

Experiences of Formal Caregivers Providing Dementia Care to American Indians

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Alzheimer's disease (AD) is a significant public health concern for all elders in the United States. It is a particular concern for the American Indian (AI) population, which is one of the fastest aging populations in the United States and the smallest, most underrecognized, and most culturally diverse group in the country. A formal caregiver understanding of AD in the AI population is scarce. This phenomenological study was designed to discern what is known about AD in the AI population by exploring the cultural beliefs and experiences of formal caregivers who provide care for AI dementia patients. Specifically, this study sought to document formal caregiver and AI dementia beliefs about AD. Data came from four in-depth interviews that included three Western and one AI formal caregiver. These interviews explored the variability of cultural beliefs regarding AD and dementia among a sample of formal caregivers who minister to AI patients; in the interviews, these participants also provided examples of challenges they faced, providing a better cultural understanding of AI dementia. The findings included using a bicultural approach to AD, illuminating interactions between patient and provider, and fostering awareness of cultural competency. Research on this topic is critical in advancing cultural, public health, and evidence-based health practices regarding AI dementia patients. The potential implications for social change include enhancing cross cultural provider–patient interactions and advancing public health policy and practice for this underserved population. Many of the issues and challenges explored may have implications for other ethnocultural minority groups.

Keywords: *caregivers, dementia, Alzheimer's disease, American Indians, healthcare culture*

Introduction

History has not been kind to the U.S. American Indian (AI) population (Zinn, 2005). For more than 5 centuries, AIs have been labeled as savages, barbarians, demons, and beasts by Westerners and early European settlers (Weidensaul, 2012). The labels have led to widespread oppression in virtually every aspect of AI lives (Satter, Randall, & Solomon, 2014). Because of fragmented healthcare systems, government underfunding, and restricted access to healthcare and healthcare services, AIs continue to suffer some of the highest rates of chronic health conditions in the United States (Centers for Disease Control and Prevention, 2010, 2012; Rhoades & Rhoades, 2014).

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Alzheimer's disease (AD) is emerging steadily in AI populations because AIs are living longer and are the fastest growing population in the age 65+ category (U.S. Department of Commerce, Economics and Statistics Administration, 2010). AIs have some of the highest disease comorbidities and lifestyle risk factors associated with dementia in the United States (Goins & Pilkerton, 2010). Jervis and Manson (2002) found disparities in tracking AI cases of AD and dementia because of the fragmented healthcare systems between reservations in rural and urban AI populations. Limited information is available regarding formal caregiver and AI understanding of AD. This has provided an incomplete picture of the experience of formal dementia caregivers.

Method

Problem Statement

The study addressed a research gap consisting of a lack of knowledge regarding the cultural beliefs and experiences of AD among the AI population.

Purpose Statement

The purpose of this study was to understand formal caregiver's cultural beliefs about AD and dementia, and how these beliefs define the course of care developed by the formal caregivers for AI dementia patients. The study fills a void in the existing literature and research by providing qualitative data on an important topic (Goins & Pilkerton, 2010; Jervis & Manson, 2002). Evaluation of evidence-based, self-management, and community-based participatory research is scarce for AD and dementia in the AI population (Daley et al., 2010; Jernigan, 2010; Orom & Gage, 2013). Current literature has not kept pace with cultural differences of AD and dementia in the AI population (Alzheimer's Association, 2014; Dixon & Iron, 2006; Goins et al., 2011; Jervis & Manson, 2002).

Research Questions

Three research questions guided the study.

Research Question 1: What are the understandings of formal caregivers for AIs about their patients' cultural beliefs about AD and dementia?

Research Question 2: What are the cultural beliefs about AD and dementia of formal caregivers for AIs?

Research Question 3: How do formal caregivers for AIs use their cultural beliefs about AD and dementia to develop courses of care for their patients?

