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“We Live on an Island:” Perspectives on Rural Family Caregiving for Adults with Alzheimer’s Disease and Related Dementias in the United States

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Abstract

As the United States’ aging population grows, there will be increased prevalence of individuals living with Alzheimer’s Disease and related dementias (ADRD), who largely rely on the support of their family caregivers. Family caregivers residing in rural areas face additional challenges with managing caregiving responsibilities and navigating support services. The purpose of this multilevel phenomenological qualitative study was to explore the assets, unique needs, and resources of rural-residing ADRD caregivers from the caregiver, provider, and policy influencers’ perspectives. The study took place between 2019 through 2021 in northern Arizona, a largely rural and geographically vast area home to caregivers from diverse backgrounds. Twenty-seven caregivers to a loved one with ADRD participated in focus groups. Twelve health and social services providers and twelve policy influencers, those involved in leadership positions for aging programs or advocacy groups, completed individual interviews. Caregivers demonstrate many assets which contribute to their ability to manage and cope with their caregiving role. However, caregivers face a series of issues related to their caregiving role and need early and ongoing education regarding ADRD. There is a lack of resources available in rural areas, in particular providers, making it challenging to obtain needed resources necessary to support their loved one with ADRD. Furthermore, there is a need for more providers trained in working with aging adults and those experiencing ADRD, and a need for more culturally relevant resources.

Keywords

caregiving, rural, dementia, Alzheimer’s disease, phenomenological approach, focus groups

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share their perspectives on caregiving in northern Arizona.

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As the United States’ aging population grows, there will be increased prevalence of individuals living with Alzheimer’s Disease and related dementias (ADRD), who largely rely on the support of their family caregivers. Family caregivers residing in rural areas face additional challenges with managing caregiving responsibilities and navigating support services. The purpose of this multilevel phenomenological qualitative study was to explore the assets, unique needs, and resources of rural-residing ADRD caregivers from the caregiver, provider, and policy influencers’ perspectives. The study took place between 2019 through 2021 in northern Arizona, a largely rural and geographically vast area home to caregivers from diverse backgrounds. Twenty-seven caregivers to a loved one with ADRD participated in focus groups. Twelve health and social services providers and twelve policy influencers, those involved in leadership positions for aging programs or advocacy groups, completed individual interviews. Caregivers demonstrate many assets which contribute to their ability to manage and cope with their caregiving role. However, caregivers face a series of issues related to their caregiving role and need early and ongoing education regarding ADRD. There is a lack of resources available in rural areas, in particular providers, making it challenging to obtain needed resources necessary to support their loved one with ADRD. Furthermore, there is a need for more providers trained in working with aging adults and those experiencing ADRD, and a need for more culturally relevant resources.

Keywords: caregiving, rural, dementia, Alzheimer’s disease, phenomenological approach, focus groups

Introduction

As the aging population grows in the United States, more individuals will be living with Alzheimer’s disease or related dementias (ADRD), with an estimated 12.7 million adults aged 65 and older diagnosed with ADRD by the year 2050 (Alzheimer’s Association, 2022). The Alzheimer’s Association’s (2022) annual report reveals the impact on family caregivers and our health and social service systems with the cost of formal care alone reaching \$321 billion a year. ADRD is a costly condition associated with receiving informal, unpaid care, most likely by a family member.

Family caregivers provide the bulk of care to individuals with ADRD. In the U.S., 11.3 million ADRD family and other unpaid caregivers provide an estimated 16 billion hours of unpaid care annually, representing an average of 27.1 hours of individual caregiving per week, which is worth an estimated economic value of \$271.6 billion in 2021 (Alzheimer's Association, 2022). Family caregivers of individuals with ADRD experience significant caregiver strain (Fonareva & Oken, 2014; Perkins et al., 2013; Wennberg et al., 2015). They also experience high rates of chronic stress, sleep deprivation, anxiety, depression, physical health conditions, and potential early mortality (Alzheimer's Association, 2022; Elliot et al., 2010; Ma et al., 2018; McCrae et al., 2016; Peng & Change, 2013; Roth et al., 2015; Seeher et al., 2013).

