**Original Research Article** 



# Representing the Needs of Rural Caregivers of People Living With Alzheimer's Disease and Related Dementias Through User Personas

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Decision Editor: Alison Phinney, PhD, RN

#### **Abstract**

**Background and Objectives:** Rural caregivers of people living with Alzheimer's disease and related dementias (ADRD) face unique caregiving challenges. Current interventions do not address many of the systemic barriers experienced by rural ADRD caregivers, including barriers related to geography, healthcare services access, and financial insecurity. The objective of this study was to gain a deeper understanding of rural ADRD caregivers' needs, strengths, and strategies in obtaining caregiving support, and to represent these attributes in the form of personas that can be used to design interventions for rural ADRD caregivers.

**Research Design and Methods:** In this qualitative user-centered design study, we conducted semistructured interviews with self-identified caregivers of people living with ADRD in rural areas. Interview data was copied to a virtual whiteboard, and affinity diagramming was used to confirm a priori attributes and yield inductive attributes relevant to rural ADRD caregivers. Attributes were assigned to personas, which were then validated through team-based discussion, consultation with a study advisory board, and review by rural caregivers and community partners.

**Results:** Analyses of *N* = 19 interviews yielded 7 inductive attributes relevant to rural ADRD caregivers of persons living with ADRD and 5 distinct personas: Capable Christine, Connected Connie, Isolated Irene, Learning Larry, and Discerning Dan. Personas differed on inductive attributes including financial security, subjective rurality, attitudes, connectedness, and information behavior, including preferences for traditional versus technology-based information seeking.

**Discussion and Implications:** The personas identified in the present study can be used as tools to represent and efficiently communicate the intersection and interaction of attributes relevant to designing interventions and technologies to meet the support needs of rural ADRD caregivers.

Keywords: Alzheimer's disease, Caregiving—informal, Rural sampling, Technology

**Translational Significance:** Caregivers of people living with Alzheimer's disease and related dementias (ADRD) who live in rural areas face unique challenges. To design interventions and technologies to meet the support needs of this population, it is vital to understand their caregiving needs, strengths, and strategies and represent these attributes in usable design tools. In this qualitative user-centered design study, we identified 7 attributes that are vital to understanding rural ADRD caregivers' needs and represented these attributes in 5 distinct rural caregiver personas. These attributes and personas offer multiple promising paths for interventions and technologies tailored to meet real rural caregiver needs.

## **Background and Objectives**

There are 55 million people worldwide with Alzheimer's disease and related dementias (ADRD), and every year this number increases by 10 million (1). As the proportion of older adults living in rural areas increases globally, the prevalence of ADRD in these areas will increase (2). One U.S.-based study found that people who live in rural areas are more likely to be informal caregivers, and provide more hours of care, than their urban counterparts (3). It is critical to understand the

significant variability within rural ADRD caregivers' experiences (4) and to create interventions that can be tailored to meet their diverse support needs, skills, and strengths.

Research has suggested that rural caregivers of people living with ADRD experience greater burden, due to challenges such as lack of access to specialized healthcare services and greater travel times to existing services (5). However, this link between rural caregiving and burden is inconclusive, with studies in rural areas of Canada (6) and the United States

(7) finding that rurality (as measured by population of the county of residence) has no relationship to felt burden or distress among rural dementia caregivers. In a rural Australian sample, rurality was a seemingly unimportant component of dementia caregivers' day-to-day caregiving experience (8), whereas in a sample of rural caregivers from Nepal, the caregiver burden was low (9). A qualitative systematic review describing the experiences and needs of rural caregivers internationally detailed the nuance and variability in rural caregivers' experiences (4). While some rural caregivers reported experiencing greater stigma and feeling misunderstood in rural environments, others saw their rural context as yielding more trustworthy, tight-knit relationships. While some rural caregivers were reticent to ask too much of their nearby family and friends, others noted that these informal sources of support often filled the gaps left by inadequate formal respite or homecare services. The ways in which rurality shapes rural caregivers' experiences may be as nuanced as caregivers themselves.