Conceptual Framework

This conceptual framework was constructed to address a negative historical perception by AIs of research conducted by Western researchers on AI persons (Humphrey, 2001; Smith, 2012). The AI conceptual framework honors AI cultural beliefs regarding AD. For the purpose of this discussion, the medicine wheel served as the example by which AIs have come to understand disease and have relied on the oral tradition to find healing (see Figure 1).

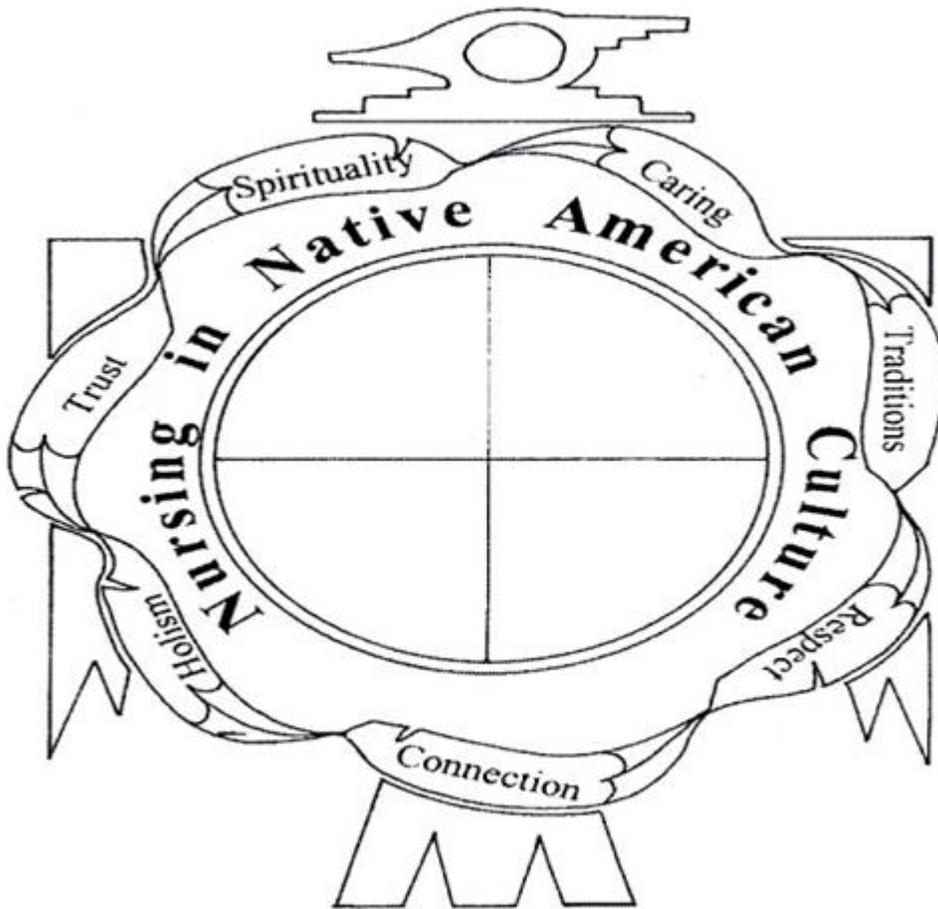


Figure 1. Conceptual model of nursing in American Indian culture. Adapted from “A Conceptual Framework of Nursing in Native American Culture,” by J. Lowe & R. Struthers, 2001, *Journal of Nursing Scholarship*, 33, p. 282. Copyright 2001 by Journal of Nursing Scholarship. Reprinted with Permission.

Approach

The specific phenomenological approach chosen for this study was transcendental phenomenology because it is the best method to research lived experience, and it allows for an open attitude needed to let new meanings emerge (Appelbaum, 2011; Lopez & Willis, 2004; Pascal, Johnson, Dore, & Trainor, 2011).

Participants

Participants were four healthcare professionals with varying levels of medical expertise: one AI family practice/psychiatrist with 40 years of medical experience, one Western physician assistant with 35 years of medical experience, and two Western nurse practitioners with 7 and 20 years of medical experience, respectively. The formal caregivers in this study ranged in age from mid-30s to mid-60s. All had obtained a graduate or postgraduate education in their fields of training.