Research about the needs of rural ADRD family caregivers is limited and is needed as rural living can create additional caregiving complexities. Caregivers in rural areas have less available services, less access to health care providers and health education, difficulties with transportation to services, and increased isolation (Castro et al., 2007; Dunn et al., 2016; U.S. Department of Health and Human Services, 2014). This study occurred in the six counties in northern Arizona, a primarily rural area, with five of the six counties in the region reporting the poorest health outcomes in the state (University of Wisconsin Population Health Institute, 2018). To improve the health outcomes among rural caregivers in the region, a deeper understanding of their population-specific experiences from an ecological perspective is needed. The purpose of this multilevel phenomenological qualitative study was to use a socioecological lens (Brofenbrenner, 1981; McLeroy et al., 1988) to explore assets, unique needs, and resources of rural-residing ADRD caregivers from the lived experiences of caregivers themselves, providers, and policy influencers.

Methods

Study Setting

Research Location, Team, and Reflexivity

The study methods are reported following the consolidated criteria for reporting qualitative research guidelines (Tong et al., 2007). All study activities were approved by the university's Institutional Review Board (Project #1404845-14). The study took place between 2019 and 2021 in northern Arizona, a sparsely populated rural region with residents from a variety of cultural groups (Sanderson et al., 2017). The research team involved in the data collection and analysis included two public health researchers, a social work researcher, a psychology researcher, a nursing researcher, two public health graduate students, a graduate social work student, and two project coordinators. The lead researcher (female) facilitated every interview and was the moderator for the majority of most of the focus groups. The two project coordinators took turns serving as a note taker during the focus groups. The lead researcher did not have any previous relationships with focus group participants and had worked previously with two of the interviewees. The lead researcher had not previously explored caregiving amongst this population, but did have the experience of being a granddaughter to someone with dementia.

Study Design. The project is guided by the socioecological model to explore multi-level perspectives on the assets, needs and resources of rural family caregivers to individuals with ADRD from the perspective of the family caregivers (N=27), health care and other service providers (N=12), and policy/decision makers (N=12), using a phenomenological approach to data collection and analysis (McLeroy et al., 1988; Polkinghorne, 1989). The

phenomenological approach focused on understanding the issues faced by rural caregivers through their lived experience and the lived experiences of providers and policy/decision makers in their attempts to support the family caregivers in the region. Participants were identified based on the inclusion criteria for the study, which included being an adult residing in the region and (a) being a self-identified family caregiver to someone with ADRD, (b) a regional/local ADRD provider, or (c) a policy maker with political or administrative influence regarding ADRD resources in the region. The inclusion criteria did not limit eligibility by participant age range (i.e., only older caregivers) or stages of ADRD disease processes as the stated purpose was to explore the lived experiences of rural caregiving in the region. Limiting the experiences to those who were older or only caring for loved ones in more advanced stages of ADRD would limit the contextual understanding of the experiences of the diverse group of ADRD issues in the region.

Participant Selection and Characteristics. The study involved interviews of providers and policy makers, as well as caregiver focus groups. All participants provided informed consent to join the study. Prior to COVID-19, participants provided written consent. After COVID-19, the IRB approved a waiver of written consent and allowed for verbal consent, which was completed at the time of the data collection and documented in the recording of the session. Provider and policy maker interviewees were recruited via direct email contacts identified through review of public records or recommended by other participants. Individual interviews were conducted by the lead researcher over the phone or in person. Provider interviewees (N=12) ranged in age from 38-72 years old (SD=12.2; Mean=55.4), eleven were White, one refused to provide race or ethnicity, nine were female, and three were male. Policy maker interviewees (N=12) ranged in age from 23-64 years old (SD=11.3; Mean=48.7), one was Asian, one was African American, one was American Indian, nine were White, ten were female and two were male.

