

Tribal Nursing Homes Report

Dementia and Alzheimer's Disease

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

Tribal Nursing Homes: Best Practices for Patients with Dementia and Alzheimer's Disease

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Introduction

Increased life expectancy in Indian Country means the American Indian and Alaska Native (AI/AN) elder population is expected to double by 2030. With an increasing number of elders, Alzheimer's disease and dementia are becoming more visible in Indian Country. Tribal communities are starting to take notice and are seeking ways to provide the best care they can to elders with dementia and Alzheimer's disease, their families, and their caregivers.

Tribal nursing facilities are implementing a number of approaches to care for patients with dementia and Alzheimer's disease. Some have dedicated "memory care units,"¹ while others house patients with dementia within their general population. Many of these programs are in their infancy, and long-term services and supports providers are seeking ways to improve care and increase capacity. AI/AN nursing homes are joining forces to share their wisdom, survey existing programs, develop best practices, and identify areas for further research and program development.

Dementia in Indian Country

Few studies have been conducted on the prevalence of dementia, including Alzheimer's disease, in AI/AN communities. Traditionally, Native populations have reported low rates of dementia, but it is unclear whether this is because of truly low rates, a lack of education in Indian Country about dementia, inadequate diagnostic tools for AI/AN elders, distrust of researchers and health care workers, or a combination of these factors.

A 14-year study published in 2015 in *Alzheimer's & Dementia: The Journal of the Alzheimer's Association* found that rates of dementia were highest among African Americans and AI/AN.² The study found an annual rate of dementia at 22.2 cases per 1,000 people for AI/AN. Researchers estimated American Indians and Alaska Natives have a 35% lifetime risk of developing dementia. This rate compares to 38% for African Americans, 32% for Latinos, 25% for Pacific Islanders, 30% for Whites, and 28% for Asian Americans.

Risk Factors

Traumatic brain injuries and lower levels of education create a higher risk of Alzheimer's disease.³ High numbers of American Indians serve in the U.S. military. According to the U.S. Department of Veterans Affairs, an estimated 177,000 AI/AN Veterans live in the United States. Military service puts people at

¹ Memory care units are designated areas of a facility that provides specialized services for individuals that have memory loss conditions, like Alzheimer's and dementia. Memory care requires an increased level of care for activities of daily living, and special considerations for the physical environment of facility.

² Mayeda, E. R., Glymour, M. M., Quesenberry, C. P., & Whitmer, R. A. (2016, March). Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 12(3), 216-224. doi: <http://dx.doi.org/10.1016/j.jalz.2015.12.007>

³ Mayo clinic staff. (2015, Dec. 22). Symptoms and causes. *Alzheimer's Disease*. Retrieved from <http://www.mayoclinic.org/diseases-conditions/alzheimers-disease/symptoms-causes/dxc-20167103>

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greater risk of traumatic brain injury. Traumatic brain injury in Veterans increases the risk of developing Alzheimer's disease by 60%.⁴ AI/ANs and African Americans are more likely to experience traumatic brain injuries caused by violence than other racial or ethnic groups.⁵

A lack of education also increases the risk of Alzheimer's disease for AI/ANs who graduated at a lower rate (70%) than any other racial or ethnic group (82%) in 2014.⁶

Cultural Considerations

Many AI/ANs view dementia differently than other ethnic and racial groups. Rather than seeing it as an illness, they may view it as a natural part of aging.⁷ Because of this, people with dementia and their families may not seek medical help. Education and outreach about dementia and Alzheimer's disease is crucial to connecting these patients to care that could help them live more joyfully and comfortably.

