

# Rural Family Caregivers' Discoveries Following a Person-in-Context Dementia Simulation

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## Abstract

**Purpose:** The purpose of this qualitative study was to discover rural family dementia caregivers' lived experience in a virtual dementia simulation and how it affected their understanding of their

family members' daily challenges. To our knowledge, this study is the first to document its impact and value in this understudied, under-reported, and under-represented population.

**Sample:** A volunteer sample of 10 rural family caregivers of persons with AD/ADRD following participation in a rural eastern North Carolina community delivered AD/ADRD simulation.

**Method:** In-depth interviews lasting 45-110 minutes were conducted. The Utrecht phenomenology analytic method was used to sort, analyze, and interpret data. Richness of data drove the sample size.

**Results:** The volunteer participants were female familial caregivers ages ranged from 49 to 81. Their care recipients' ages ranged from 62 to 93 years. Eighty percent of the caregivers provided care for their loved ones 6-7 days a week. Only one caregiver had formal (paid) assistance for care provision. The themes *Now I Understand*, *Opened My Eyes*, and *Making Changes* emerged from the participants' statements.

**Conclusion:** Rural family caregivers found the AD/ADRD simulation profoundly impacted their perceptions of AD/ADRD and expressed new understandings and eye-opening epiphanies about their family members' daily challenges with dementia and their planned changes to improve their loved ones' quality of life. The AD/ADRD simulated experience provided participants with a unique opportunity for self-discovery about their loved ones' daily challenges. This original study addresses the paucity of literature and research about AD/ADRD simulations for rural caregivers of persons with AD/ADRD. This study further demonstrates the value of AD/ADRD simulation to rural nursing practice and science. These findings may prompt rural health nurses to encourage family caregiver participation in person-in-context simulations to enhance their understanding of the loved ones' lived experience.

## **Rural Family Caregivers' Discoveries Following a Person-in-Context Dementia**

### **Simulation**

Alzheimer's disease and related dementias (AD/ADRD) touch all aspects of life and relationships and most often affect adults older than 65 years of age (Langa et al., 2017). AD/ADRD is an umbrella term for several neurocognitive syndromes, the majority of which include Alzheimer's disease, vascular cognitive impairment, frontotemporal degeneration, and Lewy body dementia (American Psychiatric Association [APA], 2013). The number of those living with AD/ADRD is projected to reach nearly 13 million by 2050, with a higher prevalence in rural areas (Alzheimer's Association, 2021).

### **Background**

Geographic and population-specific definitions cannot fully describe the holistic meaning of "rural," which, in addition to widely separated farm towns and communities with small populations, have unique cultures, attributes, and challenges (Pennington, 2015). Nearly three-quarters of the rural older population reside in the southern portion of the United States (U.S.). Older adults in rural areas are less likely to live in nursing homes, less likely to have a high school education, more likely to live in poverty, and have higher rates of chronic conditions (National Center for Chronic Disease Prevention and Health Promotion [NCCDPHP], 2019; Smith & Trevelyan, 2019). Family caregivers in rural communities constitute an informal (unpaid), critical, and valuable workforce for those living with AD/ADRD (Harrington et al., 2018; NCCDPHP, 2019). The U.S. healthcare and long-term care systems could not withstand the financial and workforce burden without the capacity for ongoing and long-term care of family members with AD/ADRD (Harrington et al., 2018).

Female caregivers constitute over 90% of the informal (unpaid) workforce who provide most care for family members living with AD/ADRD in the community setting (Alzheimer's Association, 2021; Jutkowitz et al., 2017). In 2020, family caregivers of persons with AD/ADRD provided an estimated 18.6 billion hours of informal assistance valued at \$244 billion, 400 million more hours of care than reported in 2017 (Alzheimer's Association, 2017, 2021). Nursing home space with trained health care workers is insufficient to accommodate the number of individuals with AD/ADRD who require placement if not for family caregivers. In the state where this study was conducted, 170,000 individuals have AD/ADRD, with only 351 dedicated AD/ADRD beds in 17 counties (Alzheimer's Association, 2020; North Carolina Department of Health and Human Services [NCDHHS], 2021; Pennington, 2015). Since 80 of the state's counties are considered rural, those with AD/ADRD requiring nursing home placement would likely be distantly separated from family caregivers.