Family caregivers for focus groups were recruited through social media, an ADRD research registry, flyers, and word-of-mouth. The first three focus groups were held in person, but the remaining eleven were conducted remotely using teleconferencing software (Zoom) due to COVID-19 physical distancing guidelines. There were no dropouts from the study, but eight out of the eleven Zoom-hosted focus groups involved only one participant. A moderator and note taker were present in each focus group. Focus group participants (N=27) ranged in age from 41-90 years old (SD=13.9; Mean=66.7), one participant was Hispanic, two were American Indian, twenty-four were White, nineteen were female, and eight were male.

Data Analysis

Data Collection and Analysis

The interviews and focus group guides were developed to explore the assets, needs, and resources for rural family caregivers of individuals with ADRD in the region. To explore the lived experiences of the various participants, both the interview guide and focus group guide were semi-structured, allowing for additional probing for understanding as required. The interview guides contained questions relevant to the provider and/or policy maker perspectives and the focus group guides were specific to the direct family caregiving experience. Additionally, the use of the framework method allows for the verbatim transcription of all interview and focus group data to not lose any contextual information when completing data analysis. The framework method guided data analysis and included seven steps: transcription, reviewing transcripts to familiarize with data, coding the transcript, building the analytical framework or codebook, applying the framework or codebook to the transcripts, charting data

from transcripts into the framework matrix, and interpreting the data (Gale et al., 2013). Each interview and focus group were audio recorded, transcribed verbatim, and quality checked for accuracy. Provider interviews produced a total of 181 pages of text, policy maker interviews produced a total of 191 pages of text, and caregiver focus groups produced a total of 315 pages of text for analysis. At the end of both the interviews and focus groups, information was reviewed and clarified with participants.

An *a priori* codebook was initially established based on the topics and questions in the data collection instruments. Two independent coders came to a consensus on each transcript and updated the codebook accordingly with emergent codes and relevant themes. With the interviews, the two coders reached data saturation and stopped updating the codebook after the twenty-first transcript out of a total of twenty-four transcripts were analyzed. With the focus groups, the two coders reached code saturation after the fifth transcript out of the thirteen total transcripts. The study team used NVivo to organize the data and pull the framework matrices for final analysis of themes (QSR International, 2021).

Findings

Study results across the provider and policy maker interviews and the caregiver focus groups are organized by the three larger themes: caregiver assets, caregiver needs, caregiver resources, and cultural considerations. Table 1 provides a summary of overall themes and codes and highlights where codes overlapped across levels.

Caregiver Assets

The ability to ask for help while staying connected to others and their loved one with ADRD was identified as a caregiver strength or the good aspect of caregiving: “I also see so much strength in those caregivers who are strong enough to ask for help.” (Provider 9). A caregiver discussed staying connected with their loved one with ADRD as the following: “I enjoy the fact that I still have my husband and every once in a while, we have the glimmer of his old self...there’s still a spark in there” (Caregiver JP3).

Caregivers also noted that staying connected to others was a form of self-care: “Build a life of your own. I mean, I know you must take care of your loved one, but that doesn’t mean you don’t have a life yourself. Make friends, talk to people. Isolation is the big enemy” (Caregiver JP1). Caregivers discussed the fulfillment and satisfaction they received from caregiving, and providers and policy makers described the compassion and devotion demonstrated by caregivers. “This isn’t just something they’re going through the motions. They’re putting their heart into it; they’re giving it their all. And it is really hard, but they’re going to keep doing it” (Policy 12). A provider (11) also described caregivers as committed, despite having limited resources “Their dedication to caring for their loved ones is amazing because they don’t have a lot of resources.” A caregiver shared the satisfaction they feel as a caregiver, “I get a certain amount of satisfaction from knowing that she’s still here...just being able to provide opportunity for her to see her grandkids, see her friends” (Caregiver MP1).