In addition to increasing education, work must be done to improve trust between Native communities, researchers, and medical workers. Years of negative experiences with a health care system that does not always respect cultural differences and traditional medicine must be overcome.⁸ Many AI/ANs believe that providers will disrupt family or community life by imposing non-Native or culturally insensitive patient evaluations or treatment plans on them—a fear that stems from differences between AI/AN traditional medicine and Western medical practices.⁹

More Research Needed

More research into the prevalence of Alzheimer's disease and dementia in Indian Country and how to best care for AI/AN patients is needed. However, getting accurate data about the rates of Alzheimer's disease and dementia in AI/AN populations is complicated by the fact that there is currently no culturally appropriate tool available to measure cognitive function in AI/AN patients.¹⁰ Cultural and

⁴ Barnes, D. E., Kaup, A., Kirby, K. A., Byers, A. L., Diaz-Arrastia, R., & Yaffe, K. (2014, June 25). Traumatic brain injury and risk of dementia in older veterans. *Neurology*, 83(4), 312-9. doi: 10.1212/WNL.0000000000000616

⁵ <https://www.ncbi.nlm.nih.gov/pubmed/24702677>

⁶ Common Core of Data. (n.d.). Table 1. Public high school 4-year adjusted cohort graduation rate (ACGR), by race/ethnicity and selected demographics for the United States, the 50 states, and the District of Columbia: School year 2013–14. Institute of Education Sciences National Center for Education Statistics. Retrieved from https://nces.ed.gov/ccd/tables/ACGR_RE_and_characteristics_2013-14.asp

⁷ Garrett, M. D., Baldrige, D., Benson, W., Crowder, J., & Aldrich, N. (2015). Mental health disorders among an invisible minority: depression and dementia among American Indian and Alaska Native elders. *The Gerontologist*, 55(2), 227-236.

⁸ Griffin-Pierce, T., Silverberg, N., Connor, D., Jim, M., Peters, J., Kaszniak, A., & Sabbagh, M. N. (2008). Challenges to the recognition and assessment of Alzheimer's disease in American Indians of the southwestern United States. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 4(4), 291-299. doi: 10.1016/j.jalz.2007.10.012

⁹ (see Footnote 8)

¹⁰ Jervis, L. L., & Manson, S. M. (2002). American Indians/Alaska Natives and dementia. *Alzheimer Disease and Associate Disorders*, 16(Supplement 2), S89-S95. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/12351922>

language differences across Indian Country make it difficult to create one diagnostic tool that will serve all tribal populations.

Greater research is needed to better inform tribes, health programs, and policy makers about the prevalence of Alzheimer's disease and dementia in Indian Country and about barriers preventing proper care and diagnosis. This information will help tribal nursing homes and elder care facilities build effective programs to care for patients with dementia and Alzheimer's disease.

Tribal Nursing Home Dementia Care

Many tribes are just beginning to develop practices and protocols for patients with dementia and Alzheimer's. Administrators say they place a high importance on the admitting process. Staff spend more one-on-one time with residents with dementia to help familiarize them with their new surroundings.

"We teach staff that for [patients] it is much like a puzzle that has been rearranged that [staff] have to put back together again," said Valdeko (Val) Kreil, Administrator for the Maniilaq Association's Utuqqanaat Inaat nursing home in Kotzebue, AK. "For example, the television is no longer next to the bed, or the refrigerator is no longer where the kitchen used to be. So we can expect the wandering behavior to be present when they first come in."

Some tribes do not have their own nursing home, so they work with other facilities to make sure AI/AN patients with dementia get the care they need.

Specialized Care

Memory care units offer the advantage of a smaller, less overwhelming environment, said Dr. Blythe Winchester, a geriatric specialist in Cherokee, NC. These units can minimize sensory cues, create simpler experiences where residents are faced with fewer decisions and offer additional supervision.

The Cocopah Tribe is partnering with the private Medical Management Group to build the Veterans Neurological Research Center in Yuma, AZ. The center will research traumatic brain injuries in returning vets to build a base of knowledge about how it impacts the onset of Alzheimer's disease and dementia. The Center will have 300 beds for patients with dementia and will feature state-of-the-art care designed with dementia in mind. Lighting at the center will be controlled to minimize sun-downing syndrome. The center will be divided into smaller villages that feature familiar and comfortable environments for its patients.

Archie Hendricks, Sr. Skilled Nursing Facility (AHSSF) in Arizona found the Virtual Dementia program to be of benefit for training purposes. The program allows participants to understand the daily limitations of individuals with Alzheimer's disease and other related dementia (ADRD).¹¹ AHSSF staff participate in the program so they can share their knowledge with the rest of the facility and the community.

