


COVID-19 Vaccination Experiences of Family Caregivers of Persons Living with Dementia in Rural Appalachia

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Abstract

The study investigated COVID-19 vaccine acceptance, hesitancy, and barriers among family caregivers of rural community-dwelling persons living with dementia (PLwD). Three waves of telephone interviews with 26 family caregivers (96% White, 81% Female, $M_{\text{age}} = 63 \pm 12$ years) were analyzed using thematic content analysis. At Wave 3, although all dyads were eligible, only 10 dyads had received their first dose of the vaccine. In 10 dyads, neither person had received the vaccine; in 2 dyads, the caregivers did but the PLwD did not; and in 4 dyads, the caregiver did not but the PLwD did. Perceived direct and indirect health risks, cues from trusted allies, and ability to overcome vaccination barriers affected COVID-19 vaccination acceptance. Vaccine refusals were motivated by a low perceived risk of COVID-19, vaccine fear, and personal beliefs. Findings have implications for administration of preventative care practices for dementia family caregivers living in remote locations during a public health emergency.

Keywords

qualitative methods, caregiving, dementia, rural, pandemic, vaccine

What this paper adds

- Understanding of dementia family caregivers' considerations related to obtaining the COVID-19 vaccine for themselves and their relative.
- Knowledge about COVID-19 vaccine uptake among community-dwelling persons living with dementia.
- Focus on rural dementia caregivers' perceptions and beliefs about the COVID-19 vaccines.

Applications of study findings

- Communities need to tailor communication and dissemination of public health information specifically for family members providing in-home care for persons living with dementia.
- Health care providers need to ensure that homebound persons living with dementia can readily receive the COVID-19 vaccine.

Approximately 10% of U.S. adults ages 65 and older have dementia, a neurocognitive disorder characterized by progressive difficulties with memory, judgement, and reasoning that affects a person's ability to independently perform everyday activities (Manly et al., 2022). As cognitive abilities decline, decision-making becomes more difficult for people living with dementia (PLwD), requiring surrogates to make healthcare decisions for them (Fetherstonhaugh et al., 2017). Coronavirus disease (COVID-19), caused by the SARS-CoV-2 virus that emerged in December 2019, exacerbated the vulnerability of PLwD due to the morbidity and mortality associated with this respiratory illness as well as the indirect consequences of the COVID-19 pandemic on the social

support and healthcare system on which they rely (Liu et al., 2020).

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Older adults residing in long-term care facilities were among the first to receive the COVID-19 vaccine (VDH, 2021a; Phase 1A). Thereafter, Virginia, like other states in the United States (U.S.), followed the Centers for Disease Control and Prevention (CDC, 2021) recommendations and prioritized older adults and those with high-risk medical conditions as next to receive the first dose of the COVID-19 vaccine (VDH, 2021b; Phase 1B). Although family caregivers of at-risk individuals were included in this group, the phrase “family caregiver” was not specified, leaving eligibility open to interpretation by health professionals and family members (VDH, 2021c). In addition, vaccine hesitancy, defined as a “delay in acceptance or refusal of vaccines despite availability” (MacDonald, 2015, p. 4163), on the part of family caregivers may affect the vaccine uptake by PLwD.

With the roll-out of the COVID-19 vaccines, researchers focused on the safety of COVID-19 vaccination for PLwD and the ethics of vaccine prioritization in long-term care facilities (Lv et al., 2021; McClung et al., 2020). To our knowledge, no published research is available on the uptake of the COVID-19 vaccine among community-dwelling PLwD and their family caregivers. Furthermore, even though rural residents in the U.S., particularly in the South, were more likely than their urban counterparts to express hesitancy toward COVID-19 vaccinations (McCabe et al., 2021; Murthy et al., 2021), the COVID-19 vaccination experiences of rural-dwelling family caregivers of PLwD have not been explored. The purpose of this study was, therefore, two-fold: to identify factors that influenced vaccine acceptance and hesitancy among family caregivers of PLwD residing in rural communities and to identify barriers that caregivers experienced in getting the COVID-19 vaccine for their relative and themselves.

COVID-19 Beliefs and Behaviors

We utilize the health belief model (HBM; Rosenstock, 1974) as a framework to present the literature relevant to understanding caregivers’ decisions to accept (or not) the COVID-19 vaccine for themselves and the PLwD. According to this model (see Figure 1), health behaviors are shaped by the four belief constructs discussed below.

Perceived Health Risk

Risk perception is a major determinant of health behaviors (Ferrer & Klein, 2015). Weinstein (2000) demonstrated that one’s motivation to engage in health-protective behaviors varied by one’s perceived susceptibility to the disease and the perceived severity of the disease.