Caregivers used creativity to manage their role and were a source of knowledge for others regarding the health of their loved one with ADRD, as one policy maker (3) noted, “listen to the family, because they’re the ones who live with them and they see it, you know?” Using their faith, having routines, being patient, keeping a sense of humor, and being willing to learn were also strengths of caregivers. Finally, both providers and policy makers discussed the resilience they see in ADRD family caregivers:

You have to have a strong constitution...it's like you're running a race and you know that you'll get to the finish line, even though you're totally exhausted. But you don't get to the finish line and you just have to keep going. (Provider 12)

Caregiver Needs

The unique needs of caregivers fall into either challenge they experience in their caregiving role or processes they must undertake to access needed support resources.

Challenges in Caregiving

Caregivers can struggle to admit they have limitations and need help, "almost nobody says, 'hey, I'm at my wits end. I'm burned out. I need to take care of myself.' We often have to tell people that" (Policy 5). When caregivers do ask for help, there can be feelings of guilt. However, in not asking for help, caregivers can face exhaustion due to the sacrifices they are making: "We are carrying...a heavy burden. It's a quiet burden" (Caregiver JP2).

There may also be a lack of understanding from others and a lack of emotional support, which can create isolation. "They end up being so isolated both emotionally and physically from help, and they get really discouraged" (Provider 11). A caregiver described attempts of others in their lives trying to understand and support them and how that can feel not authentic, "Generally, I find people are sympathetic, superficially. My neighbors, friends, they don't really understand the situation unless they're going through it themselves. There's a general lack of understanding of what Alzheimer's is" (Caregiver JP1). Finally, a policymaker defined the isolating impact of coping with ADRD, "The disease in and of itself isolates the individual and typically the caregiver, which means less connectivity to the community as a whole" (Policy 10).

Caregivers identified feelings of frustration, "It's just like sometimes you get two steps ahead and then you got to go three steps back, and it can be frustrating" (Caregiver KP1). They also described resistance to care from their loved one with ADRD and a lack of gratitude for the care they provide: "You get no acknowledgement, no gratefulness, no response for what you're doing. She never says, thank you for doing this for me. She doesn't know. She doesn't understand" (Caregiver JP1). There were also challenges related to the role reversals caregivers faced, in some cases it was the spouse taking on previously held roles of their husband or wife, and in other cases it was related to a child now caring for their father or mother:

This is my dad. He's the guy that was taking care of me for so long...so if I was having a problem, I would love to call my dad. And just not being able to, and then having that role reversal switch...it's an uncomfortable situation. (Caregiver CP1)

Caregivers in this rural region also face socioeconomic and financial challenges related to care: "There are a lot of people whose living conditions are poor. They don't have a car. They have their own family issues of being in a lower economic, rural community" (Provider 1). Caregivers identified that the cost of care led to financial strain and that they needed to access state-sanctioned long-term care coverage to avoid going into bankruptcy. Provider and policy makers shared that many caregivers try to uphold an image that portrays their situation better than what is happening, but in doing so this created difficulty in them being eligible to receive these needed care resources: "They're too proud and they won't say what they

need...and then that can disqualify them. And we constantly are telling caregivers, be truthful...but it's the pride" (Policy 11).

Caregivers will sacrifice their personal needs and report a sense of losing their own identity. Providers and policy makers reflected this when discussing caregivers neglecting their own health issues: "You see so often that the caregivers themselves, their health suffers because they're so devoted... so passionate about caring for their loved one" (Provider 9). There is also a loss of control and uncertainty about the future as caregivers watch their loved one with ADRD change: "Watching their loved ones disappear a little bit at a time. Having to say goodbye to that person before they're gone" (Provider 4).