¹¹ Virtual Dementia Tour. Retrieved from <http://www.secondwind.org/virtual-dementia-tour/>

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For many tribes, patients with dementia are currently housed within the general population. Staff at Utuqqanaat Inaat are trained to keep a more watchful eye on patients with dementia, said Kreil. “We do a lot of line of sight practices where residents are never out of sight,” he said.

The Alaska Native Tribal Health Consortium (ANTHC) works with nursing homes in Anchorage, Nome, Kotzebue, Bethel, and Fairbanks, said Mellisa Heflin, ANTHC’s elders outreach coordinator. They coordinate care with these nursing facilities and meet monthly with other agencies to ensure tribal elders are getting appropriate dementia care.

Cultural Considerations

Some AI/AN elders with dementia may struggle if no one at their nursing facility understands their language, said Dr. Winchester. She added that staff should be provided information about past traumas—like boarding school experiences—and other personal histories to help them understand each patient.

A “one-size-fits-all” approach will not work for dementia care in Indian Country because AI/AN traditions differ greatly by tribe and region. For instance, Utuqqanaat Inaat in Alaska grounds its nursing home care in traditions and practices common to Alaska Natives living in their far north region. Because the area is so cold much of the year, daily showers are uncommon, said Kreil. Pet therapy is not emphasized because dogs are viewed as working animals, not as pets. And, because there are 24 hours of daylight and 24 hours of darkness during different parts of the year in this region, residents do not exhibit the sun-downing behavior that patients with dementia experience elsewhere.

Tribal Nursing Home Needs

Tribal nursing home administrators and staff note a lack of resources needed to provide the best dementia care to residents. Funding for additional programming, improved facilities, and staff training are their top priorities. For instance, some facilities that have only a few staff trained to work with patients with dementia, would like to expand that training for all staff. Ms. Heflin said she would like to have staff trained on how to interact with patients at each stage of dementia, provide compassionate care, be culturally responsive to myths and taboos about memory loss, and provide help to caregivers.

AHSSF identified that community awareness and education about ADRD is equally important in the development of a dementia care program. AHSSF notes that community members need to be aware of dementia conditions and assessment tools so they can seek care for loved ones earlier in the onset of ADRD, rather than at later stages. More resources can also provide the opportunity for new memory care unit beds, activity programming, and additional staff.

Tribal Nursing Home Dementia Survey

Uniting Nursing Homes in Tribal Excellence (UNITE) is planning an expansive dementia care survey of its members in 2017. UNITE is composed of tribal nursing home administrators, board members, educators, and staff. It focuses on research, training, and the development of best practices to support its members

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and improve nursing home care in Indian Country. The survey will collect data on cases and diagnoses of ADRD in Indian Country and gather information about existing programs and resources. This information may be used to:

- evaluate the impacts of Alzheimer's disease in AI/AN communities;
- highlight successes and barriers to dementia care in tribal nursing facilities;
- identify gaps in services, programs, and research;
- create new programs, services, and training opportunities;
- develop best practices for dementia care in Indian Country;
- develop community outreach materials on ADRD; and
- apply for grants and other funding opportunities.

Conclusion

Facility care for AI/ANs with Alzheimer's disease and other forms of dementia is a new and growing facet of elder care. More research and resources are necessary to provide Native elders with the best culturally appropriate, scientifically based, and compassionate care. Tribal programs interested in implementing their own care plans for individuals with ADRD will need to consider system changes for their facilities, understand common barriers to implementing ADRD programs, and engage the community.

Resources

Use these resources to learn more about Alzheimer's disease and dementia in Indian Country and how to improve culturally competent care in tribal nursing facilities and elder care programs.

