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Appalachian Home- and Community- Based Services for People Affected by Dementia

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Abstract

Purpose: Home- and community-based services (HCBS) have the potential to address the health needs of the rapidly growing population of people with Alzheimer's disease and related dementias (ADRD) in Appalachia and their informal caregivers. Little is known about the nature of HCBS and potential barriers to their use in Appalachia. The purpose of this qualitative study was to

describe ADRD service providers' perceptions of the barriers and facilitators to providing high-quality HCBS for people with ADRD and their caregivers in the historically underserved region of Appalachia.

Sample: A qualitative descriptive study was conducted 13 HCBS settings in Tennessee, West Virginia, Virginia, and North Carolina. A standardized, semi-structured guide was used to conduct telephone-based interviews with 13 leaders of HCBS programs.

Methods*:* Using qualitative content analysis, two investigators coded interview transcripts, and the full study team used the coded data to identify themes related to HCBS barriers to providing ADRD services and strategies HCBS leaders used to address service delivery challenges.

Findings: Participants held leadership positions in governmental (n=8), non-profit (n=3), and private (n=2) HCBS programs that provided education, service referrals, respite vouchers, support groups, and other services for people with ADRD and their families. Participants described service, cultural, geographic, and funding barriers to community-based ADRD care and strategies to address barriers, including community immersion, mobile HCBS vans, transportation services, and service advocacy.

Conclusions*:* The findings describe barriers to HCBS in Appalachia extending earlier research with evidence to frame future larger-scaled studies focused on increasing the reach of community-based ADRD care. Future studies are needed to describe larger cohorts of people with ADRD, access to HCBS services, and the relationship between service access and outcomes, such as hospital admission, control of comorbid health conditions, and caregiver self-efficacy. Implementation studies are necessary to examine adaptations of proven ADRD care models for future intervention research.

Keywords: Appalachia, Home-and community-based services, Alzheimer's disease and related dementias, Qualitative Research, Rural Health

Appalachian Home- and Community- Based Services for People Affected by Dementia

Care of older adults Alzheimer's disease and related dementias (ADRD) is a serious public health concern in the 13 states within the Appalachian region of the US. Moreover, older adults in Appalachia, compared to other US regions, are more likely to develop ADRD, and approximately 2.2 million people in Appalachian states are estimated to be diagnosed with ADRD by 2025 (Alzheimer's Association, 2025; Mattos et al., 2017). Meeting the needs of people with ADRD and their caregivers is especially challenging in rural Appalachia, an area of historic economic hardship (Black & Sanders, 2004), disparity in access to health services (Morrone et al., 2021), and regional inequity in health outcomes (Behringer & Friedell, 2006). Over 40% of Appalachia's

population lives in rural areas (defined as a non-metropolitan area with no surrounding metropolitan areas) – doubling the national average of 20% (Center for Regional Economic Competitiveness & West Virginia University, 2015; Srygley et al., 2024). Appalachian geographic and cultural factors compound these challenges (Wing et al., 2020) and increase the need for specialized home- and community-based services (HCBS; Roberto & Savla, 2023). Home- and community-based services are defined as a type of long-term service and support (LTSS) provided to meet the needs of individuals and families at home or in the community. Home- and community-based services include a range of nurse-led health services (e.g., home health nursing, healthcare consultation and coordination, disease education) and human services (e.g., adult day care service, home modifications, meal delivery; Department of Health and Human Services, 2014). Understanding how HCBS function in Appalachia is essential to develop and expand care for people with ADRD and their caregivers (Khalid et al., 2022; Vipperman et al., 2023). Moreover, evidence of service gaps and strategies to address them is essential to prepare nurses in Appalachia to lead HCBS, focusing on person-centered care, management of complex health needs, and coordination of care across settings and providers of care.

Findings from multiple studies support the effectiveness HCBS in rural Appalachia, such as programs for illicit drug use (Young et al., 2020), obesity (Gillespie et al., 2021; Lane et al., 2019), physical activity (Cardarelli et al., 2020), oral health (Zhou et al., 2021), and chronic illness education (Doyle et al., 2017; McComsey et al., 2020; Vanderpool et al., 2011). Prior research also identifies the need to refine HCBS interventions for use in Appalachia, such as fitting care practices to Appalachian values of communal kinship, self-reliance, and family-connectedness (Moloney et al., 2021; Savla et al., 2022). While research with people with ADRD has included individuals and organizations from Appalachia (Nah et al., 2024), it has not focused on how HCBS address the needs of people with ADRD in this hard-to-reach region. Thus, the purpose of this qualitative study was to describe ADRD service providers' perceptions of the barriers and facilitators to providing high-quality HCBS for people with ADRD and their caregivers in the historically underserved region of Appalachia.