A recent U.S.-based integrative review found that interventions to promote rural caregiver health generally focus on increasing self-care and coping strategies among rural caregivers, with the goal of affecting psychosocial outcomes such as depression and caregiver burden (10). The authors note that challenges such as geographic and social isolation, inadequate specialized healthcare services, and financial insecurity, as well as outcomes such as metabolic measures and physical activity, are insufficiently addressed by current rural caregiver interventions (10). An international systematic review of technology-based interventions for rural caregivers found that, although interventions often resulted in improvements to psychosocial outcomes, none of the identified interventions resulted in increased dementia caregiving skills (11). The same review noted that technology-based interventions utilized landlines or basic mobile phones, and fewer integrated more advanced technologies (11). However, this focus on simple technologies may not match the technological capacity or interest of all rural dementia caregivers, as 72% of rural adults in the United States have access to home broadband and 80% own a smartphone (12). Taken together, the gaps in the intervention literature suggest a need for a greater empirical understanding of rural caregivers' diverse needs, strengths, and preferences as a first step to designing interventions that are useful for members of this population.

Engaging future end users in research is a key strategy for designing interventions that meet their needs (13). Usercentered design (UCD) is one such approach to engaging future end users across 3 stages, including discovery, design, and development, to develop a rich understanding of what they need to ease or improve the performance of their work (13). Data collection methods, such as contextual inquiry, focus groups, participatory design, or interviews, have been leveraged by UCD to develop interventions and technologies to meet the needs of specific populations, including caregivers of persons with dementia in France (14) and the United Kingdom (15). Within the domain of UCD, persona development is an analytic approach in which participant data is gathered and analyzed to create a set of representative or archetypical end users, called personas (16). Each persona is a distinct composite of co-occurring attributes, representing the variability within the end-user population. Once personas are identified and validated, they can be used to make data-driven

decisions to guide intervention development to meet future end users' needs (17).

The objective of this study was to gain a deeper understanding of rural ADRD caregivers' needs, strengths, and strategies for obtaining caregiving support, and to represent these attributes in the form of personas that can be used to design interventions.

#### Method

In this qualitative UCD study, we conducted semistructured interviews with self-identified caregivers of people living with ADRD in rural areas. Recruitment, data collection, and data analysis occurred concurrently between November 2022 and January 2023. This study was approved by the Indiana University Institutional Review Board.

## Interview Guide Development

Interview guide development was guided by the study objective to understand rural ADRD caregivers' needs, strengths, and strategies to obtain support. Questions pertained to the resources, both formal and informal, accessed by participants; characteristics of the community in which caregivers live; and successes and setbacks while seeking support. The full interview guide is included in Supplementary Material Section 1. Questions were first developed by the research team and then refined based on feedback from the study's strategic advisory board. The strategic advisory board (N = 7) included professionals who serve rural ADRD caregivers. Advisors were selected to maximize representation in terms of geographic location, types of resources provided, roles, and expertise. Additionally, one advisory board member identified as a current rural ADRD caregiver.

#### Setting and Participants

We enrolled participants who self-identified as caregivers (including family or friends) of persons living with ADRD. Eligibility criteria included: personally identifying as living in a rural area or labeling one's own geographic residence as rural; caring for someone who the participant identified as living with ADRD; providing unpaid care; being 18 years of age or older; and having access to a phone or computer on which the participant could complete the interview. We worked with community partners that serve rural geographic areas to share the study opportunity through their e-mail listservs. Our community partners included local area agencies on aging, departments of health, and service providers serving rural ADRD caregivers. Members of our strategic advisory board also shared details about the project with caregivers who may have been eligible or interested. Interested participants were invited to send an e-mail to the research team. The research team replied by sharing the study information sheet over e-mail and scheduling a time for a brief screening and consent phone call. Verbal consent was obtained and the interview was scheduled. All recruitment, enrollment, and data collection were performed remotely through videoand audio-enabled teleconferencing software, enabling the recruitment of participants throughout the United States.

## Study Procedure

Interviews were recorded and lasted 60–90 minutes. Participants who did not wish to use the software called into the interview via phone. Interviews began with participants

completing a brief online questionnaire, which included questions about the caregiver and care recipient's demographic characteristics as well as their caregiving circumstance (eg, living with or near the care recipient). Each interview was facilitated by one researcher (A.J.), who was joined by at least one additional interviewer to take notes and ask follow-up questions (J.R.H., M.Z.). Participants received a \$50 electronic gift card after completing the interview. Interview audio files were transcribed verbatim and deidentified for analysis.