Most rural caregivers of persons with AD/ADRD are over 65 and have unique characteristics that warrant special nursing considerations (Gibson et al., 2019; Greenberg et al., 2020; Sheehan et al., 2020). These caregivers tend to be older ( $M = 71.3$  years,  $SD = 8.3$ ,  $p = .02$ ), predominantly female (91%), provide significantly more hours of care per week, and manage more complex medical problems compared with those who provided care for persons without AD/ADRD (Sheehan et al., 2020). Caregivers' health disparities in rural areas are greater than those in urban settings due to the social determinants of health, environmental risks, poorer health behaviors (smoking and alcohol use), and less physical activity (United Health Foundation [UHF], 2021). Remote residences impact support and resources like primary healthcare services or acute care centers. Innovative technology like telehealth and virtual meetings are often not a feasible solution for rural older family caregivers because many older adults neither have nor use

internet services due to the expense, cost of devices, lack of skill or confidence in their use, or perceived personal irrelevance (Huffman, 2018).

Behavioral Risk Factor Surveillance System data from 2021 showed that North Carolinian older adults reported mental distress increased 21% over the past three years, while access to mental health providers and services increased 17% to 227.5/100,000 in the same period (UHF, 2021). The disparities in access to primary care services in rural communities also continue despite an overall increase in North Carolina health care providers, where 31/41 eastern counties are designated as medically underserved for primary care services (Department of Health Resources and Services Administration [HRSA], 2021). North Carolinian's increase in the frequency of reported mental distress by those 65 years and older was greater than the national average (UHF, 2021). The 21% increase in mental health providers in North Carolina to 265.5 /100,000 population had no impact on the reported frequency of mental distress in individuals 65 and older, which increased 32% between 2016-2020 (UHF, 2021).

Family caregivers of persons with AD/ADRD cannot fully understand their family member's subjective experiences; therefore, their perceptions of AD/ADRD associated behaviors may be incongruent with their family members' lived experiences. Caregivers' lack of understanding may trigger unintended relational discord or mistreatment of either care partner due to unrealistic expectations (Aspesoa-Varano et al., 2015; Harrington, et al., 2018; Orfila et al., 2018). A person-in-context AD/ADRD simulation that mimics some of their family members' neurocognitive challenges provides an opportunity for family caregivers of those with AD/ADRD to re-evaluate their contextual reality, assumptions, and perceptions.

## Virtual AD/ADRD Simulation

Several AD/ADRD simulations were found in the literature, including virtual reality experiences (Age-u-cate Training Institute, 2020; Ball et al., 2015; Second Wind Dreams, 2020; Wijma et al., 2017). Only two virtual dementia simulations provided a person-in-context simulated experience, whereby respondents experienced dementia “as if” they had the syndrome (Age-u-cate Training Institute, 2020; Harrington, et al., 2018; Han & Brown, 2019; Second Wind Dreams, 2020). These products were shown to improve awareness, empathic understanding, and sensitization toward people living with AD/ADRD for healthcare professionals and students within a variety of health care settings (AGE-u-cate Training Institute, 2020; Harrington, et al., 2018; Ping et al., 2020; Second Wind Dreams, 2020; Slater et al., 2017). Harrington et al. (2021) conducted a mixed-methods study with interpretative phenomenology to explore primary care nurse practitioner students’ ( $N = 20$ ) perceptions and understanding of AD/ADRD following a person-in-context dementia simulation. A theme “*developing empathic understanding*” emerged from the verbatim transcript analysis. Respondents believed this experience increased the likelihood that these future health care providers would engage in altruistic helping behaviors.

Two extensive literature reviews yielded one published study exploring AD/ADRD simulation with family caregivers of those with AD/ADRD (Hirt & Beer, 2020; Yu et al., 2018). Dementia Live (DL) was used in a qualitative study with formal ( $n = 12$ ) and informal caregivers ( $n = 4$ ) (Han & Brown, 2019). The DL experience was an eye-opening experience with perceived benefits for the participants, who recommended DL to other caregivers (Han & Brown, 2019).

