

An Appalachian Perspective of Alzheimer’s Disease: A Rural Health Nurse Opportunity

Lisa K. Wiese, PhD, RN, PHNA-BC, CNE¹

Christine L. Williams, DNSc, PMHCNS-BC²

¹ Assistant Professor, Christine E. Lynn College of Nursing, Florida Atlantic University,

lwiese@health.fau.edu

² Professor, Christine E. Lynn College of Nursing, Florida Atlantic University,

cwill154@health.fau.edu

Abstract

Predictions of the devastating impact of Alzheimer’s disease (AD) are heightened in disadvantaged rural populations, yet studies investigating AD in this population are limited. Other researchers have shown that when rural Appalachian people are aware of their risk for a chronic illness, they are more willing to adopt healthy behaviors (Della, 2011; Schoenberg et al. 2011), suggesting that educational programs to increase knowledge and perception of risk are needed. The purpose of this article was to report findings from exploring knowledge of Alzheimer’s disease in a southern rural West Virginia community of residents ($N = 193$) and a sample of caregivers ($n = 20$) using cognitive interview techniques of “Think-aloud” and “Laddering”. The cultural fit and relevance of the “Knowledge of Alzheimer’s Disease scale or KAD (Jang, Kim, Hansen, & Chiriboga, 2010) was also examined. Findings from the KAD included that an updated AD measure appropriate for use in rural settings is needed. Findings from the cognitive interview included that instead of fatalistic attitudes toward Alzheimer’s disease, residents often viewed AD as something potentially preventable through healthier living, use of herbs as children, and eventual discovery of more

effective treatment regimens. The themes that emerged were “preventing AD” and “personal knowing of AD”. Considering cultural perceptions and determining knowledge gaps in the communities by rural providers is an important component of changing stigma regarding routine cognitive screening for rural older adults at increased risk for Alzheimer’s disease.

Keywords: Appalachia Think-aloud technique, Cognitive interview, Alzheimer's disease knowledge, Rural older adults

An Appalachian Perspective of Alzheimer’s Disease: A Rural Health Nurse Opportunity

Every 66 seconds, someone in the United States develops Alzheimer’s disease (AD) (Alzheimer's Association [AA], 2017). Since the year 2000, deaths from AD have increased by 89%, with more persons being diagnosed with AD than breast and prostate cancer combined. The estimated cost of care for AD is \$259 billion for the year 2017 and projected to be \$1.1 trillion by 2050 (AA, 2017).

The threat of AD is heightened in rural communities (Mattos, et al., 2017) due to multiple health determinants such as decreased health care access for a high percentage of older adult residents who are at risk for the age-related disease (Russ, Batty, Hearnshaw, Fenton, & Starr, 2012). Rural communities also have less access to social services and health education than urban residents (Rural Health Information Hub, 2017). They have less health insurance and are more economically stressed (Borak, Salipante-Zaidel, Slade, & Fields, 2012). Rural residents experience a greater incidence of the chronic diseases of diabetes and hypertension (Crosby, Wendel, Vanderpool, & Casey 2012) which is now linked to higher AD risk (Li, Song, & Leng, 2015). This increased AD risk could have an impact on residents in Appalachia, where over 2.6 million residents are classified as rural (Pollard & Jacobsen, 2011). Furthermore, Appalachian residents are known to care for their “own” (Behringer & Friedell, 2007), which heightens the

burden of dementia-related caregiving, and increases their own risk for chronic illness. Thirty-five percent of AD caregivers (providing 18.2 billion hours in unpaid care in 2016) reported that their health worsened because of care responsibilities (AA, 2017).

Although research regarding perceptions and practices related to other chronic illnesses such as cancer (Bardach, Schoenberg, Fleming, & Hatcher, 2012; Hatcher, Studts, Dignan, Turner, & Schoenberg 2011; Schoenberg, Howell, & Fields, 2012) cardiovascular disease (Fahs, et al., 2013) and diabetes (Della, 2011; Huang, et al., 2014; Sherzai, Sherzai, & Lui, 2016) in the rural area of Appalachia is available, there have been no equivalent studies regarding AD. Schoenberg and colleagues (2009; 2012) demonstrated that Appalachian residents were more willing to pursue cancer screening after being informed of their disease risk, and researchers demonstrated similar findings related to dementia in underserved groups (Williams, Tappen, Rosselli, Keane, & Newlin, 2010). The question of whether rural populations are knowledgeable about AD and would be receptive to screening has not been answered. To develop relevant interventions to decrease risk of cognitive impairment in rural residents, research is needed to determine current knowledge about AD and attitudes toward screening. The purpose of this study was to explore a rural Appalachian cohort's perspective about AD using a knowledge survey and the "Think Aloud" technique of cognitive interviewing (CI).

Background

Despite the recent government mandate to include cognitive assessment in the annual Medicare wellness visit (Protection, Patient, and Affordable Care Act [PPACA], 2010), many providers are hesitant to screen (Borson, et al., 2013). Providers are often too busy or unwilling to engage in cognitive screening for fear of causing patient distress and the potential need for follow-through (Szymczynska, Innes, Mason, & Stark, 2011). However, the rural older adult

memory (ROAM) study (Boise et al., 2010), a practice-based intervention to improve dementia screening and diagnosis, demonstrated the success of using trained medical assistants to conduct cognitive screening, followed by favorable outcomes from training clinicians to diagnose and manage dementia in persons referred after screening. A workgroup convened by the Alzheimer's Association established an algorithm of cognitive screening and referral. This algorithm aligns with the Center for Medicaid/Medicare Services guidelines that nurses can follow when conducting cognitive assessments (Cordell et al., 2013). Rural health nurses can be a powerful presence in educating other providers and patients regarding the benefits of earlier detection, and in meeting the National Alzheimer's Project Act Objective Three of improving early diagnosis and coordination of care of AD (Department of Health and Human Resources, 2012).

