

Emerging LTSS Issues in Indian Country:
Alzheimer's and Dementia

Department of Health & Human Services, Centers for Medicare & Medicaid Services

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Introduction

Little is known about the prevalence of Alzheimer's and dementia among American Indians and Alaska Natives (AI/ANs). Until recently, studies that have discussed the disease brushed over the topic, often focusing more in-depth on informal caregivers supporting those living with the disease. Greater research is needed to better inform tribes, health programs, and policy makers about the current state of Alzheimer's disease and dementia in Indian Country and about the barriers preventing many AI/ANs from receiving proper care and diagnosis. This information will help build effective solutions to these issues, as well as recommendations to guide future research and program development.

Background

Dementia itself is not a disease. It is an umbrella term used to describe a variety of diseases and conditions that develop when nerve cells in the brain die or stop functioning properly. Alzheimer's disease is the most common form of dementia, accounting for 60% to 80% of dementia cases.¹ Alzheimer's disease is a progressive, irreversible disorder of the brain that slowly destroys memory and thinking skills.² Currently, Alzheimer's disease ranks as the sixth leading cause of death in the United States. Among older adults, it ranks third, behind heart disease and cancer. The National Institute on Aging estimates that more than 5 million Americans currently have Alzheimer's. This number is expected to nearly triple by 2050 (Hebert, Weuve, Scherr, & Evans, 2013).

“If you look at the numbers, it's kind of sad. Fifty percent of people never get a dementia diagnosis and, of those who do, they're often diagnosed in the moderate stage of the illness”

*– Jan Dougherty,
Family and Community Services Director*

Alzheimer's affects people in different ways; however, the most common symptom presents as difficulty remembering new information. As the disease advances, individuals begin to experience other challenges, such as difficulty planning or solving problems, confusion with time or place, changes in mood and personality, problems with speaking and writing, or decreased or poor judgement.³ As the stages of Alzheimer's worsen, so do the symptoms. Individuals in the final stages lose their ability to communicate and often become bed-bound, a state that requires around-the-clock care.

Research has identified several risk factors contributing to an individual's potential for developing Alzheimer's disease. While advanced aging is considered the greatest known risk factor, Alzheimer's is not typically a part of aging. Hereditary factors, such as family history, can also indicate risk.⁴ Studies

¹ <http://nicoa.org/for-caregivers/alzheimers-dementia/>

² <https://www.nia.nih.gov/alzheimers/topics/alzheimers-basics>

³ http://www.alz.org/alzheimers_disease_10_signs_of_alzheimers.asp

⁴ http://www.alz.org/alzheimers_disease_causes_risk_factors.asp

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also suggest that people with less education are at higher risk for developing Alzheimer's or other dementia, as are people who suffer from moderate or severe traumatic brain injuries.⁵

These factors are particularly significant for AI/AN populations. In 2014, 67% of AI/AN students graduated from high school, which is considerably lower than the national graduation rate of 80% (Executive Office of the President, 2014). Additional research also suggests that AI/ANs and Blacks are more likely to experience traumatic brain injuries caused by violence than other racial and ethnic groups (Linton & Kim, 2014). In a study conducted by Linton et al. (2014), over 32% of Native women and over 46% of Native men studied experienced violent traumatic brain injuries. Findings such as these suggest that AI/ANs may be at greater risk for developing Alzheimer's and other dementia than the general population.

Though Alzheimer's disease and dementia in minority populations has recently come to the forefront in research and policy discussions, there has been very little focus across AI/AN communities (Garrett, Baldrige, Benson, Crowder, & Aldrich, 2015). As a result, little is known about Alzheimer's and dementia in Indian Country. Traditionally, Native populations have reported low rates of Alzheimer's and other dementia. However, many health professionals in Native communities believe these figures are inaccurate. Unfortunately, no data regarding national dementia prevalence among AI/ANs currently exists (Garrett et al., 2015). According to Mayeda et al. (2016), no population-based studies on Alzheimer's and dementia have included Pacific Islanders or AI/ANs. However, a recent, smaller study found that dementia incidence was highest among African Americans and AI/ANs, suggesting that rates of Alzheimer's and other dementias among this population may be higher than previously thought (Mayeda et al., 2016).