Methods

Design

This study used a qualitative descriptive design including semi-structured interviews with leaders of HCBS in Appalachia (Sandelowski, 2010; Silverman & Marvasti, 2008). All study procedures were approved by the Institutional Review Board at The University of North Carolina at Chapel Hill. The COREQ Guidelines guided the report of this qualitative research (Tong et al., 2007).

Research Team

The five-member research team included two doctoral students and three faculty researchers with expertise in health services research, occupational therapy, aging, and dementia care. The primary investigator (MF) was born and raised in Appalachia.

Setting and Sample

Home-based and community-based service organizations were identified through snowball sampling with the following inclusion criteria: (a) provides support to people with ADRD and their caregivers, (b) provides services in Appalachia, and (c) funded by a state or local caregiver support organization, home health care agency, local government planning agency, or other organization providing community-based care for people with ADRD and their caregivers (Wenrich et al., 2012).

In each HCBS organization, one representative was recruited to participate in a semi-structured interview about services provided and barriers and facilitators to providing community-based care for people with ADRD and their caregivers. Inclusion criteria for service providers were: (a) ability to speak English, (b) being at least 18 years of age, and (c) being a mid- to senior-level health care provider or administrator in the HCBS organization. To recruit representatives in the HCBS organization, potential interviewees were contacted via email, and representatives who responded to the email were invited to participate in data collection activities.

Data Collection

The primary investigator (MF) collected study data using a standardized interview guide and semi-structured interviews with HCBS representatives. The topic list for interviews included HCBS organizational structures, services provided, barriers and facilitators to providing services, and strategies used to overcome barriers to providing services for people with ADRD and their caregivers in Appalachia (see Table 1) Interviews lasted up to one hour and were conducted in-person or by telephone or Zoom, depending on interviewee preference. All interviews were digitally recorded and transcribed with consent.

Table 1

Semi-structured Interview Guide Topic List

Topic	Example Question
Organizational Structure	How is this organization connected to other healthcare organizations?
Services Provided	What are your most widely requested dementia care services?
Delivery Barriers/Facilitators	What challenges does your organization face when providing services to caregivers of people with dementia?
Overcoming Barriers	In general, what do you think your organization is doing well at? Why do you think your organization is doing well at these things?

Data Analysis

Qualitative, manifest content analysis and ATLAS.ti were used to analyze the data (Ritchie

et al., 2003). First, the primary investigator (MF) read each transcript and developed a broad sense of the data for the qualitative analysis. Second, two investigators (MF and MT) created a codebook for classifying fragments of data in the interview transcripts. Third, two investigators (MF and CU) coded fragments of data in each interview transcript; for example, roles of HCBS staff were coded as "organizational structure" and additional codes were used to classify barriers or facilitators to the organizational structure and delivery of HCBS for people affected by ADRD. A third investigator (MT) supervised the coding and resolved coding discrepancies. Fourth, the investigators classified groups of coded data into overarching themes, such as barriers to providing HCBS services for people with ADRD. The full research team also reviewed the thematic findings, suggested additional refinements in analysis, and created narrative and tabular summaries of data (Ritchie et al., 2003). An audit trail and continuous process to monitor qualitative research procedures was maintained to support the reliability and validity of the findings.

Findings

A total of 13 program leaders in 13 HCBS organizations were invited and all 13 agreed to participate in the study. The HCBS organizations were located in North Carolina (n=8), West Virginia (n=1), and Tennessee (n=4). Leaders were employed by eight governmental organizations (municipal, county, regional, and state governments), two for-profit small businesses, and three not-for-profit organizations (NPOs). The settings where HCBS service leaders worked included four Area Agencies on Aging or Councils on Aging; three state-government facilitated programs offering education, respite vouchers, and family consulting; and two dementia consulting organizations. Of the 13 organizations, three provided services in a single Appalachian County and 10 organizations provided services in multiple counties. In addition to providing ADRD services, most organizations (n=7) also served other groups of older adults.

Table 2.