Appalachian View of Health

Appalachian residents' cultural perceptions about health often vary from traditional health views (Goins, Spencer, & Williams, 2011; Griffith, Pyle, Lovett, & Miller, 2011). The ability to work has been equated with being healthy among rural and Appalachian residents (Gessert, et al., 2015). Despite ranking in the bottom five nationally in positive health indicators (American Health Rankings, 2017), Griffith et al. (2011) found the majority of over 1,500 Appalachian residents surveyed at a regional health fair considered their health as good to excellent (2011). Mudd-Martin and colleagues (2014) conducted seven focus groups among 88 healthcare employees and residents in central Kentucky, garnering participant statements such as "if you don't eat, you're not healthy", and "We just stressed with our children the need to take care of themselves, have regular tests, and all of our children are in pretty good shape..." (p. 88). Goins et al. (2011) explored rural Appalachian older adults' definition of health in 13 focus groups across six counties and found that perceptions of well-being included (1) having a clear

sense of purpose for living and (2) being free from worry. Gratitude for God's presence and grace were integral components of their perceptions of health. Goin et al. (2011) emphasized the need for providers to recognize cultural context in the measurement of health outcomes in rural older adults (p. 13).

Theoretical Framework

Discovering "What Matters Most" is a principal outcome of engaging the "Nursing as Caring" in the Boykin & Schoenhofer (2001) philosophical framework, which offers a practical application for transforming practice (Bulfin, 2005). The constructs of the theory include coming to know the care recipient (in this case, the community) through an authentic presence, honest intention to care, and answering the call to nurse using a holistic approach. This theory is a good fit for this work with the Appalachian culture that thrives on caring for others, and where health is defined as being productive and caring for family.

Review of Literature

Studies investigating AD perceptions, knowledge, and incidence in Appalachia or in rural populations are scarce. One sentinel study that was found to specifically target Appalachia was conducted over ten years in the Monongahela River valley. This investigation compared the incidence of AD by age, sex and education between a community in Ballabgarh, India with a rural community at the foothills of the Appalachians in southwestern Pennsylvania (Dodge, Wang, Chang, & Ganguli, 2011; Dodge, Zhu, Lee, Chang, & Ganguli, 2013; Ganguli, 2000). The presence of the APOE4 allele, a known AD risk factor, was significantly higher (11%) in the Monongahela group than in the Indian group (.073%). A random sample of 1,422 age-stratified (65 to 74 years, 75-79 years, and 80+) subjects were drawn from the voter registration lists for the 23 communities served by a local health center in the rural southwestern

Pennsylvania region. Enrollment criteria included being at least 65 years old, community dwelling at the time of recruitment, fluent in English, and with a minimum of sixth grade education. Education categories were defined as less than high school graduate or high school graduate and beyond. In the ten-year longitudinal study, researchers found that persons with less than a high school education had a higher rate of cognitive impairment and had higher rates of possible/incipient dementia (CDR = .5). They also found that men, not women, had higher AD incidence. The researchers posed that perhaps this was due to the emigration of the more educated and more ambitious men from the area to take advantage of government support of education post World War II. Another theory posited was that most of men in the area worked in the coal mines and coke ovens created a chronically hypoxic state from anthracosis or black lung. They hypothesized that lower education and higher occupational exposure were risk factors that varied by gender and needed to be further investigated. The researchers admitted that the results may have been influenced by lack of literacy and/or the lack of a culturally appropriate research tools. However, knowledge of the disease itself was not addressed in this research and researchers noted a need for research to fill this gap.

An early qualitative study (Morgan, Semchuk, Stewart, & D'Arcy, 2002) targeted knowledge and perceptions of dementia among rural residents after recognizing the lack of foundational research targeting rural dementia care. A key finding was the magnified inaccuracy in perceptions among residents in closely knit rural communities where dementing behaviors were more likely to be observed and discussed. Residents were often described as “covering up” for inappropriate behavior to outsiders, thinking they were protecting their relatives, which led to loss of support from formal and informal resources. Participants identified that a major barrier to willingness of rural residents to accept outside support was the lack of knowledge

about symptoms, prognosis, and benefits of earlier detection. Researchers recently examined the effect of social isolation on cognitive function among 267 Appalachian older adults ranging in ages 70 - 94 (M = 78.5) (DiNapoli, Wu, & Scogin, 2014). They found a significant inverse relationship between cognitive function and social isolation, particularly with perceived isolation as compared to social disconnectedness. Perceptions about AD knowledge or cognitive screening were not included.

Friedman et al. (2015) conducted a meta-analysis of 1,115 studies related to the public's perceptions of cognitive impairment risk or protective factors. Only 30 studies met the inclusion criteria of empirical research of community-dwelling adults from 2007 to 2013. Only 16 studies addressed Alzheimer's disease, only one specifically targeted rural residents, and none were conducted in Appalachia. In another meta-analysis, Martin et al. (2015) reviewed 29 international articles investigating perceptions and attitudes toward dementia screening. These researchers concluded that routine cognitive screening may not be accepted by the general population. However, only one article (Boise et al., 2010) located by Martin et al. (2015) specifically included rural residents, where AD incidence is known to be higher (Mattos, et al., 2017).

A new investigation of over 2,000 adults recruited from the Health and Retirement study (Ostergren, Heeringa, de Leon, Connell, & Roberts, 2017) found that respondents with a history of AD in their family perceived a significantly greater AD threat ($p < .001$) than those with no personal experience. Although neither Appalachian nor rural residents were measured or specified, the participants were derived from a nationally representative sample.

Mattos et al. (2017) concluded that more studies are needed of representative rural samples that include Appalachian residents. There is a gap in research regarding Appalachian residents'

AD knowledge, perceptions, and AD incidence (Mattos, et al., 2017; Wiese, Williams, Tappen, Newman, & Rosselli, 2017).

Method

The purpose of this descriptive study was to gain greater understanding of rural residents' perspectives about AD. This was achieved using a type of cognitive interview technique, the Think-Aloud, (Haeger, Lambert, Kinzie, & Gieser, 2012; Lundgrén-Laine & Salanterä, 2010) when administering the Knowledge of Alzheimer's disease Scale (Jang, Kim, Hansen, & Chiriboga, 2010). The first twenty participants (10%) of a larger sample of 200 were asked to describe why they chose their answers.