Barriers Preventing Diagnosis

Most Native communities lack services to provide care for individuals with Alzheimer's or other dementia. Numerous cultural and systematic barriers, however, also prevent effective diagnosis of, treatment of, and research into Alzheimer's disease in Indian Country. For example, the incredible cultural and linguistic diversity across AI/AN communities makes it difficult to design universal clinical assessments and instruments for detecting dementia; it is challenging to translate existing instruments into different languages without altering their meaning (Griffin-Pierce et al., 2008). AI/ANs also experience higher poverty levels and lower educational achievements than any other ethnic group, suggesting a need for alternative cognitive screening tools (Griffin-Pierce et al., 2008). Currently, no culturally appropriate tools exist to measure cognitive function in AI/AN patients (Jervis & Manson, 2002). These kinds of challenges point to the need for more culturally appropriate assessment tools and increased research.

Cultural views and interpretations of the aging process may be another barrier preventing dementia identification and treatment. Many Native communities may not interpret the symptoms of Alzheimer's

⁵ <http://www.mayoclinic.org/diseases-conditions/alzheimers-disease/symptoms-causes/dxc-20167103>

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and dementia as a disease or an illness, but rather as a normal consequence of aging (Garrett, 2015). For example, a common tribal perspective of aging is that a person begins and ends his or her life as a child; other tribes see the mental confusion often symptomatic of the onset of dementia as a part of the dying process (Jervis & Manson, 2002). As a result, individuals displaying symptoms of Alzheimer's or dementia (or caregivers of these individuals) may not think to seek out help even if services are available in the community. This indicates a need for increased education and outreach efforts to improve community awareness and understanding of Alzheimer's and dementia.

The newness of this disease to AI/AN communities must be taken into account. Life expectancy in Native populations has only recently approached that of the majority population (Henderson & Henderson, 2002). AI/ANs have seen a dramatic increase in life expectancy from 51 years of age in the 1940s, to 70 in the early 1990s (Jervis & Manson, 2002).

Consequently, the AI/AN elder population is projected to double by the year 2030 (Centers for Medicare & Medicaid Services, 2016). However, even though the life

expectancy of the Native population has seen an increase over the years, the knowledge about dementia in this population has failed to keep pace. Now that a greater number of AI/AN elders are living longer and showing signs of Alzheimer's, the conversation surrounding the disease has started to grow.

Low numbers of Alzheimer's and dementia diagnoses may also be rooted in past poor experiences between Native communities and non-Native researchers and health care providers. In a study conducted by Weiner, Rosetti, & Harrah (2011), there was a strong concern and fear from the tribe about exploitation. Tribal members had no interest in supporting research that did not immediately impact them. They wanted a direct effect on health or quality of life and positive economic impact on their community. Historically, there has been distrust between Natives and non-Natives. Many AI/ANs do not feel secure when visiting physicians. Some Natives may also avoid seeking professional health care due to fear that they will be treated insensitively or that doctors will refuse to accept their beliefs and customs (Jervis & Manson, 2002; Yeo & Gallagher-Thompson, 1996). A study focusing on cancer treatment found that AI/ANs were significantly less likely to trust health care providers, clinics, and hospitals than non-Hispanic Whites (Guadagnolo et al., 2009). Many AI/ANs also believe that providers will disrupt family or community life by imposing non-Native diagnostic criteria or treatment plans on them, a fear that stems from differences between AI/AN traditional medicine and Western medical practices (Griffin-Pierce et al., 2008).

Finally, as stated previously, many Native communities lack of services to care for the particular medical and support needs of individuals with Alzheimer's and other dementia. Family members may forgo seeking services because of transportation, health insurance, or other financial issues. In the instances

“In the 10 years of working in the [tribal affairs office], I can hardly even remember dementia coming up.”