Home- and Community-based Services Leaders and Organizations (n = 13)

Attribute		n (%)
HCBS leaders	Role	
	Director/Manager	5 (38%)
	Service/ Project coordinator	5 (38%)
	Other	3 (23%)
	Years in organization	
	<5	3 (23%)
	≥6	10 (77%)
HCBS organizations	Primary services	
	Referrals	6 (46%)
	Family/Community education	9 (69%)
	Consulting/advocacy	6 (46%)
	Respite vouchers	5 (38%)

Attribute		n (%)
	Support groups	3 (23%)
	Other	4 (31%)

As summarized in Table 2, service leaders had diverse educational and experiential backgrounds, for example, two were registered nurses, two were social workers, and one was an occupational therapist. Most had a bachelor's degree, four had a master's degree or above. Most participants had personal caregiving experience with a family member diagnosed with ADRD.

Services Provided

Home- and community-based service organizations provided multiple services to their clients and communities. For clients, HCBS included education on ADRD symptoms and disease management and caregiver support. For other community organizations, HCBS engaged in education and advocacy to promote setting-specific dementia-friendly interventions (e.g., dementia-friendly menus at local restaurants, paid leave for informal caregivers at local businesses). Many organizations (46%) provided home visits, supportive telephone calls to assess client needs, and practical caregiving advice or referrals for home modifications, transportation assistance, and meal delivery. Approximately 38% of HCBS organizations were funded to provide caregiver respite vouchers for caregivers reporting high levels of stress and concern about burnout or exhaustion. Some organizations (23%) created a safe space for weekly support groups for people with ADRD and their informal caregivers.

Barriers to providing HCBS in Appalachia

As shown in Table 3 and the narrative below, HCBS leaders in rural Appalachia identified three barriers to delivering services: cultural attitudes, geography, and funding. They also described strategies used to overcome these barriers.

Cultural Attitudes in Appalachia.

HCBS leaders described cultural beliefs of people in rural Appalachia that created challenges to providing ADRD care. They reported that Appalachian values of "individualism," familial obligation, and "independence" were sources of strength, but were sometimes barriers to care. One cultural barrier was characterized as a "mountain mindset."

> It's that proud mountain mindset of we take care of our own...They're very private, they don't want handouts, they're very independent, they take care of themselves...There's some areas up there where just trying to access those people are hard. (Respondent 13)

Other service leaders described a cultural mistrust of outsiders. For example, one informant identified a fear, held by some families, that HCBS staff might take a family member away. "Some people…are afraid of losing everything. Like, they may be afraid that if the government gets

involved in helping them that they're gonna find something. Then they're gonna lose their loved one." (Respondent 5)

To address these cultural barriers, program leaders prioritized embracing the Appalachian culture in their practice and becoming an expert in their field. Recognizing the strong community ties in rural Appalachia, program leaders and their teams immersed themselves in local communities. For example, HCBS leaders built relationships with community gatekeepers and offered ADRD education to local leaders, volunteers, and caregivers before offering individual support. One organization partnered with local churches and created services for in-home music therapy. Another partnered with local community centers that acted as central distribution areas for state-provided meals. When offering individual support, home visits were reported as an effective strategy to build a trusting and therapeutic relationship with clients, often involving multiple visits. Key informants described this approach as time-consuming and requiring added effort from staff and volunteers, but ultimately an important way to deliver HCBS to the Appalachian people.

Gaining the trust of their Appalachian clients also required that HCBS leaders demonstrate their ability to "stand in the gap" and address the unmet needs of their clients. They engaged families by offering resources such as "navigation of services," "family consulting," and "referrals." Their expertise was a vital resource to instill hope, for example, one HCBS leader described her work educating community partners.

> It's about living well together…It makes me want to cry…the ability that one has to live well after a diagnosis is still there, so reducing stigma is super important for us, addressing stereotypes, really helping the community embrace people living with dementia and their caregivers through awareness and through increased communication, comfort with communication, as well as the recognition of what you can do even in the grocery store to make that one experience better. (Respondent 2)

Appalachian Geography.

Home- and community-based service leaders described physical barriers in rural Appalachia – the mountains themselves and long distances to services – that impeded their ability to reach families. One participant described the impact of the Blue Ridge Mountains on service delivery.

> [Name] County has a mountain in the middle of the county. And so, all the people on one side of the mountain will go to referral services on their side of the mountain, and the others will go to their side of the mountain, and there's this restriction by the mountain. (Respondent 3)

The mountains and geographically remote location of some family homes also limited the ability of ADRD caregivers to access supportive services. For example, the remote location of

some family homes limited internet access, cell phone service, and connections to public transportation. A service leader characterized the impact of these geographic challenges on HCBS.

> The lack of transportation in rural areas is…really apparent...If the doctor's super far from you, you're not as likely to go...or financially maybe being unable to afford it…the more rural areas up here are lower income. (Respondent 1)

Thus, providing HCBS was complicated by long drive times to reach clients, restricted communication, and unreliable or absent public transportation, which increased the cost and time to provide ADRD care.