The Think-Aloud Technique

The "Think-Aloud" technique type of "cognitive interview" (CI) has become recognized as a useful research method for eliciting more information and understanding about the reasoning behind participant survey responses (Haeger, Lambert, Kinzie, & Gieser, 2012). CI has also been used successfully with older participants (Memon, Meissner, & Frasier, 2010). Other types of CI include verbal concurrent and retrospective probing (Haeger, Lambert, Kinzie, & Gieser, 2012) and laddering techniques (Price, 2002). Investigators have highlighted advantages of using the Think-Aloud technique as compared to other cognitive interviewing methods. For example, the use of open-ended questions can help to prevent interviewer bias, as compared to concurrent or retrospective probing or laddering, where the interviewer poses further questions based on interviewee responses. Asking the participant to describe why they chose a particular answer can help to create a connection between the participant's response and their thinking process. This in turn allows for the discovery of perceptions that are at the forefront of the working memory (Lundgrén-Laine & Salanterä (2010).

The minimum training required to engage the Think-Aloud technique is another benefit, but the interviewer must practice effective listening. In this study, the PI was the only interviewer, and made every attempt to bracket any pre-conceived ideas, such as rural residents being hesitant to share their perceptions due to privacy concerns, or potentially having lower knowledge levels due to decreased health care access and information. Two questions from the ten-item Knowledge of Alzheimer's Disease (KAD) scale were selected for the interview questions as being the most likely to be more representative of the KAD, while not tiring the participants: "Alzheimer's disease is a type of insanity" and "Alzheimer's disease is generally fatal." The research assistant also took notes during the interviews. The two interview transcripts were compared. Only minor discrepancies were noted, which were resolved upon clarification. This study was approved by the investigators' Institutional Review Board (#303768-1).

Setting

The location of this study was West Virginia (WV), the only state to lie completely in Appalachia, with 38% of its residents living in rural areas (Rural Health Information Hub, 2017). WV has the second highest percentage of older adults in the country after Florida (U.S. Census Bureau, 2010), and when combined with the geographic isolation common in rural Appalachia, adds to the AD threat (Halverson & Bischak, 2008).

Nicholas County, WV, in the southern portion of Appalachia (just north of Fayette County and the famed New River Gorge) was the primary research site. This county is designated as rural by the U.S. Department of Health & Human Services Office of Rural Health Policy (ORHP/HHS, 2017). In 2016, persons over age 65 comprised 21% of the population, which increased by 4% since 2010 (United States Census Bureau, 2012). The majority (97.9%) of the

25,311 residents were non-Hispanic White, 83% were high school graduates in the past five years, and 18.5% of the population was living below the poverty level from 2011-2015, with an average monetary income of \$39,171.

Sample

The inclusion criteria for this convenience sample included southern WV residents, age 65 or older, and the ability to answer study questions. Informal caregivers were included, but formal providers or caregivers were not. A table with signage advertising the study was arranged outside the local health clinic or nearby low-cost merchandize store. When potential participants approached the investigators' table, they were invited to enroll in the study. The first 20 of 200 persons who met the inclusion criteria and completed the survey (ten percent of the whole sample) were asked to participate in a cognitive interview. Seven persons were eliminated from the overall study during analysis due to incomplete surveys; N = 193 for the large sample, and n = 20 for the Think-Aloud exercise.

Instruments

Sociodemographic survey. The participants' birthplace, gender, caregiver status, previous occupation, religion, ethnicity, marital status, age, distance in miles to a health care provider, and formal years of education (grades 1-12), were the sociodemographic information obtained.

Knowledge of AD Measure (KAD). The most widely used dementia knowledge scale has been the Alzheimer's Disease Knowledge Scale (ADKS) developed by Carpenter et al. (2009; 2011). However, the ADKS was tested in populations with higher levels of educational and socioeconomic backgrounds, health care professionals, or AD caregivers than found in rural populations. The researchers acknowledged the need to eliminate items of high difficulty, maintain an 8th grade reading level, and offer a culturally relevant, language-appropriate tool.

After determining that the ADKS measure was more appropriate for professional or student populations, Jang, Kim, Hansen, & Chiriboga (2010) designed a ten-item, true/false knowledge test to better fit the characteristics of Korean seniors. The Knowledge of Alzheimer's Disease (KAD) scale is comprised of a combination previously used AD knowledge scale questions, including the earlier Dieckmann, Zarit, Zarit, & Gatz (1988), Connell, Roberts, & McLaughlin (2005), and Ayalon & Areán (2004) scales. The KAD was translated and back-translated for confirmation of accuracy in the Korean language, and tested with 675 Korean Americans. The KAD, first written in the Korean language and designed for use among Korean Americans, was the only recently developed measure designed to investigate AD knowledge among non-health care professional older adults. Of note is that the KAD is written at a post-graduate high school level according to the Flesch-Kincaid readability statistic of 40.2, which is college-level (1948). The KAD is also limited in terms of scope, as it addresses only a few AD facts and common misunderstandings. However, the straightforward item content, brevity, and relevance of several items supported choosing this tool for use in an Appalachian community. Permission to use the KAD was obtained from the authors.

Results

Sociodemographic data and results of the KAD for both the overall sample (N = 193) and smaller cognitive interview sub-sample (n = 20) are displayed in Tables 1 and 2. Most subjects were European American (94%), female (56%), married (47%), and claimed a Protestant affiliation (85%), with little difference between the larger and smaller sub-sample. Approximate years of education (11), miles from a provider (6), and age (70) were also similar in both groups, with ages ranging from 65 to 92.

The KAD was administered to all participants in the overall study Sample (N = 193). The

mean score on the 10-item concurrent test, the KAD, was 7.9 (SD = .72) out of 10 possible points.

Item answers to the KAD are available in Table 3.