– Lynn Gall, Alzheimer's & Family Caregiver Coordinator

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where services are available in the community, family members are often unaware of their availability or may fail to recognize a family member's need for them. This, again, speaks to the need for increased awareness of the disease and more timely and culturally appropriate diagnoses.

Recommendations

To provide appropriate health care to the elder AI/AN population, health organizations should make a concerted effort to increase research on the disease, focusing specifically on its prevalence in and impact on Native families and communities (Jervis & Manson, 2002). These studies should be conducted for both rural and urban communities. The more accurate the data collected, the more likely tribes and health programs are to develop and implement effective treatment, education, and support programs and services. Policy makers should then use this data to create policies that address tribal needs regarding this issue. For example, an amendment to Title VI of the Older Americans Act would ensure provider capacity to offer accurate and relevant education to elders about dementia and other mental health needs (Garrett et al., 2015).

There is also a significant need to develop quality and culturally relevant outreach tools for Native communities (Jervis & Manson, 2002).

These tools must take issues such as language fluency, literacy, and bilingualism into consideration (Griffin-Pierce et al., 2008). The development of outreach and assessment tools for Natives must be based on research that utilizes input from community members and health professionals.

Quality of care improvement for urban and rural AI/AN communities is also

crucial to increase the timely identification and treatment of Alzheimer's and other dementia. The existing Indian Health Care delivery system should work to improve its clinical and social capacity (Garrett et al., 2015). Primary Care systems should also increase clinician training to increase clinicians' confidence and skill level in the proper diagnosis of Alzheimer's disease and dementia.

Finally, programs and facilities that offer Alzheimer's and dementia care should place a larger focus on the recognition and diagnosis of the disease in AI/AN patients. There are currently no special programs or services allocated to address the need for diagnosis and care in these communities. In addition, services must also be more accessible. A lack of community-based services and the geographic isolation of many tribal areas often makes it difficult for urban and rural AI/AN communities to reach clinics and hospitals for care.

“Physicians don’t know what [Alzheimer’s disease] looks like. They have not been well educated. You go into your doctor and we check your blood pressure and your weight every time you check in, but we don’t even annually do a cognitive assessment.”

*– Jan Dougherty,
Family and Community Services Director*

Conclusion

Minority issues in dementia research have only recently come to the forefront. These minority groups are an important component to the large dementia puzzle because they are affected harder than other racial groups (Garrett et al., 2015). Alzheimer's disease is growing into an epidemic and is expected to become a prominent health issue for AI/AN communities in the coming years. Understanding and taking a proactive stance to address these challenges offers the most effective solution to this emerging issue. Specifically, tribes, health program directors, and policy makers should consider the following recommendations for action:

- Help AI/AN communities recognize Alzheimer's and dementia as a disease.
- Strongly emphasize the need to better diagnose and treat the disease among AI/AN elders.
- Develop more culturally appropriate screening tools.
- Gather more accurate data on the incidence and prevalence of Alzheimer's and dementia in Native populations.
- Increase funding for AI/AN health and LTSS services.

More research on and additional outreach and education efforts for AI/AN communities is needed to increase knowledge, awareness, and support for Native people suffering from Alzheimer's and dementia. By understanding and working to eliminate these challenges, tribal leaders and providers can develop strategies to address this growing health issue. A greater emphasis on the AI/AN community is necessary to effectively address Alzheimer's and dementia, along with other health disparities, that have plagued a population that has already been overlooked and underserved for far too long.

At a Glance: Tribal Dementia Care Specialist Wisconsin State's Tribal Dementia Care Specialist Program

The Dementia Care Specialist Program is available at select Aging and Disability Resource Centers (ADRCs) throughout the state of Wisconsin as part of the Wisconsin Dementia Care System Redesign. The Wisconsin Department of Health Services funds three Tribal Dementia Care Specialist positions to help tribes develop dementia-friendly communities and support family caregivers of people diagnosed with dementia. This 2-year pilot program is contracted with the St. Croix Chippewa Indians of Wisconsin, Oneida Tribe of Indians of Wisconsin, and the Menominee Indian Tribe of Wisconsin.