Perceived Susceptibility to COVID-19. Perceived susceptibility is one’s subjective assessment about contracting a disease. As such, risk perception influences decisions about COVID-19 prevention and mitigation measures such as masking, safe distancing, and vaccinating (de Bruin & Bennett, 2020). For example, a mixed-methods study of 53 family caregivers in rural Appalachia found that 62% were concerned about contracting COVID-19; yet, one-fourth of the caregivers (26%) ignored public health “stay-at-home” recommendations (Savla et al., 2021a). Because COVID-19 disproportionality affected older adults, we anticipated that caregivers’ perception of their relative and their own susceptibility to COVID-19 would influence their decision to have themselves and their relative vaccinated.

Perceived Severity of COVID-19. Perceived severity of a disease is determined by an individual’s subjective understanding of the seriousness or severity of the disease. Two national

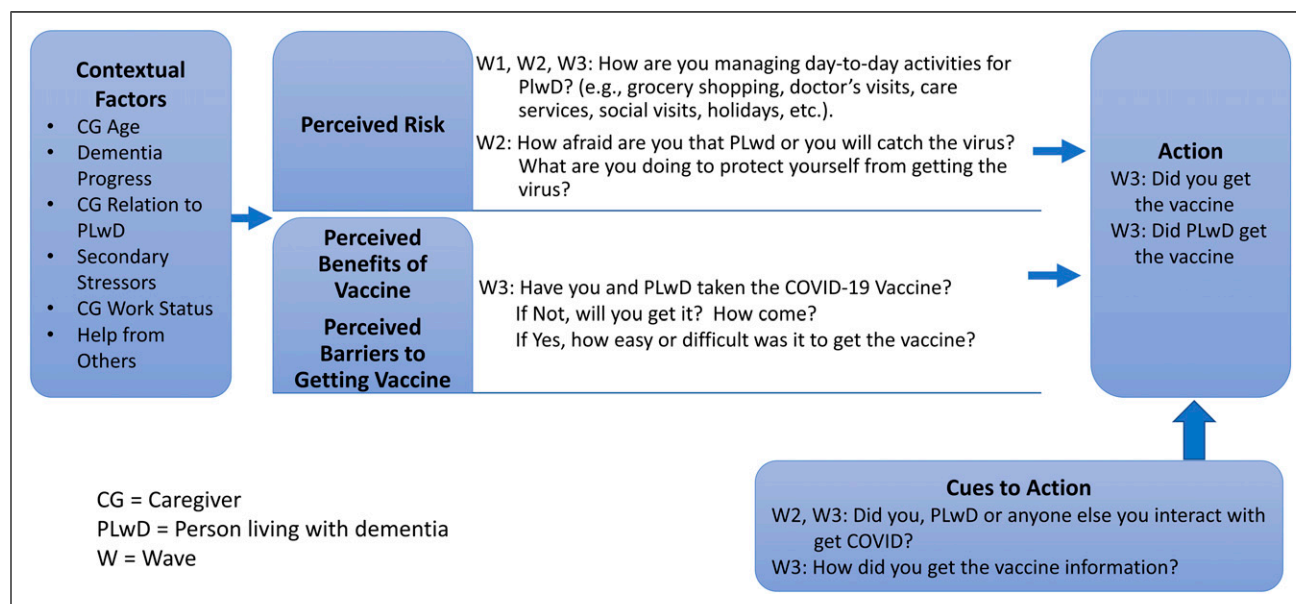


Figure 1. Conceptual model and stem questions for each domain.

studies (cited below) indicated that those who felt more in danger of getting sick or dying from COVID-19 were more likely to adopt health-protective behaviors such as hand hygiene and wearing a mask in public spaces. Health-protective behaviors were also more common among individuals who were more trusting of experts than public opinion, reported greater personal exposure, had liberal ideologies, and reported higher education and income (Callaghan et al., 2021). Investigating the relationship between risk perceptions and willingness to take a prospective COVID-19 vaccine, Malik et al. (2020) found that U.S. respondents who perceived COVID-19 to be more severe were more likely to report higher vaccination intention. Conversely, the more infectious people believed COVID-19 to be, the less likely they were to engage in protective behaviors, exhibiting the “fatalism effect” (Akeson et al., 2020).

Perceived Vaccine Benefit

Perception of vaccine benefit and safety is also important in vaccination uptake. Because COVID-19 vaccines were new, people may form opinions based on previous vaccines. Studies on various vaccines (e.g., for Human Papilloma Virus; Measles, Mumps, and Rubella; and Influenza) indicated that individuals who perceive them as safe were more likely to accept the vaccinations (MacDonald & the Sage Working Group on Vaccine Hesitancy, 2015). Paradoxically, a successful immunization program may result in complacency and hesitancy as individuals weigh the risks of vaccination (i.e., side effects) against the risk of contracting the disease once it is eradicated. In other words, when a disease is not considered high-risk, perception of the vaccine’s risk may surpass that of the disease risk. In contrast, if the perceived disease risk is high, individuals may decide to vaccinate despite vaccine concerns.