## Data Analysis and Persona Development

Descriptive statistics were used to calculate demographic information for the sample. Persona development occurred in Miro online collaboration platform (18), which provides a virtual whiteboard that allows multiple users to create, write on, and move virtual "sticky notes" to organize and reorganize ideas. Data analysis was guided by the literature on persona development and by attributes of special relevance to the rural caregiver population and the study objective (16). Attributes derived from the literature on persona development included goals, attitudes, and pain points (ie, consistent challenges) (16). Attributes of special relevance to the rural caregiver population were derived deductively from the rural caregiver literature and inductively by reviewing the first 5 interviews and using team-based consensus discussion. These additional deductive and inductive attributes were community, services used, connections or help, information behavior, and technology use (19,20).

#### Affinity diagramming

After each participant interview, we created a corresponding table in Miro in which we recorded their responses related to each attribute (see Supplementary Material Section 2). Following each interview, one research team member (A.J., J.R.H.) reviewed the interview transcript and completed the first pass at filling in the relevant excerpts related to each attribute. Next, a second member of the research conducted the same analysis to ensure the table comprehensively represented the participant on attributes of interest. After each table had been completed and reviewed by 2 team members, 2 additional team members (N.E.W., M.Z.) independently compared the table to the interview transcript to confirm completeness.

After each interview and corresponding participant table were completed, the full research team met to commence a virtual affinity diagramming process in which sticky notes from individual participants were grouped with similar sticky notes from other participants (21–23). Affinity diagramming for the first 2 participants was completed as a research team. The research team was led by 2 PhD-trained human factors engineers (J.R.H., N.E.W.) and comprised individuals with backgrounds in psychology, ADRD caregiving, and technology development. Some members of the research team were experienced in persona creation (N.E.W., M.Z., C.E.) while others were new to the method (A.J., J.R.H.).

Two researchers (A.J., J.R.H.) then completed the affinity diagramming process for subsequent participants, meeting weekly with the full research team to discuss and refine new groupings. One coder (A.J.) reviewed all interview data a final time to ensure no attributes of interest were unrepresented. This affinity diagramming process confirmed the relevance of the a priori attributes (eg, goals, attitudes, pain points) and

yielded new, inductive attributes (eg, financial security, information behavior, positive/negative affect). Some attributes were discrete or categorical (eg, one persona's pain points differ from those of another) while others exist on a spectrum (ie, the level to which a persona is an improviser vs a planner). Because participant recruitment, interviews, and data analysis occurred concurrently, the research team was able to confirm that participants produced varied and rich responses on the attributes of interest, and that saturation had been reached in both the codes and the meaning of codes, at 19 participants (24).

#### Persona creation and validation

Once all participant sticky notes had been grouped by categorical or dimensional attributes, 2 researchers (.A.J., J.R.H.) met to begin clustering attributes based on which attributes frequently co-occurred in participants. For example, it was observed that participants with many social connections tended to share certain attitudes, while those with similar information behavior tended to share certain goals. Attributes were also organized by dissimilarity; for example, it was observed that participants ranged in their use of strategies or access to resources. These differences were assigned to personas to represent meaningful distinctions between participants. Throughout the persona creation process, the interdisciplinary research team met weekly to build consensus on the assignment of attributes to personas, confirming the personas reflected commonly co-occurring traits in participants but did not disproportionately represent any one participant. To mitigate bias, the variety of professional expertise and personal experiences on the research team were consciously leveraged throughout the persona development process. Personas were then presented to the study's advisory board for feedback and refinement and interview data was reviewed to search for any cases that contradicted the developed personas.

Finally, as part of participation in a separate research study for which participants received compensation, personas were presented to 5 rural caregivers and 5 community partners for validation, refinement and to help mitigate potential research team biases. These participants were unaffiliated with the present study. Persona images were distributed, and feedback was gathered via an online survey. Participants were asked about the ways in which the personas were similar to and different from themselves (for caregiver respondents) or the rural caregivers they serve (for community partners).

## **Results**

## Demographics

A total of 27 potential participants reached out to the study team over e-mail expressing interest in participating. Of these, 19 participants completed all study activities, including screening, enrollment, and interview. Caregivers spent a median of 37.5 and a mean of 70.75 (standard deviation = 62.54) hours per week providing care. Within the sample, 16 caregivers (84.2%) lived with the care recipient, while 3 caregivers (15.8%) lived within a 20-minute drive of the care recipient. Most participants came from various counties in South Dakota (13) with others from Wisconsin (3), California (2), and Washington (1).

Complete demographic results are summarized in Table 1.