Table 1*Sociodemographics of Categorical Variables for the KAD and Think-Aloud Participants*

Variable	Overall Sample N = 193 n (%)	Think Aloud Sub-Sample n = 20 n (%)
Gender		
Male	85 (44)	3 (30)
Female	108 (56)	17 (70)
Caregiver		
Yes	39 (20)	20 (100)
No	154 (80)	0 (0)
Ethnicity		
European American	181 (94)	19 (95)
African American	8 (4)	1(5)
Afro Caribbean	0 (0)	0 (0)
Asian American	0 (0)	0 (0)
Other	4 (2)	0 (0)
Religion		
Protestant	164 (85)	17 (85)
Catholic	6 (3)	1 (5)
Muslim	0 (0)	
Other	23 (12)	2 (10)
Marital Status		
Single	29 (15)	2 (10)
Married	90 (47)	4 (20)
Widowed	55 (29)	4 (20)
Separated	1(0)	3 (30)
Divorced	18 (9)	7 (35)

Table 2*Sociodemographic of Continuous Variables for Rural Sample and Sub-sample*

Variable	Overall Sample A N = 193		Think-Aloud Sub-Sample B n = 20	
	M	SD	M	SD
Age	69.4	10.5	76.86	7.89
Education	11.4	3	10.9	3.13
Miles from Provider	9	11	4.85	4.73

Table 3

KAD Item Totals of Correct Responses for Rural Sample

Knowledge of Alzheimer's Disease (KAD) Items +	Rural Sample N (%)
Alzheimer's disease could be contagious	16 (74.5)
All humans if they live long enough, will probably develop Alzheimer's disease	106 (54.1)
Alzheimer's disease is a form of insanity	159 (81.1)
Alzheimer's disease is a normal process of aging	142 (72.4)
Alzheimer's disease can be cured with medication	153 (78.1)
Alzheimer's disease only occurs in the elderly population	115 (58.7)
The major symptom of Alzheimer's disease is memory loss*	130 (66.3)
Symptoms of depression are similar to those of Alzheimer's disease*	39 (19.9)
Alzheimer's disease is generally fatal*	111 (56.6)
Alzheimer's disease can be diagnosed with a blood test	126 (64.3)

Notes: N and % = total number correct, * = True. Reprinted with permission Jang, Kim, Hansen, and Chiriboga (2010), *Journal of the American Geriatrics Society*, 55, p. 11.

Responses to the Cognitive Interview

The participant responses collected during the think-aloud exercise were analyzed (Table 4) using Strauss and Corbin's (1998) method of open coding to organize ideas from disordered and jumbled data (Morse, 2011). Two nurse researchers read and reread the responses independently, organized statements, identified key words, defined and assigned categories, wrote down possible themes, and met together to compare and reconcile differences in findings (Tappen, 2016).

Think-aloud technique of interview. The following are examples of subject responses to think-aloud questions.

Question: "Can you tell me why you answered this question the way you did: *Alzheimer's disease is a form of insanity or mental illness.*"

"I don't know if it is or not. It kinda makes sense that it would be, cause these people to lose themselves." "No...people with Alzheimer's aren't crazy; they just lose their memory." "Yea, I

am sure it is; some people just get violent with it.” “No. You may think that they are going crazy when they try to hit you and stuff, but it is a disease, a sickness.” “I really don’t know if they think it is or not...might be...that might be too hard a word to put on someone; being mentally ill.”

Question: “Can you tell me why you answered this question the way you did: “*Alzheimer’s disease is generally fatal; nothing can be done to prevent it*”.

“I think if you got it in your genes, there is nothin’ you can do”. “There is no cure because it is a brain disease.”

Themes

Two themes were induced from the think-aloud participant statements after both independently and collaboratively discerning meanings and categorizing statements. These themes were “preventing Alzheimer’s” (Table 5A) and “personal knowing of Alzheimer’s” (Table 5 B) (Alzheimer’s was occasionally referred to as “altimers”, “old-timers”, and “senile dementia”). The theme of *Preventing Alzheimer’s* was induced from statements such as “Yep; the doctor tells me if I quit smokin’ I won’t have it; I’d rather smoke and take a pill instead” and “Maybe it [eating right] helped me; I’m still goin’ strong.”

It may be a local practice only, but there were multiple references to taking wild or yellow root to stave off illness: “Wildroot was supposed to be a cure for everything and it’s common here”; “My mother always made us drink wildroot tea, and I don’t have a touch of it”, “My mom is funny about doctors”, “I drink it [wildroot] in tea, it doesn’t taste too good. But it’s like my daily medicine”; I’m too old to go out and get it [wildroot], but maybe it helped me; I’m still goin’ strong-Ha!” “No, there ain’t no treatment; nothing you can do...my mother in law took the ginsa thing. She got it anyhow. But lots of people roun here took yellowroot growin up...It’s supposed to be good for a lot of stuff”; “I dunno; we always had to chew on wildroot as kids, and I still do a

good bit. I think I'm okay..."

Frequent statements based on knowing the person with dementia led to the theme of *Personal Knowing of Alzheimer's*, such as "Yes, because it attacks the brain my mom had no idea who we were", and "I don't think there is any treatment for it; my daddy had it, and it was an awful way to go. He didn't recognize me, and hit me, and shouted, and tried to get out. I took care of 'im for four years. He just dies (tear, sob) ...I don't even know what to do with myself, now that he's gone."

Table 4

Coding and Categorizing Think-Aloud Data to Discover Themes

Key Words	Number of References	Categories and Definitions	Theme
Mother/Mamma/Wife's mother (9) Gramma (2) Sister/Sister-in-law (3) Mother in-law (2) Husband (1) Aunt (1) Cousin (1) Granddaughter (1) Dad (2) ----- In the brain (5) Attack the brain (1) Brain disease (1) Brain gets those things in it (1) In the head/pointing to head (2) Sick in the head (1) A sickness (1) memory (loss) (3) Crazy (3) Violent (1)	41	Knowing someone with Alzheimer's disease <i>Defined as having interactions with a person diagnosed with Alzheimer's disease</i>	PERSONAL KNOWING of ALZHIEMERS
		Knowing the disease of Alzheimer's <i>Defined being familiar with various etiologies and symptoms of the disease</i>	

Treat/Treatment (5)	35	Delaying Illness <i>Defined as the ability to delay onset or disease progression</i>	PREVENTING ALZHEIMER'S
Nuthin' you can do for it (2)			
Stops it (3)			
Helps (2)			
Drugs (4)			
Medicines (3)			
Yellowroot (4)			
Wildroot (5)			
Peachtree root (1)			
Ginkgo/Ginka (2)			
Gardening (2)	10	Seeking Help <i>Defined as visiting a nurse or physician for screening</i>	
Farming (2)			
Provider (5)			
They (referring to healthcare institution or provider) (5)			