Both the DL and the Virtual Dementia Tour use specially designed equipment to simulate agnosia (failure of recognition through the senses), apraxia (loss of coordination), altered

perception (loss of depth perception), amnesia (loss of short-term memory), apathy (difficulty initiating activities) and attentional deficits (Age-u-cate Training Institute, 2020; Harrington et al., 2018); Second Wind Dreams, 2020). Both simulations provided family caregivers an opportunity to subjectively experience some of the effects of neurocognitive deficits commonly seen in the daily struggles associated with advancing AD/ADRD (Age-u-cate Training Institute, 2020; Second Wind Dreams, 2020). The Virtual Dementia Tour provides a first-person perception of dementia, whereby trained facilitators guide respondents through an 8-minute experience (Second Wind Dreams, 2020). During the simulation, respondents try to perform five ordinary daily activities (e.g., counting change, setting the table, matching socks, or buttoning a shirt) wearing patented equipment that simulates common neurocognitive changes. This equipment includes gloves (loss of fine motor skill), shoe inserts (altered pain perception), glasses (mimic the peripheral, central, and depth perception vision changes), and noise-producing headphones (auditory perceptions that affect one's ability to concentrate) (Second Wind Dreams, 2020).

The purpose of this qualitative study was to discover rural family caregivers' lived experiences in the person-in-context AD/ADRD simulation and its impact on the family caregiver's perceptions of the person living with AD/ADRD. This study was approved by the East Carolina University Medical Center Institutional Review Board (UMCIRB).

Two research questions guided this inquiry:

- What is a family caregivers' perception of those with AD/ADRD following a person-in-context AD/ADRD virtual simulation?
- How does a person-in-context AD/ADRD virtual simulation experience affect family caregivers' understanding of AD/ADRD as a lived experience?

## Method

### Design

The qualitative study combined descriptive and interpretative thematic analysis to disentangle the meaning of unique human lived experiences (Dowling & Cooney, 2012; van Manen, 1984, 2016). This approach was practical and applicable given the dearth of research to understand rural caregivers' lived experience in the context of caring for those with AD/ADRD (Dowling & Cooney, 2012; van Manen, 2016). The researchers acknowledged their preconceived contextual assumptions and held them in abeyance (van Manen, 2016). By doing so, the true nature and meaning of the respondents' lived experiences in a person-in-context AD/ADRD simulation could be revealed in their true nature (van Manen, 1984, 2016).

### Sample and Setting

The sample was drawn from five counties in the Upper Coastal Plain region of North Carolina. Edgecombe, Halifax, Nash, Northampton, and Wilson Counties are geographically located in the upper coastal plain area of northeastern North Carolina approximately 100 miles from the Atlantic Ocean (Upper Coastal Plains Council of Governments, 2012). The region's area covers 2,707 square miles of landmass of which 1,152 square miles are farmland (Upper Coastal Plains Council of Governments, n.d.). This region is designated as rural by the North Carolina Department of Commerce because its population density is less than 250 individuals per square mile (Pennington, 2015).

Three rural events where the AD/ADRD simulation was offered were chosen for recruitment. Ninety caregivers registered for the first community one-day workshop in an eastern North Carolina rural community where the AD/ADRD simulation was offered. Community partners facilitated all aspects of implementing the person-in-context simulation to maintain the



study's epistemological integrity. The principal investigator (P.I.) introduced the study at the beginning of the event then remained for those interested in the study. The person-in-context simulation was delivered by certified facilitators affiliated with an event sponsor and were not co-investigators in this study (Second Wind Dreams, 2020). Other than the AD/ADRD simulation delivery, the workshop content was not a study component and did not interfere with the study design. The partners included the study flyer in the registration materials. Sixteen potential respondents were screened using the UMCIRB approved electronic survey to establish eligibility. Inclusion criteria were adults over 18 who provided caregiving duties for a functionally dependent family member with AD/ADRD, participated in the person-in-context AD/ADRD simulation, and agreed to be interviewed within two weeks. Due to the changing nature of AD/ADRD over time, those who had prior experiences in the person-in-context simulation were included. This volunteer sample ( $N = 10$ ) provided a richness of data that precluded the need to collect further data (Sandelowski, 1993, 1995; Thorne, 2016; van Manen, 2016).

### **Procedure**

Researcher-as-instrument facilitated conversational interactions and space where respondents felt safe sharing their lived experiences and meanings (Pezalla et al., 2012). All the researchers recognized that their individual experiences with caregiving for those with AD/ADRD are just one of infinite realities. The principal investigator (P.I.) had 15 years of experience counseling and managing the care of those with AD/ADRD and their caregivers across care settings as an adult-gerontology primary care nurse practitioner in medically underserved rural areas. The research team members each had 30 years of experience as registered nurses caring for older adults. The P.I. and two research team members grew up in rural cultures and

acknowledged our limited knowledge about ethnic and racial differences in caregiving for those with AD/ADRD. Prefatory assumptions included (van Manen, 2011, 2016):

- The person with AD/ADRD had cognitive impairment that required supervision and care by a family member for instrumental activities of daily living or activities of daily living.
- The family caregivers of those with AD/ADRD demonstrated receptivity to a different perception by participating in the person-in-context simulation, had no cognitive impairment, and provided care for altruistic purposes.