Home- and community-based service staff responded to unique geographic barriers with innovative solutions. For example, one organization bought a trailer and created a mobile community-center to enter remote communities and educate people on ADRD signs and symptoms. Another organization developed a volunteer transportation system to help people with ADRD travel for appointments and shopping. A HCBS leader described bringing internet access to their clients.

> They have a van that has internet hotspots…and they have iPads in them, and we will drive it out into the community and they will go set up, like I said, at a church or somewhere in a central location that most people can get to, and people can come in and do telehealth…We'll sit down, talk to them, go through the resources and what's available. (Respondent 8)

Home- and community-based service leaders described these innovations as critical to overcoming geographic barriers to ADRD care in Appalachia.

HCBS Funding.

Many HCBS leaders reported that limited funding for HCBS restricted the reach of ADRD care to Appalachian people. Despite short-term grants, respondents consistently reported they "never have enough funding" and they reported staffing shortfalls, long waitlists, and delays in providing services, such as respite vouchers, community education, and client consultations. One participant described the challenges of relying on time-limited grant funding. "Without grant money…we don't necessarily have any funding to do public health work...without [grant] funding, all of that would cease to exist. Funding will continue to be a challenge...until we fill the needs." (Respondent 11)

Service leaders – keenly aware of the reluctance of some Appalachian families to accept outside help – lamented that funding shortfalls resulted in turning some families away. Nonetheless, HCBS leaders reported their resolve to continue to provide services and the importance of building community networks. Indeed, lacking funding for services and staff, HCBS leaders described their own personal motivation or "can-do" attitude as key drivers of HCBS

delivery in Appalachia. This personal drive was well-represented in one respondent's description of the perseverance required in her work.

> If we're going to be a community that helps community…then we have to be able to change those boundaries and barriers…Everybody has to be willing to lead in. You got to be brave and courageous, and you just got to keep slugging it out until you get in where you need... (Respondent 10)

Service leaders also valued the personal motivation of their staff and volunteers, who had a "passion" for their work, were gifted in problem-solving and building relationships, and worked "above and beyond" for their clients.

In addition to their own personal commitment to providing ADRD care, HCBS service leaders described their dependence on partnerships with other organizations to reach families of people with ADRD. They emphasized the value of educational workshops to raise awareness about ADRD. One informant described reaching out to other organizations to make his community more "dementia friendly."

> We educated the fire department...the police department in our community, so they knew the signs and symptoms [of ADRD]...As you can imagine, a first responder coming to a home, it's...important that they know how to recognize…dementia. (Respondent 9)

Finally, service leaders consistently described their reliance on community volunteers, who were essential for providing community outreach and donating funds to support outreach and educational efforts.

Table 3.

Challenges and Facilitators HCBS for people with ADRD in Appalachia with Exemplar Quotes

Challenges in Rural Appalachia	
Cultural Preferences	"One of the biggest things, is a lot of times that embarrassment. You're from Appalachia, so you'll get that mountain thing of I can take care of myself, I don't need no help." - Respondent 13
Geography	"Not only is there a shortage in actual housing, there is a shortage in safe and affordable and accessible housing. And…a number of other infrastructure issues…transportation and the proximity to other services...That population in the rural areas is definitely hard to reach." - Respondent 2
Funding	"We just never have enough funding. You know, I would like to be able to help people more." - Respondent 6
Facilitators in Rural Appalachia	
Can-do attitude of HCBS leaders	"As a group that we're continuing to not get complacent, that we're continuing to push the envelope and try new things. I really love our group, and we've got great members. We're not a big group, but everybody in it is engaged. They come to meetings, and they've got great ideas. It's not just one person driving that train, and they're excited. They've got the energy, and they've got the passion." - Respondent 9
Volunteer time and money	"They rely a lot on volunteers. And so for them they're limited by how many volunteers are willing to step up. And COVID really was devasting to the volunteers. So you got where a lot more people are wanting some services but aren't able to. Even if the funding is there, you've got the manpower isn't there through volunteers. It's frustrating for those who are running those programs." - Respondent 5
Community networks	"We do a lot of outreach and education. I developed an online education webinar that we have done that has been used with our staff at our local agencies. We've done it for the public. We've had guest speakers come in and just talk about what is dementia." - Respondent 8
Innovations to address physical and cultural boundaries	"We also have just formed a Dementia Action Collaborative, and so that group will do a few things. It will develop additional resources for community members. There's five work groups. So, one will be dementia education work group, one is caregiving work group, one is, it's like a research and data work group." - Respondent 11
Expertise in ADRD care	"The referral process is also a big part of it, because I do referral to the few adult daycares that are available in my area, and then also referrals to the geriatricians who are available, which, again, are fairly limited, especially in those rural counties." - Respondent 3

