

RESEARCH ARTICLE

Alzheimer's disease knowledge among American Indians and Alaska Natives

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Abstract

Introduction: The population of American Indians and Alaska Natives (AI/ANs) aged 65 and older is growing rapidly, raising concerns about Alzheimer's disease (AD) in their communities.

Methods: We distributed a survey incorporating the Alzheimer's Disease Knowledge Scale to 341 AI/AN community members attending cultural events. We computed average adjusted predictions and 95% confidence intervals from a linear regression model, used joint F tests to examine differences in scores according to demographic variables, calculated the percentage of correct items for each participant, and computed domain-specific averages across the sample.

Results: The average score was 19.0 (maximum 30); the average percentage of correct responses was 63%. Higher scores were associated with education but not with age, sex, or rural versus urban residence. Low scores were observed for items on caregiving and disease risk.

Discussion: Participants were moderately well informed about AD, but specific knowledge domains call for community outreach and education.

KEYWORDS

Alaska Native, Alzheimer's disease, American Indian, dementia, education, health communication, Indigenous

1 | BACKGROUND

Alzheimer's disease (AD) is the leading cause of dementia and the most rapidly increasing cause of death in the United States.^{1,2} American Indians and Alaska Natives (AI/ANs) are concerned about AD, as it has a major impact on their communities.² Although AI/ANs are culturally diverse and dispersed across the United States, they share a high prevalence of well-known AD risk factors, including limited physical activity,³ low socioeconomic status,⁴⁻⁷ hypertension,⁸⁻¹¹ type 2 diabetes,¹² obesity,^{8,13,14} smoking,^{12,15,16} and high cholesterol.^{17,18} Life expectancy among AI/ANs over the last 50 years has improved

by as much as 30 years,^{19,20} resulting in a tripling of the population share of people aged 65 and older. From 2012 to 2050, the number of AI/ANs in this age range is expected to triple again, to 1,624,000, while the number of those aged 85 and older will increase seven-fold, to 300,000.²¹ People aged 65 and older now comprise 15% of the overall AI/AN population, compared to 4.8% in the 1970s.

These changing demographics have made AD much more visible in AI/AN communities than in the past. They also underscore the need for an aggressive agenda to raise awareness of AD and address its impact among AI/ANs. Characterizing community knowledge of AD is a critical first step in developing and evaluating educational campaigns, but

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little is known about AI/ANs' AD knowledge. The few extant studies have noted diverse levels of understanding, perceptions that differ from those of mainstream society, and culture-specific interpretations of AD and dementia.²² For example, a 2010 study found that First Nation Elders in Canada believed that changes in diet during recent generations were the main cause of memory loss in later life.²³

However, only a few small studies have examined AI/ANs' knowledge of AD or dementia, including the primary clinical features of AD, its impact on function, and its prognosis and outcomes in their communities. Therefore, we surveyed AI/AN community members at four cultural events in the Pacific Northwest region of the United States by using the Alzheimer's Disease Knowledge Scale (ADKS),²² a 30-item true/false instrument that has been applied with other populations in previous studies.^{24,25} Our goals were to quantify the nature and extent of knowledge about AD and dementia among AI/AN community members and to examine potential variation associated with demographic factors such as age, sex, education, and urban versus rural residence.

2 | METHODS

2.1 | Population and procedures

A health needs assessment survey, including the ADKS, was distributed at four urban pow-wows in Seattle, Washington, in 2016 and 2017. Urban pow-wows are inter-tribal events that are open to the public but attended primarily by Native people. They are ideal venues for surveying community members, because they attract large numbers of AI/ANs who represent a wide range of ages and tribes from the Pacific Northwest and other regions of western North America.²⁶ They also reach AI/ANs who do not regularly use health-care services. In addition to celebrating Native culture, urban pow-wows attract vendors and community organizations that offer information on employment opportunities and health, behavioral, and social services, typically at booths arranged in a circular formation around the social activities of dancing and drumming.

Surveys were completed by 438 attendees, with help provided by the staff of Partnerships for Native Health, a unit at Washington State University that conducts community-centered research, training, education, and outreach to improve the health of AI/ANs. All data were collected anonymously. Attendees were free to approach staff members, learn about the survey, and participate if they were interested. To establish eligibility, interested attendees were asked to confirm that they were at least 18 years old and self-identified as AI/AN. Eligible participants received a \$5 gift card for completing the survey.