"Tribal members have been heavily involved in the entire process."

– Lynn Gall, Alzheimer's & Family Caregiver Coordinator

Program Goals

1. Create a dementia-capable tribe by increasing understanding of the disease throughout all tribal departments and the community.
2. Expand awareness of Alzheimer's disease and dementia in the community by providing training to businesses, law enforcement, and medical providers on appropriate responses to people with dementia and ways to communicate emergencies with their caregivers.
3. Identify and design caregiver supports that allow people with dementia to live at home longer through the use of natural supports and available community resources.

Services

Tribal Dementia Care Specialists provide educational outreach and training opportunities for friends, family caregivers, spiritual leaders, health care providers, social service agencies, and others about ways to communicate with people living with dementia. Common services available include:

- Providing information and assistance about Alzheimer's disease and other dementias;
- Performing memory screens;
- Connecting families with health care specialists, if requested;
- Improving the quality of life of caregivers and people with dementia by making connections with new or currently available local assistance and support programs, such as the Wisconsin Tribal Music and Memory initiative and Memory Cafés; and
- Discussing options for in-home care and long-term care, and helping families plan and prepare for their loved one's future.

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Funding

The program is funded through the Wisconsin Department of Health Service's Bureau of Aging and Disability Resources. The program grant funds three tribes for 2 years (Gall, 2016). Each tribe receives an award of \$80,000 per grant year to hire a Tribal Dementia Care Specialist.

Resources

A limited number of educational and service support organizations have resources tailored to the needs of individuals living with Alzheimer's and dementia (particularly AI/ANs) and their caregivers. Table 1 describes a few of these programs, with contact details for those seeking additional information.

Table 1. Alzheimer's and dementia educational and service support organizations

| Program Title | Description | Contact Information |
|--|---|--|
| Dementia Friendly America Initiative | This initiative aims to more effectively support and serve those across America living with dementia and their family and friend caregivers. | http://www.dfamerica.org/ |
| Touching the Spirit Through Music – Wisconsin Music & Memory | This program uses personalized music to show how elders with dementia quickly transform from quiet and withdrawn to communicative and animated. | https://www.dhs.wisconsin.gov/music-memory/index.htm Department of Health Services 1 West Wilson St. Madison, WI 53703 (608) 266-1865 Webinar: Touching the Spirit Through Music: The Wisconsin Music & Memory Program (recording) |
| Alzheimer's Family and Caregiver Support Program | The Wisconsin legislature created this program in a response to the stress and service needs of families caring at home for someone with irreversible dementia. | https://www.dhs.wisconsin.gov/aging/alzfcgsp.htm Department of Health Services 1 West Wilson St. Madison, WI 53703 (608) 266-1865 |
| Resources for Enhancing Alzheimer's Caregiver Health (REACH) in Indian Country | This evidence-based program supports caregivers of patients with Alzheimer's disease or dementia. | https://www.uthsc.edu/prevmed/memphis-caregiver-center/index.php The University of Tennessee Health Science Center Memphis, TN 38163 (901) 448-5500 Webinar: Caring for the Caregivers: Using REACH into Indian Country to Support People Caring for Patients with Dementia and Alzheimer's (recording) |

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| Program Title | Description | Contact Information |
|--|---|--|
| Wisconsin Tribal/ADRC Dementia Care Specialist Program | This ADRC program supports staff and programs, acts as a catalyst to create a dementia friendly community, and assists individuals with dementia to remain active in their homes. | https://www.dhs.wisconsin.gov/adrc/dementia-care-specialist-program.htm Department of Health Services 1 West Wilson St. Madison, WI 53703 (608) 266-1865 |

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LTSS Research: Annotated Literature Review

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