### **Data Collection**

The interview contexts included the time they entered the simulation until respondents were interviewed within two weeks. Ten face-to-face interviews were conducted using a conversational style that were recorded for transcription purposes. Conversational interviewing facilitated building a rapport quickly and established authenticity. Baseline interview questions provided a uniform guide for the interviewer with variable responses based on the participants' responses and willingness to share their stories. Guiding statements triggered recall and allowed participants the opportunity to reflect on the experience without leading respondents' answers. For instance, the interviewer asked, "Tell me how you felt when attempting to complete the tasks." Four questions guided the semi-structured interviews:

1. Let's go back to the Virtual Dementia Tour<sup>®</sup>. Walk me through your thoughts and feelings as you tried to complete the tasks.
2. What did the Virtual Dementia Tour<sup>®</sup> mean to you as your (\_\_\_\_\_ fill in the blank with the appropriate relative's) caregiver?
3. How did the Virtual Dementia Tour<sup>®</sup> impact how you thought about dementia?

4. Is there anything else you would like to share with me about your Virtual Dementia Tour<sup>®</sup> experience?

The P.I. self-transcribed the recorded interviews for data and epistemological integrity. Contact information for mental health services was provided in the informed consent to safeguard respondents' well-being. The semi-structured interviews ranged from 44-110 minutes in length and resulted in 157 pages of transcripts. After the interviews, the investigator gave each respondent a hand-written note of gratitude for their participation, P.I. contact information, a copy of their signed consent, and a gift card to compensate for their time.

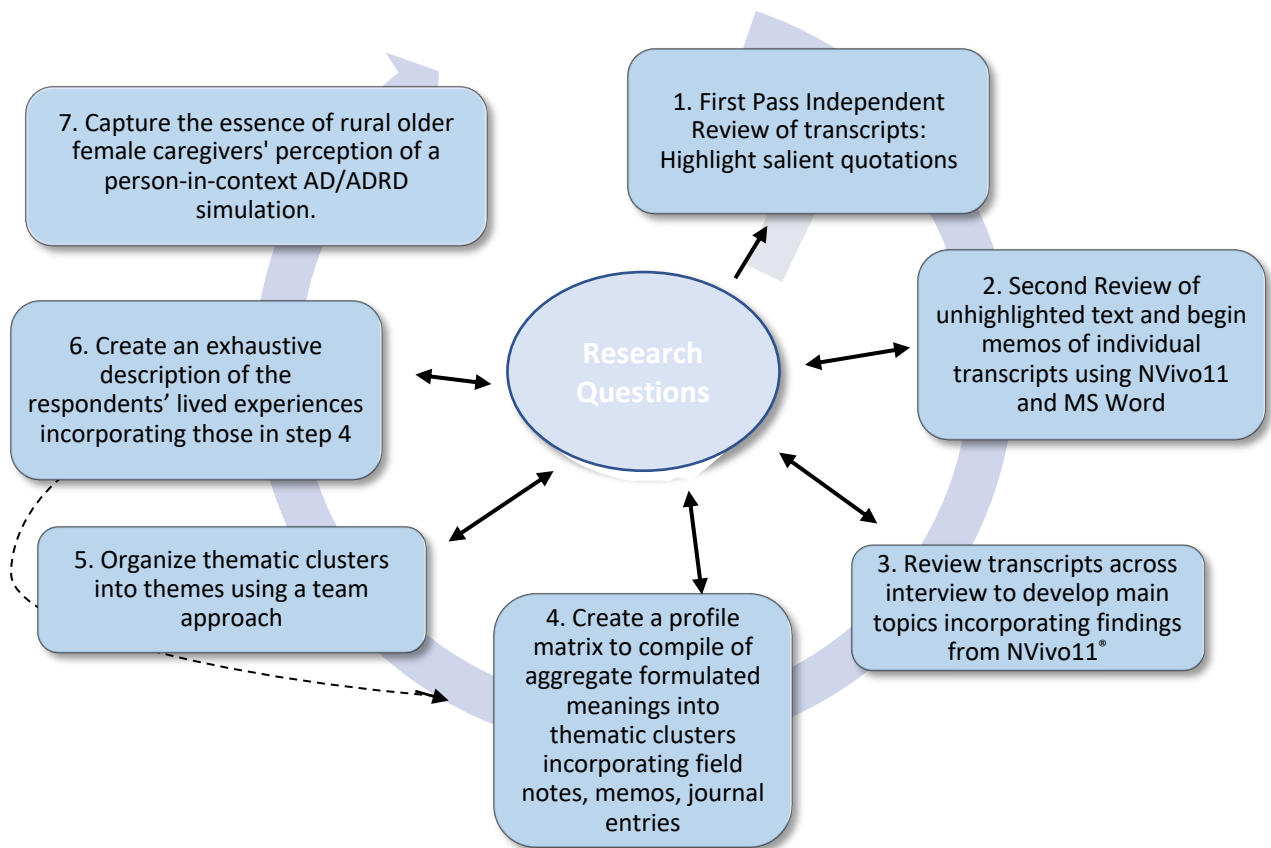
The research team used several strategies to achieve trustworthiness. The interpretative strategies and analysis of multiple data sources followed logically from the research questions. The provision of believable accounts and analytically logical findings established credibility (Koch, 1996; Sandelowski, 1993; Thorne, 2016). Interpretations were grounded in rich verbatim accounts that revealed a vivid and eidetic picture of respondents' lived experience in the person-in-context AD/ADRD simulation (van Manen, 2016). Triangulation and a confirmable audit trail occurred through team members' individual multiple reviews of transcripts, field notes, memos, and reflective journals.