2.2 | Measures

The health needs assessment survey included items related to cancer screening, kidney disease, Parkinson's disease, AD, and demographic characteristics. This report focuses on familiarity with AD based on

RESEARCH IN CONTEXT

1. Systematic review: The authors completed a comprehensive review of studies quantifying the nature and extent of knowledge about Alzheimer's disease (AD) and dementia among American Indians and Alaska Natives, but found no prior studies that administered the Alzheimer's Disease Knowledge Scale (ADKS) in this population. They cite extant empirical studies of the cultural understanding of dementia among Native people.
2. Interpretation: Native study participants were moderately well informed about AD. However, the lowest percentage of correct items involved caregiving and risk factors. Knowledge about AD was positively associated with higher levels of education, consistent with previous studies in minority populations.
3. Future directions: This study is the first use of ADKS to assess knowledge of AD in Native people. Results informed the development of a state-wide outreach and education effort involving tribal programs. Future work must improve culturally grounded recognition and interpretation of declining cognitive ability among older Native people.

HIGHLIGHTS

- A total of 341 Native people completed the Alzheimer's Disease Knowledge Scale.
- There is moderate knowledge of Alzheimer's disease (AD) among Indigenous North Americans.
- Community education is needed to improve knowledge of AD.

items in the ADKS. All 438 participants were asked if they had ever heard of AD; a response of "yes" prompted administration of the ADKS instrument in 341 participants. ADKS is a self-administered questionnaire based on the older Alzheimer's Disease Knowledge Test.¹¹ The ADKS has not been validated with AI/AN populations, yet has been validated in other populations. It takes 5 to 10 minutes to complete and is designed for use with laypeople, patients, caregivers, and health-care professionals.²² It comprises 30 true/false items in seven domains: life impact (three items), risk factors (six items), treatment and management (four items), assessment and diagnosis (four items), caregiving (five items), symptoms (four items), and disease course (four items). Each correct answer is worth 1 point, with higher scores indicating more knowledge (range 0 to 30). For each participant, the percentage of correct items in each domain is computed by

dividing the number of correct responses by the number of items in the domain.

The survey also collected demographic characteristics, including education, defined as highest grade of school completed, and primary place of residence, determined by asking where the respondent lived most of the year (reservation; rural area or town but not on a reservation; or large metropolitan area).

2.3 | Data analysis

Age in years was categorized as 18 to 24, 25 to 34, 35 to 44, 45 to 54, 55 to 64, and 65 or older. Descriptive statistics were calculated as percentages. Average adjusted predictions²⁷ and 95% confidence intervals (CIs) for ADKS score were computed from a linear regression model including age, sex, education, and place of residence as independent variables. Categorical variables were included as dummy variables in the regression model. We present average adjusted predictions where the association between ADKS score and each independent variable is adjusted for other variables in the model. We used joint F tests to examine differences in ADKS score according to each demographic characteristic. For an analysis of ADKS domains, we calculated the percentage of correct items per domain for each participant and then computed domain-specific averages across the entire sample. Due to the dichotomous nature of the ADKS items, 50% correct is expected by chance alone. Higher than 50% correct could indicate knowledge about an ADKS item or domain while lower than 50% correct could indicate misconceptions.

Multiple imputation was used, given a concern for potential bias if data were not missing completely at random. Demographic characteristics had little missing data (0.6% for age and education, and 1.8% for urban residence). "Missingness" for individual ADKS items ranged from 2.1% to 5.9%; however, 20.5% of participant were missing one or more items. Multiple imputation at the item level for multi-item instruments produces the least bias and best coverage compared to alternative imputation methods.²⁸ We used multiple imputation by chained equations.²⁹ The imputation model included age, education, place of residence, and all 30 ADKS items. We attempted to include sex in the imputation model, but the models did not converge, likely because of the small number of "Other" responses. We imputed 10 datasets and used Rubin's rule to compute combined point estimates and standard errors to account for variability due to the imputation process.²⁹ All analyses were performed with Stata 15.³⁰

3 | RESULTS

A total of 438 participants completed the survey; 341 (78%) had heard of AD. Participants who had heard of AD were older, had a similar sex distribution, had more education, and were more likely to live in a metropolitan area compared to participants who had not heard of AD (Table 1). The 341 participants who had heard of AD and responded to ADKS items were included in further analyses. This subsample included