Table 5A

Selected Participant Statements Reflecting the Theme of Personal Knowing

Statements of Personal Knowing
<i>I took care of my momma who had it; we both did (pointed to another sister)</i>
<i>My cousin was telling me, because her husband has it</i>
<i>My mom couldn't talk to us</i>
<i>You get it from your folks</i>
<i>My dad made up words</i>
<i>I took care of my aunt; she spent six years dyin from it</i>
<i>Four years my wife and I took care of her</i>
<i>Yea sure; your brain gets those things in it; everything gets clogged up</i>
<i>Everyone knows you can't remember words", "It's a physical thing in the brain", and "Yep; that [brain] is where all the problem is</i>
<i>I saw my wife's sister suffer from it; and you become someone else. I would hate that to happen.</i>

Table 5B

Selected Participant Statements Reflecting the Theme of Preventing Alzheimer's Disease

Statements of Preventing
<i>The earlier you start treatment, the better the medicine for Alzheimer's works, they think</i>
<i>Yea, there is some new treatment they got up there (the state university)</i>
<i>They are coming out with new ways to treat Alzheimer's disease</i>
<i>I heard tell of a new drug that will stop it from getting' worse</i>
<i>Hope they figure it out soon, it's awful" "Hope they hurry up with it [new drugs]</i>
<i>I think it's all that crap we are eatin' these days; all the junk; that is what is doin' us in. If we stopped and went back to farmin', that would decrease your chances</i>
<i>Well, if there is a way to prevent it, sign me up!</i>
<i>They just need to put it [ways to prevent it] on the radio and on TV; people here listen to one or the other</i>
<i>If you take care of yourself you are going to be okay, and if you don't, you won't</i>
<i>You gotta exercise, not smoke, eat right-you know, avoid the sugar, all that stuff</i>
<i>I dunno, exercise might help, and if you call workin in the coal mines all your life exercise, I did.</i>

Discussion

This study's purpose was to investigate AD knowledge in a cohort of rural older Appalachians and examine the cultural fit and relevance of the Knowledge of Alzheimer's Disease scale (Jang, Chiriboga, & Kim, 2010). Results showed that Appalachian residents scored about 80% average on the KAD.

The think-aloud revealed rich information regarding residents' personal knowing about the illness, and expectations that there might be ways to delay or prevent AD. Both findings were in contrast to the a priori expectations of the PI. This is an important lesson in realizing that prior to conducting educational sessions in varied community settings to increase awareness of risk, assessment of knowledge gaps is essential.

Throughout most of the interviews, there was a tone of positivity, even hope, for finding treatment for Alzheimer's disease, willingness to be informed, and have access to treatment. There were a few indications that the residents might be more informed than the providers. Regardless, multiple statements made by the residents regarding the benefits of healthy eating, exercise, and even taking wildroot demonstrated that most did not view themselves as powerless over Alzheimer's disease. One participant's statement to "just put it [information about ways to prevent it] on the radio or TV and people here will listen to one or the other" bears further consideration.

Limitations

Findings were limited by the singular geographic location and sample size. Results may differ in other Appalachian communities or other rural populations. Coincidentally, all the participants in the think-aloud inquiry had previous history as an informal caregiver. WV, the site for this research, has a high percentage of older adults, therefore finding participants who were not exposed to the age-related illness of AD in family and friends was difficult. There were limitations

in using the think aloud technique. Participants may stray from the topic at hand or state what they imagine the investigator will want to hear (Haeger et al., 2012). Adhering to the think-aloud technique minimizes the researcher's tendency to steer the subject's responses, but it is possible to miss valuable information. It might be of greater advantage to add a laddering method of inquiry that allows for deeper exploration while being mindful to avoid investigator bias (Price, 2002).

Implications for Education

Researchers (Schoenberg, Howell, & Fields, 2012, Hatcher, et al., 2011) conducting community based participatory research in Appalachian Kentucky have successfully demonstrated that education about prostate and breast cancer risk does increase screening rates. Work has begun regarding increasing knowledge about AD in the aging Appalachian population. The state of WV adopted a "Make A Plan" to combat AD in 2011. The WV Council on Aging now requires employed caregivers going out in the community to complete four hours of AD training. Perception of risk, rather than knowledge alone, is a proven motivator of health-seeking behavior (Boustani, Perkins, Monahan, et al., 2008). More work needs to be done in exploring perceptions of rural residents. There also needs to be a greater emphasis on the importance of conducting cognitive screening in persons over 65 in schools of nursing and medicine. This may help to eliminate incorrect assumptions by providers that persons do not want to know (Wiese, Williams, & Tappen, 2014). Persons interviewed in the think-aloud inquiry appeared hopeful about treatment, even after having personal knowledge of the illness. Education is needed to inform providers and families of the benefits of earlier detection, such as initiating medications that are more effective if started early during the disease, connection with support services, and long-term care planning (Dubois, Bruno, Padovani et al., 2016). Many patients who are aware they are losing their memory are fearful of receiving a formal diagnosis, but if they are informed of these benefits,

they may be more motivated to seek outside help.

The results of both the KAD and think-aloud inquiry revealed that the participants were more familiar with the disease manifestations than with risks or treatment, due to personal knowledge of caring for persons with AD. These findings highlight the need for nurses in rural primary care to (a) become familiar with the new cognitive screening algorithms (Wiese & Williams, 2015), and (b) to increase their own efforts in educating the communities they serve about the benefits of earlier cognitive screening.

Implications for Practice

Despite the recent government mandate to include cognitive assessment in the annual Medicare wellness visit (PPACA, 2010), there is little to no routine cognitive screening at the WV free clinics (personal communication, June 27, 2017). Providers are often too busy or unwilling for fear of causing patient distress to engage in cognitive screening and potential need for follow-through (Szymczynska, Innes, Mason, & Stark, C., 2011). However, the rural older adult memory (ROAM) study (Boise et al., 2010), a practice-based intervention to improve dementia screening and diagnosis, demonstrated the success of using trained medical assistants to conduct cognitive screening, followed by favorable outcomes from training clinicians to diagnose and manage dementia in persons referred after screening. Rural health nurses are well-positioned to make a difference by conducting brief five-minute cognitive screenings in persons at risk for AD. An update for nurses to implement screening following the Alzheimer's Association and Centers for Medicaid/Medicare Services guidelines (Cordell, Borson, Boustani, Chodosh, Reuben, et al., 2013) is available (Wiese & Williams, 2015).