### **Data Analysis**

The researchers used a seven-step systematic approach for data analysis using a stepwise process to understand the meaning family caregivers of those with AD/ADRD assigned to a simulated lived experience (Colaizzi, 1978; Kuckartz, 2014; van Manen, 2016). See Figure 1.

**Figure 1**

*Thematic Analysis Process*



In step one, the P.I. transcribed all interview recordings verbatim to ensure data integrity. The electronic transcripts were verified for accuracy by repetitive review of the recordings and transcripts. Interview recordings were deleted after the transcript content was verified for accuracy. Original names were then replaced with pseudonyms in the transcript files and analysis documents. Member checking was used to clarify information during the interview and transcription.

The research team then independently immersed themselves in the data by reading the transcripts several times for salient or poignant quotations without interpretation or analysis. Data were triangulated through multiple reviews and within-subject notations to establish a

confirmable auditable decision trail of the vertical (individual transcripts) and horizontal (across transcripts) data with memos from transcript reviews, field notes, and reflective journal entries (Colaizzi, 1978; Kuckartz, 2014; Thorne, 2016; van Manen, 2016).

Step three involved creating case summaries in Word and NVivo 11 to describe the nuances of respondents' relationships with their family members living with dementia. Colored flags were used to mark transcripts with similar quotations. In this step, significant statements about the person-in-context AD/ADRD simulation were extracted and organized.

In steps four through seven, the data analysis team consisted of three researchers. The team began the process of identifying collective meanings, which were compared to the results in the first stage. Then, formulated aggregate meanings were created. The team then identified thematic clusters of meanings. Findings were organized into three thematic clusters. Thematic definitions were derived from the data.

## **Results**

The volunteer respondents were female familial caregivers ( $M = 63.3$   $SD = 10.3$ ), ranging from 49 to 81. Their care recipients' ages ( $M = 82.5$   $SD = 8.76$ ) ranging from 62 to 93 years (See Table 1).

**Table 1***Table Dyad Summaries*

Respondent	Respondent Relationship (age)	Care Recipient Relationship (age)	Years Of Care	Days of Care per Week	Hours of Care per day	Race
1	Daughter (70)	Mother (92)	7-9	6-7	8-12	White
2	Daughter-in-law (74)	Mother-in-law (93)	4-6	6-7	21-24	Black
3	Wife (82)	Husband (72)	4-6	6-7	21-24	White
4	Wife (50)	Husband (79)	13	6-7	8-12	White
5	Sister (74)	Sister (79)	4-6	6-7	<8	Black
6	Daughter (49)	Mother (82)	1-3	2-3	<8	Black
7	Daughter (62)	Mother (86) Father (88)	4-6	6-7	8-12	White
8	Daughter (56)	Mother (78)	7-9	<1	<8	Black
9	Daughter/Wife (63)	Mother (86) Husband (62)	>15	6-7	8-12	Black
10	Daughter (57)	Mother (91)	10	6-7	21-24	Black

***Thematic Analysis***

Three themes revealed the essence of the person-in-context AD/ADRD simulation experience and its meaning for these rural family caregivers of those with AD/ADRD. Respondents described their simulated lived experience as intensely and deeply felt. The themes emerged from respondents' statements and suggested an altruistic desire to better understand their family members' lived experiences and improve their comfort and quality of life. The emergent themes included *Now I Understand*, *Opened My Eyes*, and *Making Changes*.