Caregiver Needs Related to System Processes

The unique needs of rural caregivers are reflected in the strategies they use to access resources. It was important for caregivers to find ADRD specific resources in their community, having access to early education regarding the disease process and being a caregiver. "If there was a way to reach people earlier, to make them understand... just collecting resources, learning about the disease, learning about communication skills and self-care" (Policy 5). This early education would help caregivers know what to expect and what options are available to them as they needed to find in-home supports or decide for their loved one to live in a supported setting. Caregivers also needed to know more about establishing legal and financial oversight for their loved one: "It was just horrendous, trying to get the power of attorney and getting her will done and getting the bank account in my name and all the legalities" (Caregiver BP1).

Obtaining a diagnosis was identified as critical to establishing support eligibility but could be difficult to obtain. Providers and family members described that getting an ADRD diagnosis "requires a neurology or a neuropsychology evaluation... again, that just presents another hurdle, and now we're three to six months on a waiting list" (Provider 1). Some caregivers reported that it took months to years to get the official diagnosis. In some cases, delays in identifying ADRD were related to provider hesitancy in having the discussion with families.

Even when caregivers can identify required care needs, either the care isn't available due to the rural areas lacking providers or the cost of care is prohibitive. "We have a big problem ... with lack of providers in rural areas" (Policy 8). Regarding the cost of care, one policy maker summarized the issue as follows, "I don't think our government supports our [older adult] population to live even at home with help or in a facility... And I think that that's where we fail them, is that there's got to be that financial balance" (Policy 3).

Caregiver Resources

Caregiver resources were discussed as those that were helpful, those that were not as helpful, strategies recommended to improve resources, and cultural considerations related to resources.

Helpful Resources

Groups that could provide ADRD specific education and system navigation were identified as very important to caregivers:

It's those groups whose job is to educate and spread accurate information not only about the diagnosis, about the symptomatology, about the resources

available in the local community to offer that support...to help them connect to resources they may need for their loved one. (Policy 10)

These groups also help connect caregivers to other caregivers whom they could connect with through education events or support groups:

They were six-week classes, and they were very useful from two points of view. One is you'll learn a lot of information as to what to expect. And secondly, you met other people who were in the same boat with you, and that helps a lot. Because you feel like you're unique, but you're not unique. (Caregiver JP1)

Support groups were helpful for caregivers as they connect them to others whom they can learn from regarding informational and emotional supports. Support groups helped in "connecting with other caregivers...and then also being able to share resources" (Policy 12). A caregiver reflected on the benefits of support groups, which provided assistances the health care system could not provide, "Just by everyone telling their experiences helped tremendously because you're talking with people that are dealing with the same thing you are, because sometimes the doctors really don't know" (Caregiver KP2).

Helpful resources also included the following: adult day care providers, case management, financial planning, legal planning, food assistance, hospice, in-home health supports (i.e., hospice), memory units, and transportation services. Respite was noted as important for providing a needed break, "I take those 20 hours in a seven and an eight and a five, because that gives me three days to just get away or... to be right in there taking a nap" (Caregiver MP1). Memory cafés, while not available locally, were noted as an area of growth. A memory café hosts gatherings in which the individuals with ADRD and the caregiver come together and the person with ADRD completes an art or music activity while the caregiver connects with other caregivers or gets ADRD education.

Less Helpful Resources

Respondents identified that although any resource would be helpful, the challenges caregivers must manage to get to resources made them not helpful. This included complicated application processes that caregivers must manage, with copious and very confusing paperwork: "They've got to do a whole application with them too. It's just a lot of paperwork, and caregivers don't have time to do all of that" (Policy 11). Caregivers noted that websites were outdated, and it was hard to get direct responses when speaking to others about how to access desired resources: "I can internet search everything, but that it seems like, like a specific direct question, I can't just find an answer" (Caregiver CP1). Even when resources were available, caregivers were often not approved for enough care.

Caregivers noted that some support groups were not helpful if they could not bring their loved one with them as they had no other care options. Caregivers who were still working noted that support groups were often provided at times that are inconvenient for those who work fulltime. Younger caregivers did not find support groups helpful as they were often the only one present who was a caregiver to a parent instead of a spouse.