Perceived Vaccine Barriers

Barriers refer to a person’s actual or perceived obstacles to performing a health action. Common barriers to taking the COVID-19 vaccine included trust or confidence in the healthcare system and vaccine research, as well as vaccine safety and effectiveness (Lazarus et al., 2021). Other perceived barriers were potential vaccine side effects and efficacy (Parente et al., 2021) and vaccination convenience, including travel time to a vaccine clinic, especially for rural residents (Murthy et al., 2021). A study of 124 ambulatory and homebound older adults living with Parkinson’s disease also found that difficulties traveling to clinics to receive the influenza and pneumococcal vaccines were the main barrier to vaccination (Phanhdone et al., 2021). Additionally, 32% of the participants were unsure of the vaccine recommendation for people living with Parkinson’s disease, 13% believed their doctor recommended against the vaccine for them, and 13% reported that other household members were not vaccinated.

Whether these types of barriers influenced caregivers and PLwD uptake of the COVID-19 vaccine is unknown.

Cues to Action

Cues to action are the stimuli needed to accept and act on a health recommendation. Internal cues (e.g., self-care, witnessing death or illness of others) or external cues (e.g., recommendation by an expert or trusted leader, mandatory workplace policies) can motivate vaccination. Despite acknowledging cues for action, adults who initially declined to get the COVID-19 vaccine were less likely to change their minds than those who were hesitant or unsure about the vaccine (Salali & Uysal, 2021). To further explore potential cues to action, we asked family caregivers who provided vaccine information to them and what prompted them to accept the vaccine.

Contextual Factors

Studies focused on demographics found that younger adults, women, Black persons; adults living in rural areas; and those with lower education, lower income, and no health insurance were more likely to report that they did not intend to receive the COVID-19 vaccine (Khubchandani et al., 2021; Nguyen et al., 2021). Caregivers’ priorities may also influence vaccination acceptance. For example, social distancing was introduced to reduce human-to-human contact and COVID-19 transmission in the community. The shutdown of recreation centers, congregate meal programs, churches, and adult day services posed serious challenges for dependent older adults and their caregivers (USAgainstAlzheimer’s, 2020). Significant among these challenges was loss of social interaction, hands-on help caregivers received to care for the PLwD, and respite opportunities for caregivers (Savla et al., 2021a; 2021b). In the current study, we investigated whether family caregivers who rely on help from family members and paid caregivers would be more or less inclined to take the vaccine.

Methods

Study Design and Context

Data for this study came from a longitudinal, multiphase project on home and community-based services (HCBS) use by family caregivers called FACES-AD (Roberto et al., 2021; Savla et al., 2021b). Primary family caregivers of PLwD in the rural Appalachian region of Virginia (as defined by the U.S. Office of Management and Budget classification; Virginia Rural Health Plan, 2022) were recruited through the Carilion Health Care System and Area Agencies on Aging. FACES-AD participants who had agreed to be contacted about future research were invited to participate in a longitudinal study on COVID-19. Specifically, we recruited caregivers to participate in three separate semi-structured

telephone interviews during the pandemic (Figure 2). Time and date of verbal consent given by participants was documented. This study and its consent procedures were approved by the Carilion Clinic Human Subjects Review Board (IRB-19-627; originally IRB#2284).

Study Participants

Of the 117 FACES-AD caregivers who agreed to be contacted about future studies, 53 opted to participate in the FACES + COVID nested longitudinal study. Among the caregivers who did not participate in FACES + COVID Wave 1, 51% of the care recipients died, 34% of caregivers could not be reached, 10% declined to participate, and 5% expressed interest but declined because of their poor health. 50 caregivers participated at Wave 2 and 27 caregivers participated at Wave 3. At Wave 3, Virginia residents who were over the age of 65 years, frontline workers, congregant settings workers, caregivers, and individuals with high-risk health conditions were eligible for the COVID-19 vaccine (VDH, 2021a). For this paper, we included caregivers who were interviewed at the beginning of the pandemic as well as when the COVID vaccine was made available. Thus, this analysis included 26 caregivers who were interviewed at Wave 1 or Wave 2, in addition to Wave 3 (see Table 1 for demographics).