It is imperative to refer persons who may be at risk for AD, depression, or another dementia to a provider that is further trained in geriatric and dementia-specific assessments. Gerontological

and family nurse practitioners can be trained by expert geriatricians and gerontological nurse practitioners to conduct these assessments and provide one answer to the lack of trained providers in the region.

Implications for Research

Many items on the KAD are outdated or do not address current findings. A more current AD survey with an appropriate reading level that addresses the Alzheimer's Association ten warning signs, as well as AD risk, detection, and delaying onset, would be beneficial. There is also a gap in research addressing rural residents' perceptions regarding AD. Given the high rates of AD among rural populations, an appropriate instrument to measure AD both knowledge and risk perception in this population is needed before designing future educational and screening interventions.

Conclusion

Understanding illness through a cultural lens is important for effective community management of chronic disease (Smith & Tessaro, 2005). Discovering "what matters most" to communities within their own unique culture will help local nurses and providers to identify effective ways to partner in improving health for their residents. This is especially important with the majority of the oldest-old now residing in rural communities where the threat of AD is the greatest (AA, 2017). Contrary to previously held beliefs that rural residents often view Alzheimer's as an inevitable illness, rural Appalachian older residents in this study expressed belief in the ability to delay or prevent disease through healthy diet, exercise, and herbal use. Participants also expressed hope for discovery of effective treatment. These findings suggest that rural residents may be willing to participate in routine cognitive screening that is mandated as part of the Medicare/Medicaid Annual Wellness Visit by the Patient Protection and Affordable Care

Act of 2011. Rural health nurses can be a powerful presence in educating other providers and patients regarding the benefits of earlier detection, and in meeting the National Alzheimer's Project Act Objective Three of improving early diagnosis and coordination of care of Alzheimer's disease (Department of Health and Human Resources, 2012).

Predictions of the devastating impact of Alzheimer's disease (AD) are heightened in disadvantaged rural populations, yet studies investigating AD in this population are limited. Other researchers have shown that when rural Appalachian people are aware of their risk for a chronic illness, they are more willing to adopt healthy behaviors (Della, 2011; Schoenberg et al. 2011), suggesting that educational programs to increase knowledge and perception of risk are needed. The purpose of this article is to report findings from exploring knowledge of Alzheimer's disease in a southern rural West Virginia community of residents ($N = 193$) and a sub-sample of caregivers ($n = 20$) using cognitive interview techniques of "Think-aloud" and "Laddering". The cultural fit and relevance of the "Knowledge of Alzheimer's Disease scale or KAD (Jang, Kim, Hansen, & Chiriboga, 2010) was also examined. Findings from the KAD included that an updated AD measure appropriate for use in rural settings is needed. Findings from the cognitive interview included that instead of fatalistic attitudes toward Alzheimer's disease, residents often viewed AD as something potentially preventable through healthier living, use of herbs as children, and eventual discovery of more effective treatment regimens. The themes that emerged were "preventing AD" and "personal knowing of AD". Considering cultural perceptions and determining knowledge gaps in the communities by rural providers is an important component of changing stigma regarding routine cognitive screening for rural older adults at increased risk for Alzheimer's disease.

Supporting Agency

Sigma Theta Tau International, Iota Xi chapter

References

Alzheimer's Association (2017). Alzheimer's Association Facts and Figures Report. Retrieved from: <http://www.alz.org/dementia/types-of-dementia.asp>

Ayalon, L., & Areán, P. A. (2004). Knowledge of Alzheimer's disease in four ethnic groups of older adults. *International Journal of Geriatric Psychiatry*, 19, 51-57. <https://doi.org/10.1002/gps.1037>

Boise, L., Eckstrom, E., Fagnan, L., King, A., Goubaud, M., Buckley, D. I., & Morris, C. (2010). The rural older adult memory (ROAM) study: a practice-based intervention to improve dementia screening and diagnosis. *The Journal of the American Board of Family Medicine*, 23(4), 486-498. <https://doi.org/10.3122/jabfm.2010.04.090225>

Bardach, S. H., Schoenberg, N. E., Fleming, S. T., & Hatcher, J. (2012). Relationship between colorectal cancer screening adherence and knowledge among vulnerable rural residents of Appalachian Kentucky. *Cancer Nursing*, 35(4), 288-294. <https://doi.org/10.1097/NCC.0b013e31822e7859>

Behringer, B., & Friedell, G. H. (2006). Appalachia: Where place matters in health. *Preventing Chronic Disease*, 3(4), A113. Retrieved from http://www.cdc.gov/pcd/issues/2006/oct/06_0067.htm

Borak, J., Salipante-Zaidel, C., Slade, M., & Fields, C. (2012). Mortality disparities in Appalachia reassessment of major risk factors. *Journal of Occupational and Environmental Medicine*, 54(2), 146-156. <https://doi.org/10.1097/JOM.0b013e318246f395>

- Borson, S., Frank, L., Bayley, P. J., Boustani, M., Dean, M., Lin, P. J., ... & Stefanacci, R. G. (2013). Improving dementia care: The role of screening and detection of cognitive impairment. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 9(2), 151-159. <https://doi.org/10.1016/j.jalz.2012.08.008>
- Boykin, A. & Schoenhofer, S. (2001). Nursing as caring: A model for transforming practice. Sudbury, MA: Jones & Bartlett Publishers.
- Boykin, A., Schoenhofer, S. O., Smith, N., Jean, J. S., & Aleman, D. (2003). Transforming practice using a caring-based nursing model. *Nursing Administration Quarterly*, 27(3), 223-230. <https://doi.org/10.1097/00006216-200307000-00009>
- Bulfin, S. (2005). Nursing as caring theory: Living caring in practice. *Nursing Science Quarterly*, 4, 313-319. <https://doi.org/10.1177/0894318405280401>
- Carpenter, B.D., Balsis, S., Otilingam, G., Hanson, P.K. & Gatz, M. K (2009). The Alzheimer's disease knowledge scale: Development and psychometric properties. *The Gerontologist*, 49(2), 236-247. <https://doi.org/10.1093/geront/gnp023>
- Carpenter, B.D., Zoller, S.M., Balsis, S., Otilingam, G. & Gatz, M. K (2011). Demographic and contextual factors related to knowledge about Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias*, 26(121), 121-126. <https://doi.org/10.1177/1533317510394157>
- Connell, C., Roberts, J., & McLaughlin, S. (2005). Public knowledge about Alzheimer's disease and attitudes of risk reduction: A national survey. *Gerontologist*, 45, 38-47. <https://doi.org/10.1186/1471-2458-14-661>