**Theme 1: Now I Understand.** The theme *Now I Understand* answered research question one: What is a family caregivers' perception of those with AD/ADRD following a person-in-context AD/ADRD virtual simulation? This theme involved recurrent realizations and expressed recognition of the physical and mental changes seen with progressing AD/ADRD. For example,

two respondents shared that they did not realize their family members' AD/ADRD affected multiple body systems, such as a respondent whose husband had early frontotemporal degeneration. She stated, "I didn't understand. I thought it was a mental issue and not a [depth] perception issue." When asked what she was referring to, she responded:

*When I got home and watched him ever so closely, his hand doesn't open up. I did not notice it until after the tour. I never thought about it [his dementia] disease] being a physical thing; [I] always just thought it was a mental thing.*

This respondent's recognition of her husband's change in motor function uncovered her false assumption. The simulated experience enlightened her about the sensory and motor changes commonly found and improve her awareness. Another family caregiver who worked in social services with older adults shared her reflections and understanding indicative of self-discovery:

*The virtual [dementia] tour opens up understanding and knowledge [pause] putting yourself outside of who you are and getting inside somebody else's feet as much as you can of what they are going through, which opens up your sense of empathy, sympathy, the ability to understand so you can do things differently.*

The youngest respondent related her understanding of her mother's inability to the difficulty processing information:

*It was the process that was broken. You can hear, but if you can't process it, you can't get from here to here. For me, this [simulation] taught me the processing of information and communication is not getting there. It is not even about remembering it; it is about absorbing it. It can't come out the same way.*

Themes *Opened My Eyes* and *Making Changes* emerged from the data and answered research question two: How does a person-in-context AD/ADRD virtual simulation experience

affect family caregivers' understanding of AD/ADRD as a lived experience? These themes revealed the depth of respondents' self-discovery through reflection. Their statements suggested the person-in-context simulation changed their perception of their loved one's challenges and provided subjective meaning of AD/ADRD as a lived experience.

**Theme 2: Opened My Eyes.** *Opened My Eyes* described the emotional aspect of self-discovery and described how respondents introspectively interpreted their behaviors, thoughts, and feelings in the simulation at a deeper level. The person-in-context simulation experience revealed the complexity of their loved ones' daily challenges. Upon reflection of her simulation experience, one respondent articulated her changed perception, "*It [the simulation] opened my eyes that dementia is not just a disease of the mind. It is a disease of the mind, the body, and the heart and soul of an individual.*" Another respondent revealed how deeply and strongly the simulation impacted her perception of her mother's AD/ADRD, "*When you take a step in their shoes, it sets you back, and you quiet yourself [pause]. It was like, wow! It is deep and strong.*"

**Theme 3: Making Changes.** Respondents shared how they began making changes based on their simulation experience by changing their caregiving approaches, expectations, and living environment. For example, one respondent shared, "*I tried to remove; I just started trying to get rid of extras that don't need to be. Magazines, trinkets, just "things" that don't need to be.*" Some respondents shared how they changed their emotional responses when communicating with their family members living with AD/ADRD. From her experience, a respondent reduced the stress of the day when she practiced doing dressing time in the state of calmness, "*If I see she is getting a little confused, I can guide her... start right here just like that...next thing the camisole—less stress on her.... The less stretched [sic] she is, the less stressed we are. It is calm and peaceful.*" One respondent who had dual caregiving responsibility for her husband and mother shared that



*Making Changes* meant changing her expectations about how her husband placed linens in the closet, which had a calming effect on him. She explained, “*Oh, that linen closet. I just leave it. They are just crammed in there. He is a lot calmer, and he doesn’t think I am picking on him.*”

Other respondents shared how their expectations changed and subsequently reduced relational discord. For example, one respondent shared a reflective anecdote about how she provided her husband with one task for the day to keep him occupied while she was away from home:

*He would put the clothes in the dryer and not cut [turn] it on. When I come home, there is a pile of wet clothes on the bed to be folded. He put them in the dryer and waited and then take them out of the dryer and put them on the bed for me to fold them up. It does make more sense as to why that would happen. It makes perfect sense. So yesterday, instead of being completely aggravated, I just said I don’t think these are quite dry enough [motioned hugging him] and put them back [strong emphasis] in the dryer and cut [turn] it on this time—[chuckling].*

This respondent went further to suggest that making changes in her expectations and reaction improved relational harmony with her husband:

*It has made me less frustrated with him and just let me hug him and say I don’t think these [clothes] got dry enough instead of [yelling], ‘Why did you do this when you know they aren’t dry?’*

This statement suggested that making changes in her expectations and reaction improved relational harmony with her husband.

One respondent's statements supported the a priori assumption that receptivity to a change in perception was critical to self-discovery. This respondent also reinforced how relational context

and previous familial conflict shape one's perception of the person with AD/ABRD (Aspesoa-Varano et al., 2015). This respondent shared, *"Dealing with my sister and working with seniors in my work—I was feeling that this is what life is like for them because I see it every day."* She self-excluded from the necessity to acquire caregiving skills due to a perceived lack of need, *"I stopped going to the conferences 4-5 years ago [be]cause I was hearing the same thing over and over. I decided to go back and invite one of my friend[s]."* This respondent provided insight into a counter experience that was incongruent with others' experiences. She was her sister's caregiver, who attended the AD/ABRD simulation for continuing education. When asked how this experience impacted her understanding of her sister's situation, she responded, *"No, I already understood [chuckling]"* and did not elaborate further. She then volunteered, *"You know, I did not buy into this [family caregiving role], I have my own life."* She expressed that she felt an obligation in reciprocity for her sister's financial support in the remote past and shared that their relationship was contentious before her sister's cognitive decline. Her statements and rationale for participating in the simulation suggested a lack of receptivity necessary for self-discovery and understanding. Ultimately, this respondent did not understand her sisters' lived experience. Upon reflection, if an individual does not have openness to discovery (a prefatory assumption) before a person-in-context AD/ABRD experience, reflective self-discovery within and following the experience is less likely.

### **Discussion**

Respondents' contextual statements or recurrent phrases guided the identification of aggregate themes. The person-in-context AD/ABRD experience provided respondents with an opportunity for reflection, self-discovery, subjective meaning about AD/ABRD, and perceptions of their loved ones' lived experiences.

The theme *Now I Understand* substantiated the cognitive aspect of respondents' self-discovery process, which described respondents' ability to relate to their family members' experiences, behaviors, perceptions, and emotions following the person-in-context AD/ADRD simulation. The theme *Opened My Eyes* described respondents' epiphanies whereby they interpreted personal behaviors, thoughts, and feelings in the simulation at a deeper level compared to observations of their loved ones. *Making Changes* explained how some respondents changed their care approaches by simplifying tasks and adjusting their expectations.

The time between respondents' simulation and interview allowed time for self-reflection and discovery. Several respondents expressed their intention to continue repetitive participation in community AD/ADRD simulations, as they found their subsequent experiences beneficial in understanding their family members' disease progression. All respondents who experienced the simulation a second time shared that each experience was distinctive and valuable because their loved one's AD/ADRD evolved. The research team was intrigued that several family caregivers changed their care practices within one week after the person-in-context simulation. Others with previous experience in the person-in-context AD/ADRD simulation reported maintaining the adopted practice changes made then and new changes based on this experience.

Respondents' goals to make changes were consistently reported to improve their family members' comfort and reduce their AD/ADRD challenges. Most respondents found the AD/ADRD simulation provided a unique and personal learning experience allowing them to understand their loved one's experience to provide the best quality of life possible. Most respondents believed that such simulations should become mandatory and repetitive. Those experiencing the AD/ADRD simulation for a second time felt the second simulation experience provided them with an eidetic perspective of their family members' evolving disease trajectory.

Those with previous simulation experiences enriched the researchers' depth of understanding. Respondents' biases and misperceptions toward their family members and their daily challenges with AD/ADRD were like other researchers' findings (Han & Brown, 2018).