Table 1. Caregiver and Care Recipient Demographic Characteristics

Characteristic	Caregiver		Care Recipient	
	M (SD)	N (%)	M (SD)	N (%)
Age	66.4 (10.1)		Not asked	
Gender				
Male		5 (26.3%)		11 (57.9%)
Female		14 (73.7%)		8 (42.1%)
Race				
White (Caucasian)		18 (94.7%)		19 (100.0%
Black or African American		0 (0.0%)		0
American Indian/Native American or Alaska Native		1 (5.2%)		0
No answer		1 (5.2%)		0
Education (highest level completed)				
High school diploma or GED		1 (5.3%)		_
Some college, no degree		2 (10.5%)		_
Associates or technical degree		3 (15.8%)		_
Bachelor's degree		7 (36.8%)		_
Graduate or professional degree		6 (31.6%)		_
Employment status				
Working full-time		4 (21.1%)		_
Working part-time		1 (5.3%)		_
Retired		9 (47.4%)		_
Other		5 (26.3%)		_
Household income				
<\$25 000		3 (15.8%)		_
\$25 000-\$49 999		2 (10.5%)		_
\$50 000–\$74 999		8 (42.1%)		_
\$75 000–\$99 999		1 (5.3%)		_
\$100 000-\$149 999		3 (15.8%)		_
≥\$150 000		0		_
Prefer not to say		2 (10.5%)		_
Care recipient is caregiver's				
Mother/mother-in-law		4 (21.1%)		_
Father/father-in-law		2 (10.5%)		_
Spouse or partner		11 (57.9%)		_
Grandparent		0 (0.0%)		_
Another relative (unspecified)		1 (5.3%)		_
Other (unspecified)		1 (5.3%)		_
Care recipient living situation		,		
In care recipient's own home	_			12 (63.2%)
In the community (eg, independent living)	_			5 (26.3%)
Nursing care or long-term care facility	_			2 (10.5%)

*Notes*: GED = General Educational Development; *SD* = standard deviation. No participants endorsed the following categories: nonbinary or third gender; Asian, Native Hawaiian, or other race; Spanish, Hispanic, or Latino ethnicity.

#### Inductive Attributes

The affinity diagramming process resulted in 7 inductive attributes, including financial security and subjective rurality (within the a priori attribute of community). Within the a priori attribute of attitude, the following dimensions were identified: self-dependence to interdependence, negative to positive affect, and tendency to improvise versus tendency to plan. Within the a priori attribute of information behavior, caregivers reported a spectrum of using more traditional to technology-based sources of information, as well as being

content with what they know versus wanting to learn more. These inductive attributes are summarized, along with illustrative quotes, in Table 2.

#### Persona Descriptions

Our persona analysis generated 5 rural ADRD caregiver personas, including the Capable, Connected, Independent, Learning, and Discerning caregivers. Below is a summary of each persona's needs, strengths, and strategies. We assigned each persona a name (eg, Capable Christine) to facilitate a