Cordell, C., Borson, S., Boustani, M., Chodosh, J., Reuben, D., Verghese, V., Fried, L.B. The Medicare Detection of Cognitive Impairment Workgroup (2013). Alzheimer's Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 9(2), 141-150. <http://dx.doi.org/10.1016/j.jalz.2012.09.011>

Crosby, R. A., Wendel, M. L., Vanderpool, R. C., & Casey, B. R. (2012). *Rural populations and health: Determinants, disparities, and solutions*. NJ: John Wiley & Sons.

Della, L. (2011). Diabetes beliefs in at-risk Appalachia. *The Journal of Rural Health* 27, 3–12. <https://doi.org/10.1111/j.1748-0361.2010.00311.x>

Dieckmann, L., Zarit, S., Zarit, J., & Gatz, M. (1988). The Alzheimer's Disease Knowledge Test. *The Gerontologist*. 28(3), 402-408. <https://doi.org/10.1093/geront/28.3.402>

DiNapoli EA, Wu B, & Scogin F. (2014). Social isolation and cognitive function in Appalachian older adults. *Research on Aging*, 36(2), 161-179. <https://doi.org/10.1177/0164027512470704>

Department of Health and Human Services. (2014). *National plan to address Alzheimer's Disease update: June 2013*. Retrieved from <http://aspe.hhs.gov/daltcp/napa/NatlPlan2014.shtml>.

Dodge, H. H., Wang, C. N., Chang, C. C. H., & Ganguli, M. (2011). Terminal decline and practice effects in older adults without dementia: The MoVIES project. *Neurology*, 77(8), 722-730. <https://doi.org/10.1212/WNL.0b013e31822b0068>

Dodge, H. H., Zhu, J., Lee, C. W., Chang, C. H., & Ganguli, M. (2013). Cohort effects in age-associated cognitive trajectories. *Journals of Gerontology Series A: Biomedical Sciences and Medical Sciences*, 69(6), 687-694. <https://doi.org/10.1093/gerona/glt18>

- Dubois, B., Padovan, A., Scheltens, P., Rossi, A., and Dell’Agnello, G. (2016). Timely diagnosis for Alzheimer’s disease: A literature review on benefits and challenges. *Journal of Alzheimer's Disease* 49(3), 617-631. <https://doi.org/10.3233/JAD-150692>
- Fahs, P. S., Pribulick, M., Williams, I. C., James, G. D., Rovynak, V., & Seibold-Simpson, S. M. (2013). Promoting heart health in rural women. *The Journal of Rural Health*, 29(3), 248- 257. <https://doi.org/10.1111/j.1748-0361.2012.00442.x>
- Flesch, R. (1948). A new readability yardstick. *Journal of Applied Psychology*, 32, 221–233. <http://dx.doi.org/10.1037/h0057532>
- Friedman, D. B., Becofsky, K., Anderson, L. A., Bryant, L. L., Hunter, R. H., Ivey, S. L., . . . Lin, S. (2015). Public perceptions about risk and protective factors for cognitive health and impairment: A review of the literature. *International Psychogeriatric*, 27(8), 1263-1275. <http://dx.doi.org/10.1017/S1041610214002877>
- Goins, R. T., Spencer, S. M. and Williams, K. (2011). Lay meanings of health among rural older adults in Appalachia. *The Journal of Rural Health*, 27, 13–20. <https://doi.org/10.1111/j.1748-0361.2010.00315.x>
- Haeger, H., Lambert, A. D., Kinzie, J., & Gieser, J. (2012, June). *Using cognitive interviews to improve survey instruments*. Paper presented at the annual forum of the Association for Institutional Research, New Orleans, LA.
- Halverson, J., & Bischak, G. (2008). *Underlying socioeconomic factors influencing health disparities in the Appalachian region*. Retrieved from https://www.arc.gov/research/research-reportdetails.asp?REPORT_ID=9

- Hatcher, J., Studts, C., Dignan, M., Turner, L. & Schoenberg, N. (2011). Predictors of cervical cancer screening for rarely or never screened rural Appalachian women. *Journal of Health Care for the Poor and Underserved*, 2, 176–193. <https://doi.org/10.1353/hpu.2011.0021>
- Huang, C. C., Chung, C. M., Leu, H. B., Lin, L. Y., Chiu, C. C., Hsu, C. Y., ... & Chen, J. W. (2014). Diabetes mellitus and the risk of Alzheimer's disease: a nationwide population-based study. *PloS one*, 9(1), e87095. <https://doi.org/10.1371/journal.pone.0087095>
- Jang, Y., Kim, G., Hansen, L., & Chiriboga, D. A. (2010). Knowledge of Alzheimer's disease, feelings of shame and awareness of services among Korean American elders. *Journal of the American Geriatrics Society*, 55, 616-620. <https://doi.org/10.1177/0898264309360672>
- Li, X., Song, D., & Leng, S. X. (2015). Link between type 2 diabetes and Alzheimer's disease: From epidemiology to mechanism and treatment. *Clinical Interventions in Aging*, 10, 549–560. <https://doi.org/10.2147/CIA.S74042>
- Lundgrén-Laine, H., Salanterä, S. (2010) Think-Aloud technique and protocol analysis in clinical decision-making research. *Qualitative Health Research*, 20(4), 565-575. <https://doi.org/10.1177/1049732309354278>
- Mattos, M. K., Snitz, B. E., Lingler, J. H., Burke, L. E., Novosel, L. M., & Sereika, S. M. (2017). Older rural-and urban-dwelling Appalachian adults with mild cognitive impairment. *The Journal of Rural Health*, 33(2), 208-216. <https://doi.org/10.1111/jrh.12189>
- Martin, S., Kelly, S., Khan, A., Cullum, S., Dening, T., Rait, G... & Lafortune, L. (2015). Attitudes and preferences towards screening for dementia: A systematic review of the literature. *BMC geriatrics*, 15(1), 66. <https://doi.org/10.1186/s12877-015-0064-6>