We developed a semi-structured interview protocol for each wave of the FACES-COVID study that included questions about care of the PLwD, use of services, help from other relatives, and COVID-related stressors and adjustments. Specific probes elicited detailed responses about how the pandemic had affected the participants' care responsibilities. In Wave 3, we included questions about vaccination efforts. The HBM was primarily used to organize the research

literature and our study findings; the stem questions that mapped on to the domains of the HBM are presented in Figure 1. Each of the three interviews, which typically lasted 30-minutes (*Mean* = 38.33, *Range* = 21.26–60.05), were audio-recorded, transcribed, verified, and de-identified. The study investigators and three interviewers participated in weekly debriefing meetings to review interview protocols and note initial observations and emerging themes.

Analysis

We used a four-stage, trajectory-based thematic content analysis strategy. A trajectory approach (Grossoehme & Lipstein, 2016) considers data from all waves, focusing on individual trajectories. This approach is ideal when researchers want to study how processes or experiences of individuals or small groups (e.g., families) change over time. The first stage entailed data immersion (reading transcripts from all three waves) and the development of a coding frame based on a priori themes from the HBM and other themes that emerged from the data. The first three authors read a random selection of interviews and met to discuss initial themes specific to each family's experiences and identify common themes across families to understand the decision-making process of getting vaccinated. From this initial coding and preliminary discussions, we developed a coding scheme that identified themes and situated them within dimensions of the HBM (see Supplementary Table 1 for the coding scheme). Next, the three team members independently coded one-third of the interviews and verified the coding accuracy. We examined any inconsistencies in codes and interpretations at team meetings to reach a consensus on which themes corresponded to which theoretical concepts. In the third stage,

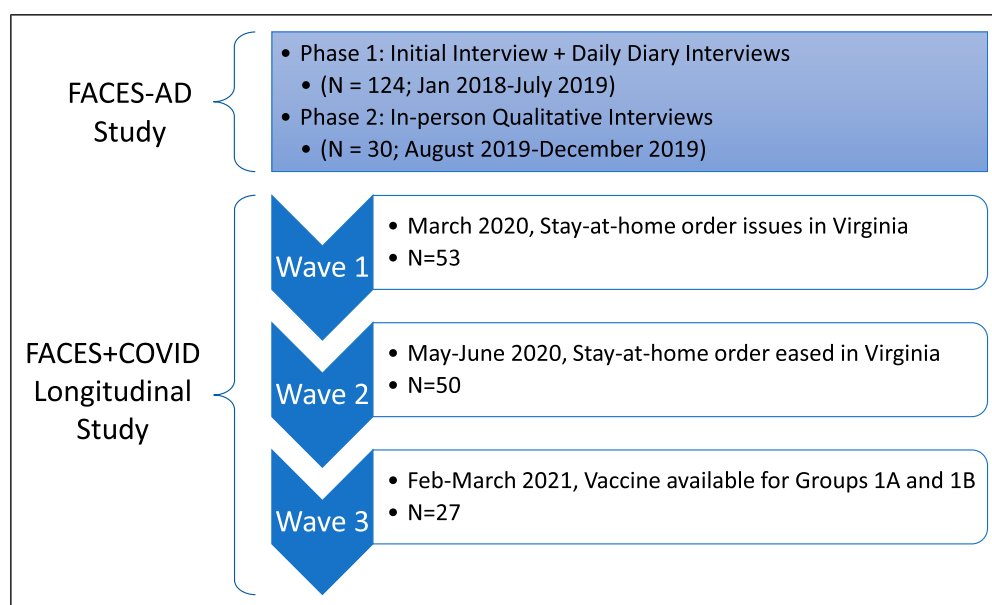


Figure 2. Timing of data collections by waves.

Table 1. Contextual and Demographic Characteristics (N = 26).

Characteristics	M±SD or n (%)
Person living with dementia (PLwD)	
Age (range: 60–93)	77.62 ± 9.27
Sex (female)	19 (73.08)
Limitations in ADL (range = 6–24)	11.19 ± 6.25
Limitations in IADL (range = 8–32)	25.27 ± 7.55
Memory and behavior problems (range: 3–22)	11.12 ± 4.62
Years since diagnosis (range: 1–11)	3.98 ± 3.18
Caregiver	
Race (white)	25 (96.15)
Sex (female)	21 (80.77)
Age (range: 30–82)	63.46 ± 12.36
Self-rated health (range: 1–4)	2.12 ± 0.82
Income	
Cannot make ends meet	0 (0)
Have just enough; never any left over	4 (15.38)
Have just enough with little leftover	12 (46.15)
Always have money leftover	10 (38.46)
Relationship to person living with dementia (PLwD)	
Husband	5 (19.23)
Wife	6 (23.08)
Son	1 (3.85)
Daughter	11 (42.31)
Sister	1 (3.85)
Niece	1 (3.85)
Grandson's fiancé	1 (3.85)

Note. M = Mean; SD = Standard deviation; ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living.

we summarized the coded data and displayed it in individual family charts. Data were entered on the same chart within columns denoting the data source (i.e., Wave 1, 2, or 3). The data were organized in this fashion to visualize the progression of the family's caregiving experiences as it unfolded over the course of the pandemic. Finally, we merged the family data and created a single chart with the Y-axis organized by codes and the X-axis organized by Family ID to identify the caregivers' decision-making process in relation to their vaccination status.