 Table 2. A Priori and Inductive Persona Attributes

Attribute	Description	Quote	
A priori			
Goals	Caregiver's purpose, plan, or desired end state that moti- vates their caregiving behavior	"It's to give her a good life and a good chance to live in her own home as long as she can." (P109)	
Attitudes	Caregiver's generalized stance or approach to caregiving	"I am not an easygoing person by nature. Like I am typical Type A." (P112)	
Community	Geographic or social aspects of the area in which caregiver lives, as these aspects pertain to caregiving	"My church is a fairly small church, an episcopal church, and it is, it has maybe 45 or 50 active members. And everybody, over time, has understood what the situation is. And since they know [the care recipient], you know, they kind of are the second, third, and fourth, fifth sets of eyes when I'm busy running around on Sunday morning." (P102)	
Services used	Formal resources (eg, members of care team, resource centers) caregiver uses to facilitate caregiving	"So much of the information that I've gotten over the last 2 years has been through the ADRC. We have a weekly dementia care Zoom meeting." (P105)	
Connections/help	Informal resources (eg, friends, family members) caregiver uses to facilitate caregiving	"I had some medical procedure in June, so I flew [the care recipient's] sister in for a couple of weeks. So that was nice. I have neighbors that are just wonderful, you know I needed a ride to the doctor's office and, you know, back So the neighbor drove me, and that was very nice." (P104)	
Pain points	Problems or challenges that prevent the caregiver from reaching their goals	"My wife doesn't qualify for assisted living, but she really doesn't qualify for a nursing home either. She's kind of in that in-between stage. And so, but regardless, the waiting list is 18 months or more And the prices are outrageous" (P114)	
Information behavior/technol- ogy use	Caregiver's tendencies and strat- egies for seeking information, including technological- and non-technological strategies	"I couldn't find any kind of technology that would help So I initially was, one of my big searches was how do I use technology to help my parents stay safe and help me keep them safe and keep my stress down?" (P103)	
Inductive			
Financial security	Caregiver's access or lack of access to money, as it pertains to caregiving	"It would be so much easier if I could afford to just take care of him myself. The home health is really expensive. It's \$35 an hour. So that's tough And we don't qualify, you know, for any other assistance." (P118)	
Subjective rurality	Caregiver's perceptions of the area in which they live that distinguish it from an urban area	"We live in the country. The nearest town where our address is, don't laugh, it's less than 80 people. It's between 70 and 80 people." (P119)	
Attitude: self-dependent to interdependent	Self: Caregiver feels solely responsible for providing care, or tends to take on tasks themselves	"I didn't have a lot of help. I'm kind of a do-it-by-myself person." (P110)	
	Inter: Caregiver is inclined to ask for help or prefers distrib- uting caregiving work	"If I had to deal with this by myself, without these other people, I'm not sure that I would be able to do it." (P101)	
Attitude: positive to negative affect	Negative: Caregiver demon- strates an optimistic or grateful attitude towards their caregiving situation	"it's a tough old world out there, but I've lost [the care recipient]." (P110)	
	Positive: Caregiver demonstrates a pessimistic or depressed atti- tude towards their caregiving situation	"the Good Lord has been taking care of me" (P107)	
Attitude: proneness to improvise versus plan	Improviser: Caregiver takes challenges as they come	"So when my partner, my wife, wanders off, people know her, and they know to bring her back." (P106)	
	Planner: Caregiver anticipates future problems and has plans in place for them	"I don't want to just sit around on my hands." (P103)	
Information Behavior: content versus curious to	Content: Caregiver believes that they know enough about caregiving for ADRD	"I could probably teach it, teach the class. I mean, I've been doing this stuff for 12 1/2 years." (P114)	
learn more	Curious: Caregiver wants to learn more about caregiving or ADRD	"I just kind of listen to everybodyI take notes all the time." (P104)	

Table 2. Continued

Attribute	Description	Quote
Information behavior: tradi- tional versus tech- based sources	Traditional: Caregiver seeks and accesses information through conventional means (eg, word-of-mouth, paper resources)	"I got the magazine. That was helpful. We still get that. More from the staff as far as classes that you can take. I didn't do a whole lot online. I'd rather talk in person, or I'm better one on one or a small group than I am going online. I don't typically get on and go, okay, tell me about dementia." (P116)
	Technology-based: Caregiver uses technology to seek and access information (eg, online resources, apps)	"I'm constantly googling. And I'm constantly googling what stage he's in, what medical resources are there out there" (P115)

Notes: ADRD = Alzheimer's disease and related dementias; P = participant.



Figure 1. The Capable Caregiver.

narrative description. Each persona is followed by a visual representation of their characteristics (Figures 1–5).

## Capable Christine

Christine lives in the largest town in a rural state. She lives a short drive from her parents, who are both in the later stage of dementia. She feels misunderstood by people who are not caregivers; however, she knows few other caregivers, which she attributes to living in a rural state. She also perceives dementia as stigmatized in her home state. Christine struggles to convince her parents to accept formal help (eg, meal delivery services, assisted living arrangements), which means her own caregiving workload remains high. Christine's strengths include being a planner, having financial resources, and being technologically savvy. She uses her technological savviness to seek out dementia-related information and resources, both within and beyond her home state. When she does find a formal resource or technological tool that she trusts, she is able to pay for it.

# **Connected Connie**

Connie lives in a small town. She lives with her mother, who is in the early stage of dementia. Connie has a physical disability, which will make it more difficult to care for her mother as the disease progresses. Further, due to her rural location, there are few jobs that accommodate her disability, meaning she is financially insecure. Connie also finds it complicated

to apply for financial support (eg, state-sponsored grants for low-income caregivers). Connie's strengths include positive affect, openness to asking for help, and a rich social life, which includes supportive members of her church. She leverages her tight-knit social network to support her caregiving, with church members providing respite care free of charge and sharing with her about free or low-cost resources for caregivers.