- Memon, A., Meissner, C., & Fraser, J. (2010). The Cognitive interview: A meta-analytic review and study space analysis of the past 25 years. *Psychology, Public Policy, and Law*, 16(4), 340-373. <http://dx.doi.org/10.1037/a0020518>
- Morgan, D. G., Semchuk, K. M., Stewart, N. J., & D'Arcy, C. (2002). Rural families caring for a relative with dementia: Barriers to use of formal services. *Social Science and Medicine*, 55(7), 1129-1149. [https://doi.org/10.1016/S0277-9536\(01\)00255-6](https://doi.org/10.1016/S0277-9536(01)00255-6)
- Office of Rural Health Policy (2017). Data Warehouse; Rural Grants Eligibility Analyzer. Retrieved from <https://datawarehouse.hrsa.gov/tools/analyzers/geo/Rural.aspx>
- Ostergren, J. E., Heeringa, S. G., de Leon, C. F. M., Connell, C. M., & Roberts, J. S. (2017). The influence of psychosocial and cognitive factors on perceived threat of Alzheimer's disease. *American Journal of Alzheimer's Disease & Other Dementias*, 32(5), 289-299. <https://doi.org/10.1177/1533317517714552>
- Protection, Patient, and Affordable Care Act (2010). Patient protection and affordable care act. Public Law 111 (2010): 48.2. Retrieved from <https://www.gpo.gov/fdsys/pkg/PLAW-111publ148/content-detail.html>
- Pollard & Jacobsen, Appalachian Chartbook. (2011). The Appalachian Region in 2010: A Census Data Overview Chartbook. Population Reference Bureau. Retrieved from <http://www.prb.org/pdf12/appalachia-census-chartbook-2011.pdf>
- Price, B. (2002). Laddered questions and qualitative data research interviews. *Distance Learning*, 37(3), 273-181. London, UK: The RCN Institute. <https://doi.org/10.1046/j.1365-2648.2002.02086.x>
- Richards, L. & Morse, J. (2013). *ReadMe First for a user's guide to qualitative research* (3rd ed.). New York, NY: Sage Publishing.

- Russ, T. C., Batty, G. D., Hearnshaw, G. F., Fenton, C., & Starr, J. M. (2012). Geographical variation in dementia: Systematic review with meta-analysis. *International Journal of Epidemiology*, 41(4), 1012-1032. <https://doi.org/10.1093/ije/dys103>
- Rural Health Information Hub. (2017). Health Resources and Services Administration, U.S. Department of Health and Human Services. Retrieved from <https://www.ruralhealthinfo.org/>
- Sherzai, D., Sherzai, A., Lui, K., Pan, D., Chiou, D., Bazargan, M., & Shaheen, M. (2016). The association between diabetes and dementia among elderly individuals: A nationwide inpatient sample analysis. *Journal of Geriatric Psychiatry and Neurology*, 29(3), 120-125. <https://doi.org/10.1177/0891988715627016>
- Schoenberg, N., Bardach, S., Manchikati, K. & Goodenow, A. (2011). Appalachian Residents' experience with and management of multiple morbidity. *Qualitative Health Research*, 21(5), 601-611. <https://doi.org/10.1177/1049732310395779>
- Schoenberg, N. E., Hatcher, J., Dignan, M. B., Shelton, B., Wright, S., & Dollarhide, K. F. (2009). Faith Moves Mountains: An Appalachian cervical cancer prevention program. *American Journal of Health Behavior*, 33(6), 627-638. <https://doi.org/10.5993/AJHB.33.6.1>
- Schoenberg, N. E., Howell, B. M., & Fields, N. (2012). Community strategies to address cancer disparities in Appalachian Kentucky. *Family Community Health*, 35(1), 31-43. <https://doi.org/10.1097/FCH.0b013e3182385d2c>
- Szymczynska, P., Innes, A., Mason, A., & Stark, C. (2011). A review of diagnostic process and post diagnostic support for people with dementia in rural areas. *Journal of Primary Care & Community Health*, 2, 262-276. <https://doi.org/10.1177/2150131911404705>

- Smith, S. L., & Tessaro, I. A. (2005). Cultural perspectives on diabetes in an Appalachian population. *American Journal of Health Behaviors*, 29(4), 291-301. <https://doi.org/10.5993/AJHB.29.4.1>
- Strauss, A. & Corbin, J. (1998). *Basics of qualitative research techniques and procedures for developing grounded theory*, (2nd Ed.) London: Sage Publications.
- Tappen, R.M. (2016). *Advanced nursing research: From theory to practice* (2nd ed.). Sudbury, MA: Jones & Bartlett.
- U.S. Census Bureau. (2010). *State and county QuickFacts*. Retrieved from <http://www.census.gov/2010census>
- Wiese, L., & Williams, C. (2015). Annual cognitive assessment for older adults: Update for nurses. *Journal of Community Health Nursing*, 32, 1-13. <https://doi.org/10.1080/07370016.2015.1087244>
- Wiese, L. K., Williams, C. L., & Tappen, R. M. (2014). Analysis of barriers to cognitive screening in rural populations in the United States. *Advances in Nursing Science*, 37(4), 327-339. <https://doi.org/10.1097/ANS.0000000000000049>
- Wiese, L., Williams, C., Tappen, R., Newman, D., & Rosselli, M. (2017). Assessment of basic knowledge about Alzheimer's disease among older rural residents: A pilot test of a new measure. *Journal of Nursing Measurement*, 25(3), 519-548. <https://doi.org/10.1891/1061-3749.25.3.519>