiver replied, "Nursing home care is probably the only option.... I don't think mentally he's ready for that. We're out of options at that point."

A nurse who wasn't sure her facility had the capacity to provide skilled diabetes management also discussed the implications of private pay diabetes management on both the ALR and the family:

> "I have somebody who's on insulin three times a day. How do I own that? And how's the family going to pay $75, practically, an hour to have a nurse come out each time to do that insulin? That's a huge no way. The family ends up having to either keep somebody at home or they go to a skilled setting."

Another nurse agrees:

> "As a private homecare agency, it has to be a licensed nurse. So, you'd be paying $65 a visit for someone to have their blood sugar checked and their insulin given. Because you're pulling... a nurse to come in for 15 minutes to do this... they would bill you, like, for an hour at 65 bucks an hour... So it's very, very, very expensive to the residents [and as often as four times a day]... So [it] could be... almost 300 bucks a day just to make sure that they're insulin is managed on top of our fees that we charge for medication administration or care services. So, it becomes very, very costly."

Some residents and family members are simply not measuring blood sugar because of the cost and hoping it just works out. As one family caregiver reports, "Some people here who are diabetics, they have like a [skilled care agency] come in, or there are other outside agencies. [Our family has] kind of been just spot checking her because we see her quite a bit... as long as it's not getting in crazy ranges... we're going to play it out and see what her range was, see what turns up in the next three months."

> **"Caregiving for somebody with dementia is—especially if it's a loved one—just damn stressful. I won't sugarcoat it. It's not easy."**
>
> **—RESIDENT'S FAMILY MEMBER**

# Perceived Challenges and Concerns

## Right Time to Try Providing Skilled Care?

Study participants shared their experiences during COVID-19 and its impact on staffing and resident experiences in assisted living (9, 46). One nurse (from an ALR that chose not to provide skilled care) spoke of how providing skilled care was not possible during the pandemic due to their need to focus on COVID-19 precautions and monitoring. For this residence, the decision was made to bring nursing staff in from outside agencies to support resident care, even non-skilled care, until COVID-19 was no longer the primary concern for the ALR. An ALR nurse who provided skilled care agreed:

> "I don't know what to say. I think during the pandemic, it was a matter of being present to help where you can, but it was real draining. If you're thinking of what you're making, you will think maybe it's not worth it. But thinking you want to help people, people are suffering; you want to be there.... During COVID-19, things changed—before, [an outside skilled agency did] blood pressure [checks], monitoring, wound, [and] skilled nursing. During [COVID-19], we had to do it. It was too much. Need of residents was too high. Not done something for a while and then you have to do them."

## May Not Be Enough Staffing

Even though many of the nurses interviewed pointed to the benefits of providing skilled care to these residents (e.g., a familiar face and knowledge of the resident's needs), there was concern among some that dementia can make providing skilled care more difficult, and as a result, take away nursing staff time from other needed tasks. According to one nurse, "We have to have a balance of how much skills can we do and how much we shouldn't do, because we want to be able to do it safely. If we have too many, I don't know." Another nurse said, "I think the downside is obviously it's increased workload. Right? But the issue of that is not just increased workload. Assisted living, we're basically assisting people in their daily lives. Having that coupled with providing skilled living, I think is a lot. We're not just maintaining their health—their physical wellbeing—but it's a lot of running their day-to-day lives."

## May Turn ALRs from a Social Model to a Medical Model

There was concern among some nurses that offering ALR skilled care would lead to more people moving into assisted living with skilled care needs, resulting in the overall environment shifting to be more medically-driven. According to one nurse, "we don't want it to get to a point where it's going to be taking us to a nursing home-type of environment." Another stated, "This is a home-like environment, so we don't want to look like a nursing home or a hospital." The consensus was that, with the right training support, providing this skilled care would be appropriate as long as it did not take away from the social or community nature of assisted living.

This is especially true and yet challenging, for dementia residents. "With memory care, it'd be a little harder, more challenging... you probably need the right training, but it is difficult with resident with behaviors. Like we say, we want to focus on giving them a quality of life and not just trying to take care of their needs and not controlling their behaviors and things like that. That's our focus here in memory care versus trying to just do skills. It depends on the facility."

*Interviewer: Do you ever worry about having to move out of here?*

**Resident: No.**

*I: No? How long do you plan on staying here?*

**R: 'Til I die.**

*I: Until you die? Would there be ever a reason why you had to leave?*

**R: Ran out of money.**

*I: Does that worry you at all?*

**R: No. I just take everything day by day. I don't know where they'd put me.**

## Need a Clear Roadmap

While some nurses would rather have skilled care performed by outside agencies, most felt that there was no risk to ALR nurses performing this care if the appropriate staffing was possible. A nurse from an ALR that did not offer skilled care during the pandemic reported that they were too busy addressing COVID-19 and did not have the "roadmap" to provide skilled care. She felt that it was more appropriate for outside agencies to do this. Another nurse that did provide skilled care believed that there were many "gray areas" that required clarity on activities that would require consent and/or specific medical orders so as to minimize liability risks. This nurse reported, "I would say the risk in that—I do not know if we ever got consent to do that. I do know there was a need, and everybody—it looked like we didn't have a roadmap. Everybody was trying to figure out where to go. Legally, it's like we didn't have enough protection if you give an order that you're not supposed to."