This study supports the National Institutes of Health's strategic plan to increase research in rural caregivers of those with AD/ADRD (2021). A longitudinal study may elucidate whether family dementia caregivers' experiences in the person-in-context AD/ADRD simulation have a long-lasting effect and, if so, how long these effects last. Reported reductions in frustration, aggravation, and stress voiced by the respondents might improve caregiving longevity and mutually beneficial care for the family dementia dyads. Some respondents were unaware that they held unrealistic expectations and verbalized that adjusting their expectations improved relational harmony.

These respondents expressed that the experience was extremely valuable to inform positive changes in their loved ones' lives. Based on respondents' insights about repetitive participation in person-in-context dementia simulations, one area for future research should address the value of repeated exposures to person-in-context simulation as neurocognitive degeneration progresses.

### **Nursing Implications**

Rural health nurses are uniquely positioned to educate caregivers on critical measures to protect the emotional, mental, and physical well-being of the AD/ADRD caregiving dyad. Rural health nurses who offer person-in-context AD/ADRD to enhance community caregiver education may improve caregivers' awareness of the need for different communication strategies for expected behavioral changes associated with AD/ADRD. Area Agencies on Aging caregiver specialists often offer person-in-context dementia simulations and may be an excellent resource

for rural nurses and caregivers. Anticipatory approaches for managing the inherent frustrating situations in family caregiving of those with AD/ADRD are crucial to dyadic harmony and caregiving longevity.

Although the person-in-context simulation for this study was offered in a community event, the individual family versions of this or similar simulations may be acquired through grant funding as a valuable and feasible option for rural nurses to promote caring behaviors and expectations toward family members with AD/ADRD. Home delivery may be a safe alternative for those who wish to practice social distancing and avoid community events. In rural nurses' role, they connect residents with local resources and procure services (e.g., home health). Interprofessional collaboration with the federally supported Area Agencies on Aging in rural nurses' regions who deliver person-in-context simulations in the community or home environments strengthen the nurses' collaborative efforts, provide access to caregiver support specialists, and establish the trust needed to build a stronger support network. Rural nurses may benefit from participation in person-in-context AD/ADRD simulation to guide advocacy for those with AD/ADRD and caregiver education. Although not intended, these findings may be transferable to other contexts, situations, and settings (van Manen, 2016).

### **Limitations**

Understandably, the person-in-context AD/ADRD simulation is an intense simulation experience (Merizzi, 2018). Although these respondents reported experiencing negative emotions, all respondents expressed positive impressions of their person-in-context simulation. No adverse outcomes were reported to the P.I. or UMCIRB. This team would discourage participation in AD/ADRD simulations soon after losing a loved one from AD/ADRD, which may intensify grief reactions (Merizzi, 2018). Those who choose to participate soon after the

death of a loved one caused by AD/ADRDR have no opportunity for positive change, as seen in those who have current caregiving responsibilities. Their participation under these circumstances may lead to regret and emotional pain that may be difficult to process without professional bereavement counseling. Although adverse outcomes were not seen in the study, safeguards for respondents' mental and emotional health need to be planned for those who may experience an adverse reaction following any person-in-context AD/ADRDR simulation.

While caregivers planned and reported implemented changes, further study using person-in-context AD/ADRDR simulation is needed to examine if the changes reported bring about better care strategies or changes in caregivers' health outcomes. The chosen sampling method may have introduced volunteer bias. However, the all-female sample was congruent with the prevalence rates of female caregivers cited in the literature (Alzheimer's Association, 2021; Jutkowitz et al., 2017). Prior exposure to education and previous participation may have biased the respondents' perceptions. However, those who participated in the person-in-context AD/ADRDR simulation three years prior vividly recalled their previous experiences and reported maintenance of changes made in care across time, which added to the researchers' depth of understanding.

### **Conclusion**

Rural family caregivers found the AD/ADRDR simulation profoundly impacted their perceptions of AD/ADRDR and expressed new understandings and eye-opening epiphanies about their family members' daily challenges with dementia and their planned changes to improve their loved ones' quality of life. The AD/ADRDR simulated experience provided participants with a unique opportunity for self-discovery about their loved ones' daily challenges. This original study addresses the paucity of literature and research about AD/ADRDR simulations for rural caregivers of persons with AD/ADRDR. This study further demonstrates the value of AD/ADRDR simulation

to rural nursing practice and science. These findings may prompt rural health nurses to encourage family caregiver participation in person-in-context simulations to enhance their understanding of the loved ones' lived experience.

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