Findings

Although all family caregivers and PLwD (N = 26 dyads) were eligible for the vaccine at the Wave 3 interview, only 10 dyads received the vaccine during Wave 3. In addition, in two families, the caregivers received the vaccine but the PLwD had not, and in four families, the caregiver had not received the vaccine but the PLwD had received it. Figure 3 shows the thematic findings in relation to the Health Belief Model.

Vaccination Acceptance

We identified five factors that contributed to successful vaccine uptake by caregivers and PLwD. The perceived direct and indirect health risks associated with COVID-19, as well as cues from trusted allies, and the capacity to overcome barriers in getting the vaccine, all played an important role in vaccination acceptance.

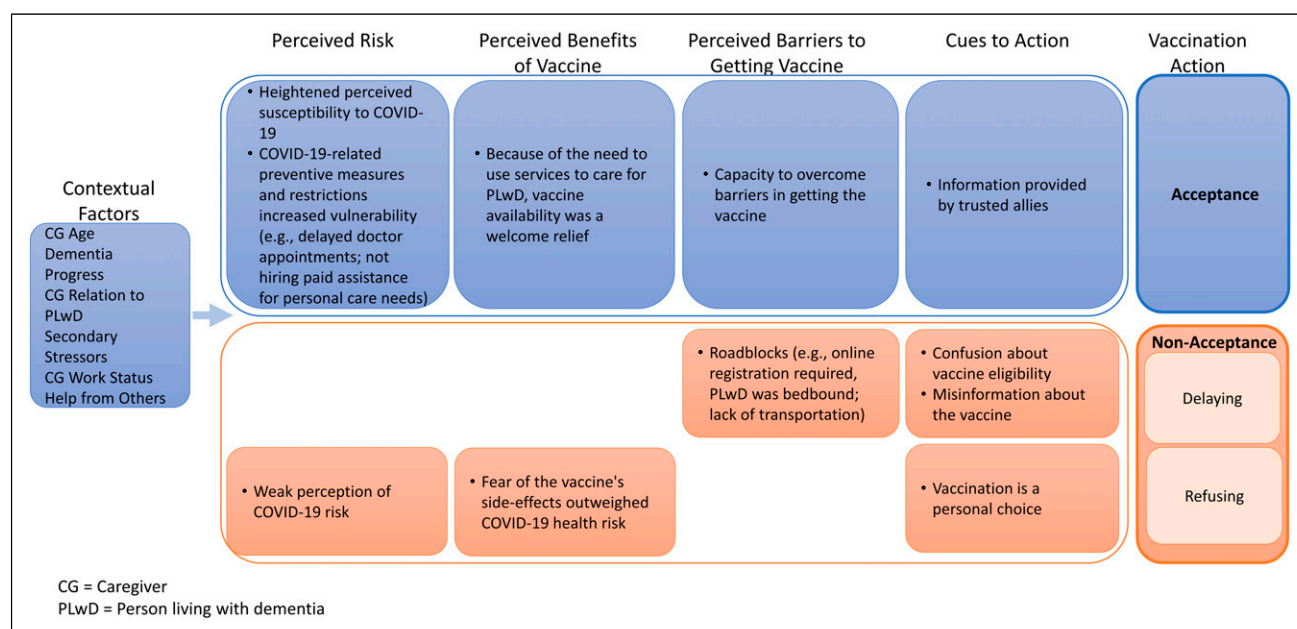


Figure 3. Health belief model: Thematic findings.

Heightened Perceived Susceptibility to COVID-19. All 10 family dyads that had received the vaccine were characterized by the caregiver's consistent belief that they or their relative were susceptible to COVID-19. One wife caregiver (P19230) at Wave 1 was typical in saying: "We are both high-risk, so I am extremely careful." She described how they would spend time with family members such as her sister-in-law and niece, who she believed were also cautious, but restricted other visitors and outings. At Wave 2, they were abstaining from visits with relatives because her niece had gone to a public group event, and P19230 wanted her niece to quarantine before resuming visits. Three caregivers whose relative got the vaccine, but they did not, also noted higher susceptibility of their relative getting COVID-19.

Trade-off between Healthcare and Risk of COVID-19. Despite feeling highly susceptible to COVID-19, 11 caregivers who were vaccinated took risks so they could get help from informal and paid helpers to care for their relative. For example, a wife caregiver (P19414) struggled with keeping herself and her husband living with dementia and physical health problems safe during the pandemic. At Wave 1, she reported following all the precautions, such as getting groceries delivered and having fewer home health workers to care for the PLwD. In addition, she reported meeting with family members for holidays, following social distancing and masking precautions. By Wave 3, she relied on three different personal care workers concurrently. She explained that she and her husband were especially susceptible to the virus because she had to take risks to get the help they needed.