Discussion

In this qualitative study, we described HCBS leader perceptions of cultural, geographic, and funding barriers to providing community-based ADRD care in rural Appalachia. Moreover, we detailed innovative strategies HCBS leaders used to address challenges to providing supportive ADRD care for older adults and their caregivers. These findings suggest the potential of HCBS to drive culturally-engaged ADRD initiatives in a region that has historically been challenging to reach with community-based support.

First, we found that community-immersion of HCBS leaders and gatekeeper engagement promotes sustainable service implementation and delivery in rural Appalachia. This finding aligns with prior research showing that HCBS are more effective than other public health approaches to address service gaps in Appalachia because of their role as trusted gatekeepers to a range of healthcare and other resources (Savla et al., 2022; Studts et al., 2020). Extending previous studies, our findings suggest that a committed group of local community members, including gatekeepers and HCBS leaders, is a powerful, culturally sensitive support for people with ADRD and their families in Appalachian settings. This finding underscores the need for research focused on the nature of Appalachian gatekeeper outreach and impact on ADRD and caregiver health outcomes.

Second, we found that the agencies applied multiple strategies to address the geographic barriers created by the Appalachian Mountains and long travel distances. These strategies included innovations to bring services to isolated communities (i.e., mobile service vans, home visits) and bolstering transportation services (i.e., volunteer drivers, supporting public transportation efforts). This finding supports prior research reporting geographic, cultural, and socioeconomic barriers to meeting the needs of individuals with ADRD in rural Appalachia (Khalid et al., 2022; Savla et al., 2021). Our findings align with ADRD service studies set in rural communities across the US, in particular, the call for building infrastructure and exploring the feasibility of innovative solutions such as mobile health clinics (Crosby et al., 2012; Kenny et al., 2013; Intitute of Medicine, 2005; Moscovice, 1989; Orrell et al., 2017; Strasser, 2003). Adding to previous research, our findings suggested the importance of home visits and phone calls to building trust in Appalachian communities. For future research, we hypothesize that HCBS organizations that apply culturally-sensitive approaches to provide services to remote and rural communities, such as Appalachia, will have higher patient satisfaction.

Finally, funding issues were reported across all HCBS settings. We found that while short-term grants were helpful to initial implementation of HCBS, organizations were limited by the narrow window of available funding. Moreover, while HCBS were in high demand, initiation of services was often elongated as HCBS leaders labored to build trust with local Appalachian communities, which sometimes limited sustainment of services due to the short time frames of grant funding. This finding supports the need for additional funding for public health initiatives in rural communities. For future research, we hypothesize that HCBS organizations awarded long-term funding will provide sustainable and higher quality services to individuals affected by ADRD. Our findings also suggest the vulnerability of these community-based ADRD services, dependent

as they are on funding and the determination of individual program leaders and staff. This suggests the need for broader, more systematic program development and integration in the Appalachian region (Gillespie et al., 2021; Kellett et al., 2023). More broadly, healthcare professionals and researchers, especially nurses, are urgently needed to advocate for policy changes to increase funding for evidence-based HCBS strategies for vulnerable and geographically isolated populations like Appalachia.

This study has limitations. First, the small sample size and geographic diversity of HCBS organizations limited the generalizability of the findings. Second, the heterogeneity in the HCBS organizations created difficulty in thematic analysis owing to the diversity of services provided.

Based on the limitations and challenges faced by this study, we recommend expanded research to understand the role of HCBS in Appalachia. Future research with larger samples of HCBS organizations is necessary to generate replicable, culturally-sensitive evidence to guide ADRD program planning. Lastly, future study is needed to describe the extent that programs are effective and to identify models with the greatest efficiency, effectiveness, and capacity to provide equitable care.

Conclusion

Home- and community-based services are an essential but poorly understood resources to increase access to ADRD services in Appalachia. In this qualitative study, HCBS leaders identified challenges and facilitators for providing care to Appalachian people with ADRD and their caregivers. Findings include strategies to provide more equitable and holistic nursing care for individuals affected by ADRD. Further research is needed using quantifiable outcomes data to evaluate program effectiveness and identify ADRD HCBS for replication and scale-up.

Conflict of Interest

The authors declared no conflict of interest, financial or otherwise.

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