

## Spotlight Article

# Addressing the Needs of Rural Caregivers of Individuals With Alzheimer's Disease and Related Dementias During and Beyond Coronavirus Disease 2019 (COVID-19)

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More than 25% of those 65 years or older in the United States reside in rural areas (Skoufalos et al., 2017). Aging family caregivers of individuals with Alzheimer's disease and related dementias (ADRD) provide critical daily supports for their loved one. Caregivers in rural areas face unique challenges in accessing needed health and social services, while also having limited informal supports from family and friends due to geographic isolation (Cho et al., 2016; Greenwood et al., 2015; Pinquart & Sörensen, 2005). Rural-residing ADRD caregivers living in northern Arizona have been disproportionately affected by the coronavirus disease 2019 (COVID-19) pandemic, with higher rates of COVID-19 than urban areas and with limited community resources (Arizona Department of Health Services, 2020; Kaplan, 2020; Sanderson et al., 2017). Prior to the pandemic, 43% of those aged 60 or older reported feeling lonely or socially isolated, a situation often compounded in rural areas (National Academies of Sciences, Engineering, and Medicine, 2020). COVID-19 public health actions, including social distancing, self isolation, and sheltering in place, may be effective for curbing the spread of COVID-19. However, the emotional and psychosocial impacts of these prevention efforts are yet to be understood among

already strained aging caregivers providing constant care for a person with ADRD.

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The primary resource for many aging caregivers in rural regions is the local Area Agency on Aging (AAA). AAA branches depend upon face-to-face gatherings for preparing, planning, and providing caregiver support services. Unfortunately, COVID-19 has introduced a virtually insurmountable barrier to in-person meetings with caregivers. Social distancing, self isolation, and sheltering in place have limited AAA and comparable community organizations' access to traditional pathways for community outreach, and these practices have posed challenges to the continued provision of services. Many social service organizations are attempting to use

technology-based resources to reach their community members, but ADRD caregivers residing in rural areas may experience difficulty responding to technology-based outreach. Previous research has identified that 74% of older adults (ages 65+) lack confidence in their ability to use technology to connect with others (Anderson & Perrin, 2017). Additionally, rural caregivers may not have access to the technology and resources that support telehealth, nor have the skills or privacy needed to use such devices to access support.

This “digital divide” experienced by older adults and rural providers is creating additional barriers for local AAA chapters to keep in touch with the aging family caregivers they are attempting to serve during COVID-19. Through our interactions with AAA staff, we have learned that caregivers in our region report not feeling comfortable joining support groups via technology, because they do not want their loved one with ADRD to overhear them discussing the difficulties posed by caregiving. Other caregivers have expressed that navigating phone- or web-based meetings adds to their stress, rather than relieving it. Many caregivers are now “stuck” in their homes without respite services that were previously provided. Family and friends who assisted with caregiving tasks have reduced the frequency and duration of in-home visits because they fear exposing those with ADRD and their aging caregivers to the virus (Brody, 2020).

As we continue to respond in real time to the COVID-19 pandemic, there is a need to continue conversations surrounding the health and wellness of the aging family caregivers in rural communities. There is promising evidence that telehealth resources could be beneficial for ADRD caregivers (Chi & Demiris, 2015; Godwin et al., 2013). However, more needs to be done to evaluate how these technology-based opportunities can be implemented among those with limited resources or those who may not have the time, space, and confidence to utilize technology. COVID-19 has shed light on the need to address social isolation among aging family caregivers, as it can have serious repercussions for health and quality of life (Holt-Lunstad, 2017). We need to identify best practices for keeping this population less isolated in the future via use of technology, while also advocating for continued flexibility in service delivery options after COVID-19.

The impact of COVID-19 on rural family caregivers remains to be fully understood. Aging family caregivers play a pivotal role in the day-to-day lives of their loved ones with ADRD, and in these times their role is being strained by additional COVID-19 pressures. As Congress works to implement COVID-19 public health solutions, they must remember these rural aging caregivers and the supports they require. Congress succeeded in reauthorizing the Older Americans Act in March 2020: a critical piece of legislation to support aging family caregivers (Kunkel, 2019; National

Council on Aging, 2020). Congress will still need to ensure full funding for the Older Americans Act during the budget appropriation process. The Coronavirus Aid, Relief, and Economic Security (CARES) Act (2020) provided \$1 billion to support older adults and those with disabilities. A vast majority (\$905 million) of the CARES funding is being distributed to states to support local service providers. This funding will support existing services for older adults, including options to provide technology-enhanced services. As of this writing, The Heroes Act has been passed by the House and not the Senate. The Heroes Act would further bolster funding to federal aging programs through September 2021, to continue to effectively serve older adults during COVID-19 (The Heroes Act, 2020).

The aging of the U.S. Baby Boomer generation is creating a demographic shift, and now is a critical time for government at all levels to invest in resources that will support aging adults, including ADRD family caregivers, in continuing to live and thrive in their communities after COVID-19. A vast majority of aging adults in the United States, especially those living with ADRD, will continue to rely on the daily support of family caregivers (Reinhard et al., 2019). We need to invest in developing a robust, long-term service and support workforce to provide community-based services supporting caregivers of aging family members (Super, 2020). We also need to consider how technology can be used to expand services to rural communities and aging adults. Older Americans historically have higher voter turnout rates, compared to younger generations (File, 2017). Future electoral candidates should have a clear plan for addressing the needs of older adults: in particular, the needs of rural-residing, aging adults who are also family caregivers.

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## Conflict of Interest

None declared.

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