I had to decide. . . he wasn't gonna get enough care with just me. [...] I had to have the help and fortunately we'd been careful [...] and] you know, we haven't had an issue with it, but it was a risk we chose to take—you gotta sometimes pick and choose.

Thus, for some families, the availability of vaccine was a welcome relief.

COVID-19 Restrictions Increased Vulnerability. Four caregivers did not think they nor their family member were at substantial risk of getting COVID-19; however, they were worried about the indirect health effects of COVID-19 on the PLwD. For instance, at Waves 1 and 2 P28013, a husband caregiver said that because his wife rarely left the house, he was not worried about her contracting the virus. By Wave 3, however, he was very concerned about his wife's physical health. She needed routine gall bladder surgery, but he was having difficulty scheduling it because of COVID-19-related hospital restrictions. He was frustrated because even though they were both vaccinated, his wife's surgery was delayed. This scenario is typical of the caregivers in the vaccinated group, as they were more concerned about the impact of preventive measures (e.g., not seeing a doctor, not hiring paid assistance for personal care duties) on their relative's health and daily quality of life.

Cues to Action Provided by Trusted Allies. Among the 14 PLwD who were vaccinated, 10 caregivers reported they had an easy time obtaining the vaccine for their relative. Three of the PLwD lived in a healthcare facility at the time of vaccine dispersals and received their shot there. The other seven caregivers received information and help early in the vaccine rollout that ensured their relative got the vaccine. They relied on their doctors or family members to schedule appointments or give them detailed instructions on how to sign up with drug stores that were distributing vaccination doses. For example, P19414 said that her cousin, who was a nurse, knew where to sign up for the shots, and they had already had their second dose at Wave 3. She commented, "It pays to know the right people, I guess." Caregivers like her received successful cues to action from trustworthy community allies and health professionals, enabling them to protect themselves and the PLwD.

Overcoming Barriers. Caregivers of four PLwD who received the vaccine indicated that they had to overcome substantial barriers to get their relative vaccinated. Nevertheless, they were persistent in their quest to get the vaccine as soon as possible. One son caregiver (P20069) reported that it took his wife 5 weeks of chasing down appointments for themselves and his mother. A spouse caregiver (P19087) said that he read that people were supposed to contact their local health department to schedule an appointment. He repeatedly tried to do so but could not get through. When he finally talked to someone, they told him all available slots were taken. Frustrated, he called his primary care physician and asked, "How in the world are we supposed to get a shot?" He shared that a staff member at the doctor's office called the health department three times for him before finally being able to schedule an appointment. He said the process for getting the shot—"except for standing in line for a long period of time"—was "acceptable." Two caregivers whose relatives received the vaccine in a nursing home faced similar barriers to getting the vaccine for themselves.

Vaccine Non-Acceptance

At Wave 3, 10 dyads, 4 caregivers, and 2 PLwD had not received the vaccine. Some caregivers expressed hesitancy and, therefore, delayed their decision, whereas others were more adamant in refusing to take the vaccine.

Delaying. Five dyads were characterized by the caregiver's patience in waiting to get the vaccine for both them and the PLwD. Four caregivers had their relative get the vaccine but were waiting to get it themselves. Common factors contributing to their hesitancy and delay in getting vaccinated revolved around communications about the vaccine.

Confusion about Vaccine Eligibility. Of the four caregivers who had their relative vaccinated, two had signed up and were

waiting for an appointment for the vaccine, and two believed they were not eligible because they did not meet the requirement to get the first dose. When the interviewer suggested to an adult daughter (P20307) that caregivers were eligible to be vaccinated, she replied that she was not a “caregiver,” believing that only paid personal care workers fit under the CDC definition of caregiver.

Misinformation about the Vaccine. Of the five dyads in which both caregiver and PLwD were signed up for an appointment, two of the caregivers reported that they had contracted COVID-19 in the past few months. The daughter caregiver (P19582) noted that her mother had also contracted COVID-19 and was hospitalized but survived. She, therefore, believed that they now had antibodies and did not need the vaccine immediately.

A third caregiver (P20228) expressed concern about the vaccine’s side effects and delayed getting the vaccine. Although he and his wife were signed up for the vaccine, they were waiting until the Johnson and Johnson vaccine became available in their health district because they had friends who got sick after taking the second dose of the Moderna and Pfizer vaccine.