#### Independent Irene

Irene lives in the country outside of a very small town. She lives with her husband, who is in the middle stage of dementia. Irene lives far from all formal sources of healthcare and respite care, which means she is unsure how she will continue to provide care as her husband's health declines. Furthermore, because Irene is geographically isolated and worries about leaving her husband alone at home, she rarely meets other caregivers. However, Irene is financially secure and technologically savvy and enjoys solving problems. By going online, she learned how to install cameras and sensors to improve safety at home. She also found information and virtual classes to improve her own health and respond to the care recipient's evolving needs.

#### **Learning Larry**

Larry lives in a small town with his wife and his father, who is in the middle stage of dementia. Larry knows little about



Figure 2. The Connected Caregiver.

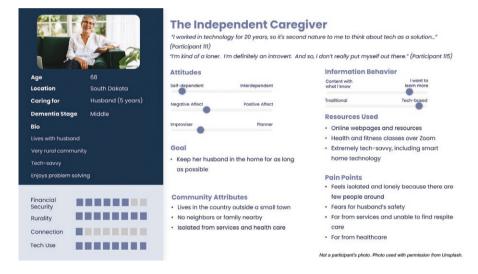


Figure 3. The Independent Caregiver.

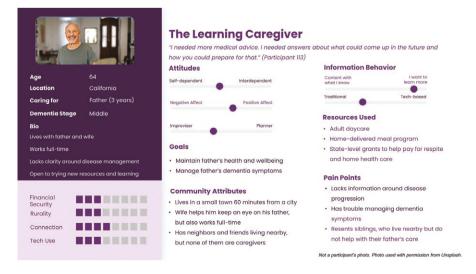


Figure 4. The Learning Caregiver.

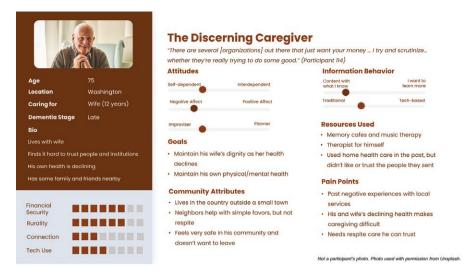


Figure 5. The Discerning Caregiver.

dementia or how to manage the symptoms, in part because he knows few other caregivers. Further, although his siblings live nearby, they do not assist with caregiving, which creates resentment and overwhelm for Larry. Larry is willing to accept caregiving support from his wife, his neighbors, and adult daycare. Further, he uses a state-level caregiver grant to pay for occasional respite care. Because he lives only 60 minutes from a metropolitan area, in-home respite care is limited but available. Larry's strong desire to learn more helped him to learn about resources like these.

## Discerning Dan

Dan lives in the country outside of a small town with his wife, who is in the later stage of dementia. Because he lives far from a metropolitan area, few home health and respite care services are available, and Dan has had negative experiences with the limited services that do exist which have caused him to discontinue use. As a result, he receives little formal support for caregiving. Much of Dan's family has moved to urban areas, and thus he only receives their informal support (including respite care) a couple of times per year. Dan's health is declining along with that of his wife, and he does not know how he will manage his own and his wife's health as her disease progresses. Dan trusts his neighbors, as people look out for each other in his rural community; he knows that if he needs help, they will be there for him. Therefore, he is hesitant to move closer to the metropolitan area where more healthcare services are available.

### **Discussion**

In the present study, we identified and elaborated upon key attributes on which rural ADRD caregivers differ, including financial security, subjective rurality, attitudes, information behavior, and technology use. Through the affinity diagramming process, these attributes were assigned to 5 rural ADRD caregiver personas, each of whom possesses different goals and pain points and has access to different services and sources of help. The resulting rural caregiver personas can be used as tools to answer key questions of future interventions. These questions include who should be targeted for interventions, what would make interventions useful, and the mediums of

intervention delivery that would best reach subsets of rural ADRD caregivers (20).

The implications of the present study, combined with previous research, suggest that designing for rural caregivers is not a one-size-fits-all prescription and may not be related to burden in predictable ways (6–8). First, our results suggest that, for some rural caregivers, subjective rurality is at least as important to their experience as low population density. Some caregivers in the present study perceived their home state as rural, regardless of their geographic location within the state (ie, near or far from a metropolitan area). Some caregivers indicated that living in a "rural state" came with a lack of resources or policies that serve caregivers, as well as greater stigma associated with ADRD. Caregivers in the present study described building close connections in and even outside of small towns. In contrast, even caregivers close to family and city center sometimes felt under-supported. Thus, those recruiting rural caregivers for interventions should consider subjective or felt rurality in addition to more objective measures.