Participants in this study met the following criteria: (a) formal caregiver presently providing AD or dementia care to AI patients and their informal caregivers, (b) formal caregiver who had never been diagnosed with cognitive impairment, and (c) formal caregiver of an AI dementia patient who resides in northern rural New England. At the time of the study, each participant was caring for AI dementia patients. The two nurse practitioners provided care on reservations in northern rural New England, whereas the psychiatrist and physician assistant provided care in rural cities and towns in that area.

The recruitment strategy included contacting an AI medical doctor who is also a public health researcher. The AI doctor provided email addresses and telephone numbers of possible participants. Only four out of eight referred formal caregivers consented to participate in the study. Because of the small response, 20 additional requests were sent by email to locate formal caregivers throughout the rural and urban New England area to request their participation in the study. These formal caregivers did not respond or declined to participate because they either had no experience with AI dementia or in most cases had never seen or were not currently seeing AI patients with dementia. Subsequently, only four formal caregivers consented to participate.

Instrumentation

For this study, audio-recorded semistructured interviews, observations, and analyses of the memos and reflexive journal were made. This study was based on three semistructured interview questions that assisted in identifying and understanding the cultural beliefs of formal caregivers and AI dementia patients, and the cultural aspects of the course of care provided (Atkinson, 1998).

Results

The results of this study are organized by major themes and then further divided by the responses of formal caregivers. This framework provides an opportunity to elicit and analyze essential themes from the data.

Themes

Theme 1: AD and Dementia Are Understood Differently Among AIs

All four of the research participants recognized that AD and dementia are viewed differently in the AI culture than in Western society. AD and dementia are not seen as problematic in the AI population; they are viewed in terms of a passing over to the spirit world, and not seen as something that is broken, needs to be fixed, or out of balance. For AIs, disease is viewed as a lack of harmony with the earth. AIs with AD are still seen as living human beings who are imbued with a special gift of living in the body and living in the spirit world. Understanding of AD and dementia varies from tribe to tribe based upon a tribe's worldview.

Theme 2: AI Worldviews Regarding AD and Dementia Treatment Are Different From Westerners

Another major theme that emerged was the way in which AI dementia patients access healthcare treatment for AD or dementia. All of the formal caregivers practiced in northern rural New England, and their AI dementia patients came from traditional tribal backgrounds. Therefore, traditional AI worldviews had a significant role in the way in which AI patients access healthcare for AD and dementia. AIs, unlike their Western counterparts, access healthcare for specific reasons other than dementia (e.g., diabetes, cardiovascular disease). A dementia diagnosis is usually diagnosed in tandem with another health-related illness, and treatment for dementia is always secondary to the

primary illness. Westerners, on the other hand, seek dementia-specific treatment. Theme 3: The Main Source of Support for AI Patients With AD and Dementia Is the Family

Throughout the four interviews, all of the formal caregivers agreed that the family is the main source of support for the patient. Two of the four formal caregivers also reported the importance of the family being the chief source of information about the patient. AIs have been historically tied to their families and tribes as the source of support, especially in times of need. AI families tend to be multigenerational, and support can come from not only immediate family members, but from cousins, in-laws, and other extended family members who live on and off the reservation. The formal caregivers in these interviews talked about the high esteem for elders within the AI community.

Theme 4: All Providers Stressed the Need for Cultural Competence and Bicultural Approaches When Working With AI Patients With AD and Dementia

All four of the formal caregivers discussed the importance of creating culturally competent course-of-care plans for AI patients with AD and dementia and related that when developing these care plans, both AI and Western beliefs were incorporated. However, central to this theme was honoring AI worldviews. Culturally competent care plans should be tailored to each AI tribe to provide dementia and AD services. As previously discussed, each tribe has its own worldviews concerning dementia and AD. Central to this theme was honoring individual AI tribal, spiritual worldviews that need to be integrated into course-of-care plans along with Western approaches to treating disease.