Road Blocks. Two PLwD and one caregiver in the unvaccinated group were willing to take the vaccine but faced barriers in getting the vaccine. For example, health districts and pharmacies required advanced online registration for vaccinations. A daughter caregiver (P#19697) had neither a computer nor reliable transportation. While she somehow managed to make vaccine appointments for her mother and herself when we interviewed her at Wave 3, she still needed to arrange for transportation to get to their appointment. The other PLwD who was not vaccinated (P20307) was bedbound and could not physically get to the vaccination site.

Refusing. Five caregivers had no immediate plans to obtain the vaccine for themselves or the PLwD. Two caregivers had taken the vaccine but were not intending for their relative to receive it. Factors that contributed to their refusal included perceived risk level, fear, and freedom of choice.

Weak Perception of COVID-19 Risk. The role of susceptibility was more complex among the unvaccinated than for those who had been vaccinated. Four caregivers used fatalistic language such as “if I’m on God’s list that day, I’m going regardless” (P19656) at Wave 1 or 2 when discussing the risks of getting COVID-19. These caregivers often perceived COVID-19 to be less severe than depicted by the media, comparing it to influenza. They took basic precautions such as mask-wearing in the early days of the pandemic but continued visiting with family and close friends. For example, at Wave 1, an adult daughter caregiver (P19564) said she wore a mask when out in public. At Wave 2, she explained that she was

required to wear a mask at work and if she had a mask with her when out in public, she put it on, but if not, she did not worry about it. When asked at Wave 3 about getting the vaccine, she explained that on the day vaccines were offered at her workplace (she was an essential employee), she “opted out.” When asked about getting the vaccine for her mother, who was bedbound, the caregiver had not yet scheduled a vaccination appointment for her and said, “We’ll see,” implying that she had no immediate plans to get her mother vaccinated.

Fear of Vaccine. Five caregivers were skeptical about the efficacy of the vaccine. One caregiver (P20237), who is a healthcare worker, did not believe that the vaccine could be developed so quickly. Another caregiver (P28009) who was vaccinated was hesitant about getting the vaccine for her spouse because she worried that a reaction to the vaccine might cause further decline in his health.

But I’m not sure whether to give it to him or not. [...] I’m afraid if he got sick [after taking the vaccine] that it would not be a good outcome. [...] I don’t know. Maybe I’ll get it for him later—I don’t know. . . . I was totally against getting it myself and then I decided that I better get it because I have to stay well to take care of him.

The caregivers’ fear of the vaccine’s side effects was greater than their fear of the potential detrimental health effects associated with COVID-19. Also, some had heard about other family members and community members who got COVID-19 before the vaccine became available and had successfully recovered from it.

Vaccination is a Personal Choice. Three families believed that receiving the vaccine was a personal choice, not a societal obligation. A daughter caregiver (P19683) explained that from the early days of the pandemic, she wore a mask when out in public and reduced non-family and non-church related social interactions to protect her mother but indicated that taking the vaccine was a family decision. She said that their family had been “on the fence about it” because they did not trust the messaging around the vaccine rollout. She explained, “we’ve all been lied to so much about so many things. . . Well, it’s for the same reason that I wouldn’t eat a bite of sausage if I don’t know what’s in it.” This caregiver further mentioned that her daughter took the vaccine because she worked in the healthcare field but discouraged her parents from getting it for themselves and her grandmother (PLwD).

Discussion and Implications

In this study, 54% of PLwD and 46% of the primary family caregivers living in rural counties of Appalachian Virginia had received their first COVID-19 vaccine dose. Collectively, our results show that perceived risks along with cues to action

increased the likelihood of caregivers and the PLwD getting the COVID-19 vaccine. Consistent with prior studies (Malik et al., 2020), caregivers who were concerned about the possibility of the PLwD being exposed to COVID-19 and becoming gravely ill from the virus, and those who followed COVID-19-related health safety guidelines, were most likely to seek the vaccine for the PLwD and themselves.

Some caregivers had difficulty obtaining the vaccine for themselves or the PLwD. These difficulties were primarily encountered by those seeking information through calls to their health department. Caregivers who received information directly from their healthcare providers, whether it be their nudging them to get vaccinated or scheduling the vaccine with the health department on their behalf, and those who received information about vaccine availability from a family member or friend who worked in the healthcare system, had a relatively easy time getting vaccinated. These findings suggest that directly contacting caregivers and enlisting medical professionals to advocate for vulnerable older adults may be the most effective strategy for public health messaging. This method may be particularly effective in rural communities that have attempted to increase their healthcare workforce by educating and recruiting community residents. Because these healthcare workers are from the community and are familiar with the area's resources, rural families frequently place their trust in them (Magilvy & Congdon, 2000). Similarly, community service agencies (e.g., Area Agencies on Aging, Meals on Wheels) that employ community members and local volunteers can play an essential role in identifying and encouraging caregivers to sign up for vaccination (Morris et al., 2019). Wherever possible, these trusted organizations should be leveraged to address COVID-19 vaccine-related questions or concerns and assist caregivers in securing vaccines for their relative and themselves (National Association of Area Agencies on Aging, 2021).