Previous interventions for rural caregivers have largely targeted psychosocial outcomes, such as depression and caregiver burden (10,11). The results of the present study affirm a broader range of outcomes with which rural caregivers require support. Rural caregivers require no-cost resources and assistance with obtaining financial support (25,26); opportunities for social connection and understanding (27,28); greater access to formal healthcare services (29,30); and key caregiving skills and knowledge of dementia (31,32). The present study exemplifies how these unmet needs intersect with caregiver attributes in ways that may shape caregiver receptiveness to interventions. For example, our results suggest that caregivers who want to learn more, who are interdependent, or who tend toward positive affect may be more motivated overall to participate in interventions that target their unmet needs. Future work should consider how to reach caregivers who tend toward negative affect or independence.

The results of this study suggest that modes of intervention delivery should be tailored depending on rural caregivers' attributes. Caregivers who are adept with technology may be most receptive to technology-enabled interventions. However, technology-enabled interventions are currently sparse (11). Useful technology-based interventions may share

detailed information about the key decisions facing caregivers, such as those involved in advanced care planning (33,34). Technology-savvy caregivers may also be well-matched to interventions that allow them to connect with caregivers in virtual environments, such as online forums and support groups. In contrast, caregivers who are less technologically savvy or prefer traditional forms of communication may benefit from "point people" who can share information in their preferred, face-to-face format. Alternatively, an intervention could position technology "brokers" at local libraries or aging and disability resource centers who can show caregivers how to access and evaluate the quality of online information (35).

This study was not without limitations. First, while the sample of caregivers was diverse in terms of education level and household income, it was primarily made up of married women and was almost exclusively white. The experiences of caregivers of people living with ADRD are invariably shaped by cultural norms (36), as well as systemic racism (37) and other forms of prejudice (38). The personas in the present study do not represent caregivers who do not speak English, who are sexual or gender minorities, or who are persons of color. Second, our sampling strategy largely reached participants who were already connected to organizations that serve rural ADRD caregivers. Thus, our personas may represent a group of caregivers with greater interest in or ability to connect with resources and may have excluded more isolated caregivers. Third, there is no single definition of rurality, nor was a definition provided when caregivers were screened for inclusion in the study. Participants were eligible for this study if they personally identified as living in a rural area, which is a more subjective and potentially more inclusive definition of rurality relative to other studies. Definitions used in previous research have integrated population size, population density, rural-urban commuting area codes, and rural-urban commuting area codes (39). Fourth, caregivers were not required to submit evidence of a medical diagnosis of ADRD on behalf of the person living with dementia, or asked if they met specific diagnostic criteria. Thus, the resulting personas may not represent all conceptions of rurality and may include caregivers of people with subclinical ADRD.

# Conclusion

Findings from the present study emphasize the significant variation in needs, strengths, and strategies among rural ADRD caregivers. Therefore, this population needs a variety of discrete, adaptive, and customizable interventions to meet their diverse needs. While some caregivers need interventions that provide specific, accurate information and social support through technological mediums, for example, others want to learn, connect with others, and receive assistance in-person. The attributes and personas identified in this study therefore offer multiple viable paths for effective intervention development.

## **Supplementary Material**

Supplementary data are available at Innovation in Aging online.

# **Funding**

This work was supported by the National Institutes of Health's National Institute on Aging (1R43AG080849-01). The content is solely the responsibility of the authors

and does not necessarily represent the official views of the National Institutes of Health.

#### Conflict of Interest

C.E. is the CEO and co-founder of CareVirtue Technologies, and developed CareVirtue. M.Z. is the caregiver support officer and co-founder of CareVirtue Technologies, and developed CareVirtue; is an Associate for HFC, which is a 501c3 with a mission of Bringing Light to Alzheimer's; and is a member of the Alzheimer's Impact Movement, which is the advocacy affiliate of the Alzheimer's Association.

# **Data Availability**

Interview data are not openly available due to the sensitivity of the data. Data are located in a securely controlled platform at Indiana University—Bloomington and are available from the principal investigator upon reasonable request (newerner@iu.edu). This study was not preregistered.

# Acknowledgments

We would like to thank the members of our strategic advisory board for their advice on this project. We would also like to thank the caregivers who participated in the interviews and provided feedback on the results.

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