Theme 5: Formal Caregivers Expressed Frustration and the Essential Need for Early Intervention in Working With AI Patients With AD and Dementia

The formal caregivers interviewed for this study stressed the importance of early intervention in the treatment of AI patients with AD and dementia.

Theme 6: Early AI Mortality

The last theme extracted from the interviews was the early mortality rate of AIs even before the onset of AD.

Research Questions

Research Question 1: What Are the Understandings of Formal Caregivers for AIs About Their Patients' Cultural Beliefs About AD and Dementia?

All four of the formal caregivers revealed they had some type of experience with AI patients with AD or dementia. The major themes that emerged for this research question included that AD and dementia are understood differently among AIs. This is particularly true from one tribe to another. There is variability with how one tribe addresses AI and dementia, copes with it, and uses prevention and interventions. Most remarkable is the fact that AI worldviews of AD and dementia treatment are different from mainstream Western culture, and the family is the main support for AIs who have either AD or dementia.

Interviews with formal caregivers showed that there appears to be a lack of knowledge among non-AI formal caregivers. This lack of knowledge, in turn, causes barriers and challenges as it relates to AD and dementia prognosis, diagnosis, and intervention. This was particularly illuminating in one Western nurse practitioner's explanation: "It's very difficult sometimes for them to have a non-Native caregiver come in and even come into their home. They are—they are very community oriented" (Formal Caregiver 4).

Research Question 2: What Are the Cultural Beliefs About AD and Dementia of Formal Caregivers for AIs?

All four of the formal caregivers interviewed had varying beliefs regarding their own cultural beliefs regarding AD and dementia. This particularly held true for the three non-AI caregivers, who experienced challenges in applying cultural competence in their caregiving, a theme that emerged within the context of this research question. One Western nurse practitioner expressed her trying to balance Indigenous cultural beliefs with her own Western cultural beliefs regarding AI and dementia:

No, they've not changed. I think what I try to bring to the table is my experience in helping the families, keeping the person safe. I don't feel that a person has to be in a nursing home to be safe. What I've tried to do, though, is really early on promote safety, you know, with the cooking and the driving and things like that that are going to come up. (Formal Caregiver 1)

The one AI physician interviewed talked a lot about his formal medical education in a Western medical school where he was trained and expressed the following:

Well, I was trained in a time when people thought it was unalterable, irreversible, progressive, and too bad. So the idea that people can get better or can slow the rate of decline, which is now becoming more accepted in the mainstream, but that would be unheard of when I was in training. (Formal Caregiver 2)

After 40 years of practicing medicine in both Western and Indigenous cultures, this physician related how he has tried to incorporate his Indigenous world view of medicine:

I think it's been demonstrated, you know, in studies that the more meaning and purpose you have, the healthier you are. And so I think that, you know, being a part of a storytelling process is absolutely conducive to wellness. (Formal Caregiver 2)

This AI physician related that stories and storytelling are a part of the Indigenous worldview of medicine and are essential in Indigenous healing and treatment.

Research Question 3: How Do Formal Caregivers for AIs Use Their Cultural Beliefs About AD and Dementia to Develop Courses of Care for Their Patients?

Central to this research question was assessing AI understanding of AD and dementia, formal caregiver beliefs about AD and dementia in the AI population, and how formal caregivers use their understanding and beliefs to develop a course of care. Although the formal caregivers interviewed had varying ways of expressing their cultural beliefs in their care plans, all agreed that cultural competence and bicultural approaches were essential in treating AI patients with AD and dementia. Formal Caregiver 2, the AI physician, said, "And I think that relates to the culture's perception of aging. You know, old people are honored more in both Native American and Asian cultures than they are in the contemporary Western society." This same sentiment was expressed by a Western physician assistant:

And I think the Native American community is much better at seeing that the Alzheimer's is just one part of what's happening to the person. And they—they seem to be very calm about it. It's like it doesn't change who that person is to them. (Formal Caregiver 3)

Table 1 presents a summary of the research questions and associated themes.