Finally, formal health care providers were identified by some participants as not helpful. Caregivers noted that providers did not seem to know how to communicate with their loved one with ADRD: "One nurse practitioner didn't understand what Alzheimer's was, because when she would come in and talk to my husband, she would yell at him. And finally, I said, 'You know, he's not deaf. He has Alzheimer's'" (Caregiver JP3). Caregivers were

prescribed expensive medications that didn't always work and found health providers hesitant to talk about ADRD. A need for training health providers about ADRD was identified:

I find a lot of incompetence in the medical field with Alzheimer's... they don't have the training. They don't get it... and that's why I say, if my mom was in a facility, she'd be dead because people go in facilities, and they die because they don't get real care. They don't get that continuous supervision that they need in order to stay safe. (Caregiver M)

Strategies Recommended to Improve Resources

A mechanism to provide care coordination services was seen as important by providers and policy makers, "one point of entry and it's all connected to one assessment of your needs and then you have a case manager throughout, that's from one place" (Provider 4). Caregivers referred to a desire for a single place to go, or a catalogue of resources they could access to learn about resources available in their area. "All in one place... because the caregivers of dementia, we don't have a lot of the resource of time and freedom to shop and to search...we are home bound, and we're just isolated out here. We live on an island" (Caregiver MP1).

Providing better training and pay to the professional caregiver workforce could also help reduce turnover while improving quality of care. There is a need to invest more funding into the system, so caregivers have more access to affordable and well-trained caregiving and health resources. "We haven't got used to the aging population, we haven't had the good policy for supporting aging segment of our population" (Policy 2).

Improved access to transportation was noted, especially in rural areas, and often resources are far from the caregiver:

Transportation at the local level... we have a lot of [older] folks who are no longer able to drive and/or due to the distance the cost of gas sometimes for those that are able to drive they'll say, 'I'd like to come to your seminar... but you're holding it in such and such area, and that's about 40 miles.' (Policy 4)

Cultural Considerations for Resources

The region in which this study was completed is rural, and many residents identify with racially or ethnically diverse backgrounds. Providers and policy makers were asked how resources could be made more culturally relevant in the region. Stigma was noted as an issue that may make some groups reluctant to discuss ADRD. The need to culturally adapt resources was described, as the terminology used within resources or approaches to providing the resource does not resonate with all groups. "The word dementia is not a word that translates into the [Native Nation] language. So, we have to be aware of the language we are using" (Provider 2). It was noted to take respectful approaches and honor the cultural knowledge of the communities, allowing them to help guide the content and format of the resources:

I think as a professional, we tend to have the presentation method. I think that format may be not good for all the communities...so, we need really a partner from the community...they can guide us to how we can adapt, and they can deliver. (Policy 2)

Caregivers also echoed this sentiment regarding the need to make resources more culturally appropriate:

My mother is from [tribal name] ... it'd be nice if you could find somebody here that could speak her language... and there just isn't... even just somebody who understands things like the humor or the food and things like that, I think would make a huge difference in the day, other than what I, and my family, can provide. (Caregiver JP4)

Caregivers identified that being a caregiver was something valued in their family tradition and providers and policy makers reflected on caregiving sometimes aligning with a cultural gender role expectation:

Female caregivers, they see it almost as their duty... and they think they have to bear it alone and they're not as receptive to reaching out because that's not what they should do. They should take care of their own families. (Policy 4)

Many caregivers also identified the importance of their religion or spirituality to the way in which they coped with caregiving: "There are times when I need like spiritual help, and I need to go back to the reservation maybe ceremonies that are conducted" (Caregiver EP1).