Organizations

Table 1. Tribal nursing facilities and elder care organizations

Organization	Description
Alzheimer's Association http://www.alz.org/	The Alzheimer's Association is a national organization with local chapters that seeks to provide care and support to those inflicted with Alzheimer's and other dementia. This includes support groups, a helpline, resources, and tools.
Banner Alzheimer's Institute Native American Outreach Program http://banneralz.org/education-events/native-american-outreach-program.aspx	This Native American Outreach program focuses on awareness and scientific understanding of Alzheimer's disease and dementia in tribal communities. It features a number of community and caregiver services, professional programs, and research resources.
Pioneer Network https://www.pioneernetwork.net/	Pioneer Network advocates for patient-centered, individualized care in organizational settings. This organization provides toolkits, and other resources shift providers from system-directed to person-directed perspectives.
Resources for Enhancing Alzheimer's Caregiver Health (REACH) in Indian Country https://www.uthsc.edu/prevmed/memphis-caregiver-center/index.php	REACH supports Alzheimer's disease and dementia care in tribal communities through a number of community and caregiver services, professional programs, and research resources.
Virtual Dementia Tour http://www.secondwind.org/virtual-dementia-tour/	Second Wind Dreams developed the Virtual Dementia Tour to provide users with first-person experiences of the physical and mental challenges faced by people with dementia.
Uniting Nursing Homes in Tribal Excellence (UNITE) http://tribalnursinghomes.weebly.com/	This organization of tribal nursing home administrators, board members, educators, and staff establishes best practices, provides technical support, and provides training on caring for patients with Alzheimer's disease and dementia.

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Organization	Description
Wisconsin Music & Memory Program https://www.dhs.wisconsin.gov/music-memory/index.htm	This program provides training for nursing home staff to improve care for people with dementia by using personalized music to unlock memories and positive emotions.
Wisconsin Tribal Dementia Care Specialist Program https://www.dhs.wisconsin.gov/adrc/dementia-care-specialist-program.htm	This Wisconsin Department of Health Services pilot program funded three tribal dementia care specialist positions to help tribes develop dementia-friendly communities and support family caregivers of people diagnosed with dementia.

Research

Table 2. Research on tribal nursing facilities and elder care organizations

Research	Description
Emerging LTSS Issues in Indian Country: Alzheimer's and Dementia (PDF, 10 p.) https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/pdf/CMS-319_LR-BP-MiniTopics_Alzheimers-and-Dementia.pdf	This 2016 paper provides a snapshot of current information about Alzheimer's disease and dementia in Indian Country, barriers preventing diagnosis, and recommendations for tribal communities to take proactive measures to address challenges.
Inequalities in dementia incidence between six racial and ethnic groups over 14 years http://www.alzheimersanddementia.com/article/S1552-5260(15)03031-9/fulltext	This article in <i>Alzheimer's & Dementia: The Journal of the Alzheimer's Association</i> , highlights a 13-year study of dementia in six racial and ethnic groups that found dementia incidence to be highest among African Americans and American Indians.

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Webinars

Table 3. Webinars on tribal nursing facilities and elder care organizations

Webinar	Description
Caregiving: Trends and REACH into Indian Country https://www.youtube.com/watch?v=sRO289Zjy-g&feature=youtu.be	This recorded webinar explores the U.S. Department of Veterans Affairs' Resources for Enhancing Alzheimer's Caregiver Health (REACH VA) program, how it is being used to support caregivers of veterans with Alzheimer's disease and other forms of dementia, and how it can be implemented in Indian Country.
Touching the Spirit Through Music—Wisconsin Music & Memory Program https://www.youtube.com/watch?v=5sstND9vG2k&nohtml5=False&ab_channel=CMSHHSgov	This recorded webinar explores how music rekindles the spirit of elders with dementia through the Wisconsin Music & Memory Program. It also features the Wisconsin Dementia Care System Redesign Project and the goals and objectives of the Wisconsin Tribal/Aging and Disability Resource Center Dementia Care Specialist program.
Alzheimer's Disease Services and Supports for Tribal Communities https://www.youtube.com/watch?v=oTE-gEJ_1q0&feature=youtu.be	This recorded webinar focuses on Alzheimer's impact on Native communities and existing services and supports. This webinar connects elders and families to care information that can address their unique needs.
Using REACH into Indian Country to Support People Caring for Patients with Dementia and Alzheimer's https://www.youtube.com/watch?v=X5vOunOmH24&feature=youtu.be	In this recorded webinar, Indian Health Service and U.S. Department of Veterans Affairs staff discuss coordination, collaboration, and training opportunities for the REACH into Indian Country program. REACH is an award-winning, evidence-based program that supports caregivers of patients with Alzheimer's disease or dementia.