# Nurse Readiness and Training

## ALR Nurses Have the Training and Experience

Most nurses reported that their previous work experience prepared them well to assume the role of providing basic skilled care, and in most cases, nurses appreciated the opportunity to practice skills (8, 41). As one nurse reported, "We've done the basic blood sugar check, track wound care. We've done that. At least for me, personally, I've been trained to do that as a nurse."

Even so, two nurses did recognize that providing basic skilled care in this context was different because it had not been allowed in the past and they were unsure about whether it was going to be continued at the end of the pandemic. "I wasn't nervous about it because before [I worked in ALR] I worked in nursing home; nothing new to me." A second nurse agreed, "It wasn't new to me either. I work in nursing home and home care. The only thing it did blur the lines for me is this COVID-19 only or is it moving forward only."

## Some Nurses, Facilities Not Ready or Willing

ALR nurses recognized that those who work in assisted living tend to be more experienced nurses, often coming from other skilled care environments. That said, because up until this point there had been very little ALR-based skilled care provided in the residence, some felt isolated from the equipment and skills- practicing opportunities afforded in settings that were more clinical. As a result, they felt that additional staff training and oversight would be necessary to continue to provide skilled care in-house. One nurse who did not have direct experience providing skilled care in assisted living, shed light on nurse perceptions that may create hesitancy to adopt this new role. This nurse relayed, "[In skilled settings,] you have like an emergency E-Kit with every possible med you could need that you can break the latch on it. You don't have that in assisted living. You also have emergency narcotics. You have emergency insulin. Wow. That's a big, huge arena if you open that up. That's huge, cause who's going to give you those orders to open those boxes? That's a kicker right there."

> **"[Some assisted living nurses] don't want to pursue those skills…. maybe a better way of saying it… 'Okay, I've maybe already lived my life in a hospital. I've lived my life in home care… I'm at an assisted living because I just want to focus on dealing with the resident more, dealing with the families maybe a little bit more and not so much the skills."** — ASSISTED LIVING RESIDENT NURSE

> **"If we were going to continue to provide skilled care, I think everyone across the board would need education, everybody from managers to employees.... I think everybody would need training."**
>
> **—ASSISTED LIVING RESIDENT NURSE**

## Additional Training May Help Support Nurses in New Role

Some nurses discussed the formal training they received to refresh their skills in preparation for their new role. Such training included COVID-19 specific measures (e.g., vital signs and nose swabs) as well as resident-specific needs (e.g., diabetes management and wound care) (8, 41). This training was provided in-person by lead nurses, by skilled care agencies (e.g., through a window at the height of the pandemic), through computer-based trainings, and/or through nurse observation and supervision. Moving forward, most nurses agreed that ongoing training may be helpful (and welcomed) to support successful (basic) skilled care in assisted living, including trainings and refreshers on wound care and dressings, vitals, blood sugar monitoring, and injections.

## Nurses May Leave During a Worker Shortage

Some nurses pointed to the potential risk of staff turnover among ALR nurses providing skilled care, which is especially problematic given the already existing worker shortage. These nurses believed that many of the ALR nurses did not expect to be providing such services when they joined the ALR. According to one nurse, "If one of my nurses wanted to work in a skilled nursing facility, she would be there. She's here for a different reason because she wants to provide different care.... I think what happens when you change things midstream—I think it could have some negative effects. People might say, 'It's not what I signed up for. It's not what I want to do.' "

> **"They're seasoned nurses. None of them are new nurses. Including myself, everyone had prior experience in a skilled facility at some point in their career...they were ready. They were prepared. It was nothing out of the ordinary. It wasn't any type of complex wounds or anything to that sort.... Yes, I think they were knowledgeable for sure."**
>
> **—ASSISTED LIVING RESIDENT NURSE NOT PROVIDING SKILLED CARE**

# Case Vignette: "Ralph"

One assisted living resident, "Ralph," is a 92-year-old male who has lived in his ALR for 5 years now. Ralph has diabetes, high blood pressure, hydrocephalus, and is incontinent. He requires some assistance with bathing and dressing. Ralph has a history of urinary tract infections and falls. Ralph's family is very involved in his life, and prior to the pandemic, was visiting Ralph multiple times a week to socialize, monitor his care, and help manage his diabetes.