A self-reliance aspect of the rural culture was also discussed regarding approaches to caregiving and perhaps not asking for help:

It's a different culture... but when you look at service provision overall, my dad's not one of those people that in general is going to seek out help overall just because he comes from the generation of hard work, you do it all yourself and you keep things inside your house. You don't share it to the world. (Policy 6)

A caregiver reflected on this as well, "the downside that if that is your cultural background, 'hey handle it yourself,' you don't ask for help very easily. People have caught me on that several times. Why didn't you ask for help? It never occurred to me" (Caregiver GP2).

Table 1
Summary of Themes

Theme	Policy Level Codes	Provider Level Codes	Caregiver Level Codes
Caregiver Assets	Asking for help	Asking for help Attentiveness to their own health Staying connected with others	Connecting with others Self-Care & Balance
	Compassion Devotion	Compassion Devotion Faith Patience	Fulfillment Grateful Improved relationship with person with ADRD Showing loyalty
	N/A	Creativity Having routines Willingness to learn	N/A

	Awareness of loved one's health	Awareness of loved one's health	N/A
	N/A	Sense of humor	Sense of humor
	Resilience	Resilience	
Caregiver Needs/ Challenges in Caregiving	Admitting their limitations	Feelings of guilt when asking for help	Asking for help
	Exhaustion	Exhaustion	Burden & sacrifice Lack of sleep
	Lack of emotional support Lack of understanding from others Isolation	Lack of emotional support Lack of understanding from others Isolation	Lack of understanding from others
	N/A	N/A	Frustration Person with ADRD difficult or not grateful Role reversal
	N/A	Socioeconomic	Financial strain
	Upholding an image	Upholding an image	N/A
	Uncertainty about the future Watching their loved one change	Uncertainty about the future Watching their loved one change	Loss of control Accepting their loved one as they change
	Navigating health issues Neglecting their own health	Navigating health issues Neglecting their own health Not enough time for themselves	Lack of personal time Loss of self
Caregiver Needs/ Caregiver Needs Related to System Processes	Contacting ADRD resources Early education	Contacting ADRD resources Early education	Education about ADRD Establishing legal and financial changes
	Cost of care	Cost of care	Establishing long term care coverage
	Get diagnosis Provider hesitancy Lack of access to experts	Get diagnosis Provider hesitancy Lack of access to experts	Get diagnosis Provider hesitancy Lack of access to experts
	Lack of access to needed resources Location of resources	Lack of access to needed resources Location of resources	Location of resources
	Lack of knowledge of resources	Lack of knowledge of resources	Poor health provider interactions

	System navigation	System navigation	
Resources/ Helpful Resources	ADRD specific Education about ADRD	ADRD specific Education about ADRD	ADRD specific Education about ADRD
	Support groups	Support groups	Support groups
	Faith-based	Faith-based	N/A
	Respite Hospice In-home supports	Respite Hospice In-home supports	Respite Hospice In-home supports
	Memory cafes	Memory cafes	Adult day care
	Food assistance	Food assistance	Food assistance
	Paying caregivers	Paying caregivers	N/A
	N/A	Financial planning	Case management Legal supports
	N/A	Living options Memory units	N/A
	Transportation	Transportation	N/A
Resources/ Less Helpful Resources	Complicated application processes	Complicated application processes	Navigation challenges
	Resources that do not provide enough care	Resources that do not provide enough care	N/A
	N/A	N/A	Support groups
	Need for health care provider training	Need for health care provider training	Health care providers and hospitals
Resources/ Strategies to Improve Resources	Care coordination Easier to identify resources Improve access to care	Care coordination Easier to identify resources Improve access to care	One place to go Less paperwork
	Caregiver workforce Provider training (health care providers)	Caregiver workforce Provider training (health care providers)	
	Caregiver training Early education on ADRD	Caregiver training Early education on ADRD	Caregiver training Early education on ADRD
	Transportation	Transportation	
Cultural Considerations for Resources	Cultural adaptation Respectful approaches	Cultural adaptation Respectful approaches	Culturally receptive services
	Stigma	Stigma	N/A

	Gender roles	Gender roles	Caregiving valued by family
	Generational differences	Generational differences	Self-reliance
	N/A	N/A	Religion