Table 1. Paired Research Questions and Themes

Research Question	Theme
1. What are the understandings of formal caregivers for AIs about their patients' cultural beliefs about AD and dementia?	AD and dementia are understood differently among AIs AI worldviews regarding AD and dementia treatment are different from Western worldviews The main source of support for AI patients with AD and dementia is the family
2. What are the cultural beliefs about AD and dementia of formal caregivers for AIs?	Bicultural
3. How do formal caregivers for AIs use their cultural beliefs about AD and dementia to develop courses of care for their patients?	Cultural competence when working with AI patients with AD and dementia Early intervention Early mortality in the AI population, do not live long enough to develop AD or dementia

Note. AD = Alzheimer's disease; AI = American Indian.

Discussion

The findings of this study aligned with previous findings in AI patients with AD and dementia. Within AI groups, AD and dementia as well as the concept of disease, differ among AIs from that of their Western counterparts. Study findings validated the selection of a conceptual framework honoring AI worldviews concerning disease and using a bicultural approach to understanding the cultural beliefs of formal caregiver and AI dementia groups. One of the most important findings derived from the data was the notion that Westerners need to develop an empathetic understanding of AI worldviews concerning not only AD and dementia, but the concept of disease as a whole.

One of the most important findings of this study was how formal caregivers and AI dementia patients view AD and dementia. According to Goins et al. (2011), a common coping strategy for AIs dealing with any type of disease is passive forbearance, "defined as accepting and adapting to the caregiving role rather than trying to control it" (p. 311). The review of the literature and interview data analysis also supported that this is the same way in which the AI population deals with disease as a whole. A common example of passive forbearance is the way in which AI families help one another during a time of need and sickness. AIs have also used passive forbearance to effectively deal with the mental health aspects of the historical and cultural traumas faced by AIs in the United States over the past 5 centuries. AIs rely mainly on one another for support (Goins et al., 2011). According to Goins, Spencer, Goli, and Rogers (2010), AIs "value autonomy and not imposing needs on others" (p. 2190). In other words, AIs are more adept at finding solutions than their Western counterparts, rather than relying and being an imposition on others.

In the current study, regional, tribal, and cultural beliefs were found to be a major factor in the ways that AIs and their formal caregivers address AD and dementia. While Westerners generally believe in diagnosis, prognosis, and a linear course of care, AIs generally believe in the notion that all things are in nature and are imbued with nature (Deloria, 2003; Lowe, 2002) and that disease is a symptom of disharmony and imbalance in one's life. The data analysis of the formal caregivers' experiences with AI dementia patients also indicated that any studies and treatment of disease including AD and dementia need to focus on the social determinants that prohibit unequal access to healthcare, stress of life, and poverty. These appear to be indicative of the larger picture of morbidity and mortality

among these groups of AI patients with AD and dementia. This was discussed by all four of the formal caregivers who mentioned that the life expectancy of AIs is less than that of their Western counterparts. This is consistent with Solomon and Randall's (2014) statement that "Native people suffer from not only one disease state but often from multiple co-morbidities" (p. 29).

Results from this study also suggest that formal caregivers and AI dementia patients did operate with the same definition of AD and dementia. Both the formal caregivers and AI dementia patients were far less concerned than their Western counterparts with prognosis and diagnosis, and more centered on quality of life. Western formal caregiver understanding of cultural competence and cultural sensitivity as well as a basic understanding of a particular tribe's cultural beliefs and worldviews were cited as essential in working with their respective tribes. The AI formal caregivers also discussed the need for cultural competence and sensitivity as it related to using bicultural approaches with AI dementia patients. The AI physician in this study advocated for a balance between AI worldviews and Western approaches particularly in relation to the use of Western medications, which is consistent with Joe's (2014) finding that "cultural awareness about a problem in a special population includes not only knowledge about the population but also about the population's ongoing interventions in addressing the problem" (p. 87). Among all four of the formal caregivers, there appeared to be a cultural humility, in keeping with Joe's definition of this as "a process by which one attempts to evaluate his or her own perceptions based on experience in order to expand one's knowledge and improve his or her ability to function more effectively in a different culture" (p. 91).