Ralph takes insulin—what initially was twice a day: before breakfast and before dinner. Up until COVID hit, Ralph was administering his own insulin. The family had concerns with Ralph's ability to dial the insulin pen appropriately; they believed his inconsistency was leading to his self-administration of too little or too much insulin. The family was concerned that his blood sugar levels were to blame for his unsteadiness and his frequent falls.

Over time, Ralph's fluctuating A1C levels continued to be a big concern to his family. Ralph and his family considered paying a skilled agency to administer his insulin, but they learned the cost would be about $150.00 a day, an additional $4,500 a month over the nearly $12,000 Ralph was already paying to live at his residence. Even with this cost, Ralph and his family were told that daily assistance, especially two times per day, would not be guaranteed due to the worker shortage. The family knew his funds were running out, and Ralph already downsized his apartment to save funds. He had about 18 months of rent left. Once the funds were depleted, the family planned to help Ralph transition to a nursing facility.

When COVID-19 hit, the assisted living residence shut down visitor access. No one was allowed into the residence to help Ralph with his blood sugar monitoring. With the Executive Order, the ALR stepped in to support Ralph with his blood sugar testing and his insulin injections. The family noticed benefits of this change within weeks, and Ralph eventually had A1C levels that were consistent and at levels his family had not seen in years. Ralph's balance appeared to have improved and his falls decreased. He seemed to have more mental clarity, even with the pandemic lock down.

The family is fearful that Ralph's health will deteriorate if Ralph returns to self-managing his diabetes. If they hire an external skilled agency, they will have no way to get there last minute to help Ralph, if the agency staff are unavailable. For the money Ralph is paying for assisted living, Ralph's family believes an ALR nurse should be able to measure his blood sugar and administer his insulin when they provide him his daily medication. They believe doing so will not only support better health outcomes, but also help him save funds and delay nursing facility care.

# Case Vignette: "Roger"

"Roger" has lived in his ALR since fall 2021 and has multiple chronic conditions, including congestive heart failure, diabetes, and atrial fibrillation. He has had multiple strokes which have limited his speech and mobility and have led to lengthy skilled nursing rehabilitation stays.

Roger requires fluid intake monitoring and restrictions and skilled nursing for his diabetes management, including blood sugar monitoring and insulin injections. His family caregiver is concerned that if he does not have consistent, therapeutic relationships with those responsible for his day-to-day support and medications, he could suffer severe long-term and even fatal consequences.

While Roger's family caregiver can financially afford to pay for skilled care out-of-pocket, his family caregiver believes the best quality care is provided by ALR nurses who are consistently present and know Roger. The family caregiver also worries about residents who cannot afford to pay private agencies to provide skilled care and believes skilled care in assisted living should be available to all residents, not just those with the means to pay for it privately.

Roger's family caregiver also shed light on the complexities of advocating for older adult family members who need well-coordinated medical care in home like settings. The family caregiver communicated the importance creating "patient ambassadors" to help bridge the gaps between the medical complexities experienced by older adults and the older adult's goals. Roger's family caregiver felt that this was especially important for older adults who lack family members who are experienced advocates.

# Conclusion

It is clear from our interviews that the overwhelming sense of these stakeholders is that providing basic nursing care in assisted living residences offers significant benefits to residents, families, and staff. While there may be a need to invest in some ongoing staff training to prepare them for successfully providing basic skilled services, the benefits of doing so are many. Some of the most obvious include reducing costs for families, assuring that individuals can age in place longer than they may otherwise be able to, reducing resident turnover by potentially delaying transfers to nursing homes, providing more consistent and timely care to residents (thus assuring higher quality standards), and potentially reducing the need for short-term acute care services in a hospital setting. While some nurses may not wish to provide such care in ALRs, in part due to a sense that there may not be sufficient clinical infrastructure or they have no desire to provide this care, they were in the minority of those interviewed. The majority of interviewees seemed to endorse ALRs providing some level of basic skilled care for residents.

# Study Limitations

The results of a qualitative study that is based on a relatively small number of interviewees is, by definition, difficult to generalize, even though we found a high level of agreement on certain recurrent themes and views among those we interviewed. Our focus on skilled services that were conducted during the pandemic also makes it difficult to disentangle interviewees' views about more general pandemic-related experience versus their experience administering basic skilled care to residents during the pandemic. Obtaining resident views was particularly difficult because the pool of individuals in ALRs who actually needed skilled care was fairly limited, which is not surprising given that it is not a service that had been provided by the ALR before the pandemic. For the most part, basic skilled care was provided to individuals in memory care units, many of whom would not respond to an interview or who had passed away by the time our study commenced. For that reason, we were not able to obtain the views of as many residents as we would have wanted, although we were able to engage with family caregivers. Finally, the COVID-19 crisis in senior housing has not abated and the workload on staff has been significant, making it difficult in some circumstances to schedule and conduct interviews.