Discussion

Results of this study point to the need for updates to practice, areas for future research, and policy changes needed to support caregivers of older adults in the United States. Across all stakeholders, it was identified as important for caregivers to avoid isolation and stay connected with others. Caregivers shared their sense of obligation but gratefulness in caregiving as it kept them connected with their loved one, which has been noted in previous work (Greenwood & Smith, 2019). However, caregiving in a rural region of the country created unique challenges. The U.S. health system currently requires a diagnosis to access needed resources, and aging adults living in rural areas struggle to find the needed specialists to provide the ADRD diagnosis (Alzheimer's Association, 2022). Even with a diagnosis, there is still a large gap in providers readily trained to work respectfully with the aging population and those from a variety of cultures. Despite a 2008 Institute of Medicine call to action to increase the number of providers trained to work with older adults, over a decade later, the U.S. is still falling short. This is unfortunate since the number of ADRD caregivers is expected to double by 2060 and the need for geriatric specialists will become more dire (Alzheimer's Association, 2022).

Providing resources that are not culturally relevant could further inequities experienced by racial and ethnic minoritized groups. Due to a history of discrimination in the U.S., racially and ethnically marginalized groups experience health disparities, including higher rates of ADRD (Bailey et al., 2017, 2021; Rajan et al., 2021). There is a need for more research on multicomponent caregiver interventions that are effective with diverse populations (Alzheimer's Association, 2022; Gaugler et al., 2017; Pinquart & Sörensen, 2003). Previous research identified that interventions are more effective if they involved input from family caregivers and were flexible to change over time as needed (Gitlin & Hodgson, 2015). Also, caregivers who are provided necessary education on managing their care responsibilities demonstrate improved health (Grossberg et al., 2010; Vickrey et al., 2006; Voisin & Vellas, 2009).

Regarding policy, the Biden-Harris Administration has proposed an American Jobs Plan and an American Families Plan, which call for an investment in caregiving resources and more inclusive paid leave for family caregivers (The White House, 2021). Legislators considering these policies should also add a mechanism for reimbursing providers so they can be paid for services completed, specifically targeting family caregivers (Haggerty et al., 2020). They should encourage patient-centered and family-centered care, as these approaches also focus on moving away from a deficits alone approach and provides opportunities to leverage the unique strengths and needs of individuals with ADRD and family caregivers (Alzheimer's Association, 2022; National Academies of Sciences, Engineering, and Medicine, 2016).

This study is limited in its transferability as it occurred in one geographic area of the U.S. and our sample did not reflect the full diversity of the region. However, Arizona does have one of the largest aging populations in the country, with a projected 33% increase in ADRD by 2025 (Alzheimer's Association, 2022). Additionally, COVID-19 moved the focus groups to an online platform, Zoom, which may have lowered participation of caregivers with limited technology skills or resources. Future research is needed that can capture the perspectives of

caregivers via face-to-face discussion, which could capture more in-depth collective knowledge. Finally, it is unknown how some issues faced by caregivers were exacerbated due to the pandemic.

Conclusion

Finally, the study team published a brief report and resources guide based on study results that can be used to advocate for needed policy and practice changes (Bacon et al., 2021). Policy and practice recommendations to address the needs of rural ADRD caregivers included expanding access to both financially and geographically accessible services; allowing flexibility in the delivery of services so they can be locally relevant; providing system navigation support to caregivers; establishing specialized ADRD care providers in rural areas, such as senior day care and memory units; and utilizing existing senior centers to house programs and services.

Family caregivers play a vital role in supporting older adults with ADRD in the United States. This study illuminated the pressing need for policy and practice changes to support family caregivers, especially those in rural areas. Investment in resources to build a stronger health and social services workforce prepared to help caregivers navigate their caregiving role over time is needed. Additionally, given the growing diversity in the United States, more research is needed to create and promote culturally relevant caregiver support resources.

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