One area where the literature and data analysis differed was that U.S. Census data indicate that AIs are the fastest growing aged population in the United States (U.S. Department of Commerce, Economics and Statistics Administration, 2010). However, within the context of the interviews, and further discussion of morbidity and mortality among AIs, the literature indicated that most AIs do not have long life spans. In fact, in two of the interviews with the AI physician and one Western physician assistant, both discussed that AIs tend to die long before any indication of AD or dementia is evident. The literature review and interviews discussed the fact that due to comorbidities, many AIs die before reaching the age of 70. In fact, it was found that AIs have higher rates of diabetes, cardiovascular disease, and cancer than their Western counterparts.

Recommendations

Several actions for further study of the phenomenon of cultural beliefs and improving understanding of AD and dementia among formal caregivers are recommended:

1. Research needs to be conducted by AI researchers interested in this timely topic.
2. Cultural competence and cultural sensitivity training needs to occur in medical and public-health-based educational programs.
3. Relationships with AI tribes and communities need to be established with Western researchers prior to any AI-centered research topic is executed.
4. Community-based research and evidence-based programs need to be established with individual tribes that focus on "interventions that would reduce morbidity and mortality" (Solomon & Randall, 2014, p. 24).
5. Epidemiological studies that look at risk behavior, disease status, and healthcare need to be conducted (Solomon & Randall, 2014).
6. Research needs to be conducted on AD and dementia within rural, tribal, and urban communities, both qualitatively and quantitatively.

7. Cultural competence and cultural sensitivity trainings need to occur on reservations staffed by Western healthcare professionals.
8. Screenings for AD and dementia in the AI population need to be established that consider areas of cultural competence and cultural sensitivity.
9. AD and dementia information sessions need to occur with AI rural and urban populations as well as their formal caregivers that specifically focus on AD and dementia.
10. Education of AI patients with AD and dementia needs to explore alternative medications along with lifestyle changes and risk behaviors.

Implications

AD and dementia affect every racial group in the United States. Because the AI population is so small and diverse, attempts must be made to produce further research that will enhance understanding for AI formal caregivers and AI patients with AD and dementia. There has been very little research in the area of AD and dementia in AIs and the experiences of formal caregivers caring for AI dementia patients. Extending the literature and research within this area is important because of the high comorbidity patterns that exist in this population, which, in turn, may have an impact on the level of AD and dementia in AIs. Future qualitative studies that build upon this current study may enhance understanding of AD and dementia in AIs as well as the cultural beliefs and experiences of formal caregivers caring for AI patients with AD and dementia. These types of ethnocultural studies are needed to assist researchers in developing feasible community-based research, tribal-based research, and evidence-based research, as well as appropriate public health and public health policy research that addresses this special population. Moreover, as Solomon and Randall (2014) stated, "All research should be consistent with the values of the population study. Core values of Native communities such as family, respect, honesty, kindness, caring, and sharing should be honored" (p. xv). The implications for positive social change within this study include considering AD and dementia from a bicultural approach rather than from a Western approach, which may advance formal caregiver knowledge of how to address AD and dementia in AIs.

Conclusion

Rather than considering AD and dementia from a Western perspective, formal caregivers and other healthcare professionals need to adopt a bicultural approach in addressing AD and dementia in AIs. Future research on AD and dementia patient care in AIs is of marked importance and needs to be balanced in both the specific AI tribal worldviews and Western worldviews of disease. It should include Western and traditional AI approaches to disease and, more specifically, to AD and dementia. Different attitudes about AI health and a clearer understanding of AI beliefs, hopes, fears, and perception as it relates to research and disease are needed. Moreover, Western and traditional approaches to AD and dementia require a mutual acknowledgement of cultural beliefs with the overall goal for improving social, cultural, and public health. Solomon and Randall (2014) best summed this up by writing, "scientific discovery in its purest state is the understanding that we do not have answers; thus, researchers have a healthy respect for what is unknown" (p. 212).

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