Caregivers for a person who was housebound encountered several additional challenges. While their relatives had access to paid care services (e.g., personal care aides), caregivers reported that adequate transportation for their relative and storage equipment to deliver the vaccine to their home were unavailable in their area. Special considerations are required to provide equal access to COVID-19 vaccinations for homebound older persons and people with mobility difficulties living in rural regions to reduce barriers to vaccine access. Although costly, it is imperative that mobile vaccination clinics and in-home vaccination programs be made available to the homebound rural population (Beste et al., 2021).

A few caregivers delayed taking the vaccine because they did not fully understand the CDC or their local health department guidelines. This misunderstanding stemmed in part from the way the vaccine rollout was communicated. For example, in the guidelines of who was eligible for receiving the vaccine in Phase 1, the term "family" caregiver was not clearly defined. These findings, which corroborate prior

research (Phanhdone et al., 2021), underscore the critical importance of clear communication of health guidelines, particularly in regions with fewer resources. Providing clear directives, opportunities to engage with professional or laypersons trained to provide community education, and an understanding about the language and terms used in the rural cultures are essential, particularly for reaching residents who may have less access to or understanding of the information being conveyed by reputable medical sources.

Like many Americans, caregivers who expressed reservations about receiving the vaccine for themselves and the PLwD expressed doubt about the vaccine's efficacy. They were not convinced, despite medical advice, that they or their relative should receive the vaccine immediately. This apprehension about the vaccine may have been exacerbated by misinformation spreading on social media and other platforms (Sun & Monnat, 2021). Public health experts have made numerous suggestions, ranging from disseminating accurate information about COVID-19 and the vaccine's risks and benefits to validating caregivers' concerns and assisting them to address them (National Rural Health Association, 2021). In addition, involving faith leaders and other community gatekeepers who are viewed as trusted allies by rural residents (Levin, 2014) is another effective approach for reaching hesitant individuals.

Unlike previous research (Salali & Uysal, 2021), we found no evidence that illness in family and friends underscored the substantial health risk of COVID-19 and motivated participants to get the vaccine. In contrast, some caregivers perceived the severity of COVID-19 as low because they or their family members had contracted the virus and recovered. Further, some believed they had developed antibodies that protected them from re-infection and thus did not require immediate vaccination. COVID-19 hotlines and online chats with vaccine experts to address caregivers' questions and concerns would have been a beneficial service for many rural families as the pandemic and vaccine plans unfolded. Public messaging that addresses myths and facts about COVID-19 and antibodies with language commonly used in a region can increase vaccine receptivity in rural and isolated communities.

Many persons with advanced stages of dementia required assistance with daily living activities from home health nurses and personal care providers. Some also had other comorbidities that required regular health check-ups. Some caregivers also cared for other family members (e.g., grandchildren) or needed to rely on others to care for the PLwD because they were required to work outside the home during the pandemic. COVID-19 prevention guidelines came at a higher cost than benefit to these families. As a result, these caregivers were more likely to violate COVID-19-related prevention guidelines. Providing easily understood information on viral infections, transmission prevention techniques, and vaccine guidance tailored to families caring for vulnerable older adults should be a priority for all public health and service entities.

Future Research

Although vaccine availability has caught up to demand in Virginia's Appalachian region, our findings identified barriers to care delivery in response to a public health crisis, particularly for people with cognitive and physical impairments and their caregivers living in rural areas. Nevertheless, study limitations point to future research directions. First, study is based on a small sample. Larger and more diverse community-based samples are required to understand the needs and concerns of dementia family caregivers and identify what the future holds for the care of their relative (e.g., need for additional booster shots; homecare staff shortages) as the pandemic continues to play out. Second, the number of homebound PLwD in our sample was small, but it was clear that they were particularly vulnerable due to the absence of a clear vaccination pathway. Future research should focus on hard-to-reach older populations to understand their care needs as the pandemic transforms into an endemic. Third, PLwD were not interviewed for this study; thus, their stance on the vaccine is unknown. Future research aimed at understanding the power dynamic between caregivers and PLwD when making healthcare decisions is warranted. Finally, our interviews suggested that the fluidity of knowledge about the spread of the virus and the efficacy of vaccines influenced the caregivers' beliefs about how to proceed with the care of their relative and themselves. Thus, additional longitudinal designs and rigorous qualitative investigations that examine care practices and needs throughout the course of pandemic and other health crises are warranted.

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Supplemental Material

Supplemental material for this article is available online.

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