TABLE 1 Demographic characteristics among participants who have and have not heard of Alzheimer's disease, American Indian/Native Alaskan pow-wow attendees (n = 438)

Characteristic	Heard of Alzheimer's disease		P
	No %	Yes %	
Age in years			.02
18–24	24	13	
25–34	29	21	
35–44	18	20	
45–54	9	19	
55–64	12	18	
65–85	8	10	
Sex			.26
Female	56	62	
Male	44	36	
Other	<1	2	
Completed education			<.001
<High school	21	7	
High school, GED, Vocational school	45	25	
Some college	25	39	
College graduate	9	30	
Residence most of year			.05
Reservation	17	14	
Rural area or town, but not on reservation	36	25	
Large metropolitan area	47	61	

a wide age distribution (mean 43; range 18 to 85 years) and was mostly female (62%). Nearly one-third of participants (30%) were college graduates and 61% lived in a large metropolitan area (Table 2). The mean ADKS score was 19.0 (95% CI 18.6–19.4); scores did not differ according to age or sex. Mean ADKS scores increased with increasing education but did not vary by primary place of residence.

The average percentage of correct responses for the full survey was 63% (95% CI = 62%–65%, Table 3), but this percentage varied according to ADKS domain. Most participants (86%, 95% CI = 82%–90%) answered more than half the ADKS items correctly. The lowest percentage of correct responses was observed in the caregiving domain (55%, 95% CI = 53–58%), while three other domains—assessment and diagnosis, disease course, and life impact—all had the highest percentage (69%, 95% CI = 66%–72% for all). The percentage correct also varied according to survey item (Table 4). Two items in caregiving had the lowest percentage of correct responses (28%, 95% CI = 23%–33%, and 38%, 95% CI = 33%–44%), and one item in disease course (87%, 95% CI = 83–90%) and one in assessment and diagnosis (85%, 95% CI = 81%–89%) were similar for the highest percentage of correct answers.

TABLE 2 Alzheimer's Disease Knowledge Scale according to demographic characteristics, American Indian/Native Alaskan pow-wow attendees (n = 341)

Characteristic	%	Average Adjusted ADKS* (95% CI)	P for difference in ADKS
Age in years			.59
18-24	13	18.2 (17.2-19.3)	
25-34	21	18.8 (17.9-19.7)	
35-44	20	19.0 (18.1-19.9)	
45-54	19	19.5 (18.6-20.4)	
55-64	18	19.0 (18.1-20.0)	
65-85	10	19.4 (18.1-20.7)	
Sex			.25
Female	62	19.2 (18.7-19.7)	
Male	36	18.6 (17.9-19.3)	
Other	2	20.6 (17.6-23.5)	
Completed education			<.001
< High school	7	15.3 (13.7-16.8)	
High school, GED, Vocational school	25	17.2 (16.4-18.1)	
Some college	39	19.2 (18.6-19.8)	
College graduate	30	21.0 (20.3-21.7)	
Residence most of year			.43
Reservation	14	18.4 (17.3-19.4)	
Rural area or town, but not on reservation	25	18.9 (18.1-19.7)	
Large metropolitan area	61	19.2 (18.7-19.7)	

*ADKS = Alzheimer's Disease Knowledge Scale. Values are average adjusted predictions from a linear regression model including independent variables age, sex, education, and residence.

TABLE 3 Alzheimer's Disease Knowledge Scale (ADKS) domains among adult American Indian/Native Alaskan pow-wow attendees (n = 341)

ADKS domain	Average percent of items correct % (95% CI)
≥ 50% of ADKS item answered correctly	86 (82-90)
Overall ADKS (30 items)	63 (62-65)
Assessment and diagnosis (4 items)	69 (67-72)
Disease course (4 items)	69 (66-72)
Life impact (3 items)	69 (66-72)
Treatment and management (4 items)	68 (65-71)
Symptoms (4 items)	62 (59-65)
Risk factors (6 items)	57 (55-59)
Caregiving (5 items)	55 (53-58)

TABLE 4 Performance on the Alzheimer's Disease Knowledge Scale (ADKS) by adult American Indian/Alaska Native pow-wow attendees (n = 341)

ADKS item	Provided correct response % (95% CI)
Assessment and Diagnosis Domain	
If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer's disease (FALSE)	51 (46-57)
Alzheimer's disease is one type of dementia (TRUE)	85 (81-89)
Symptoms of severe depression can be mistaken for symptoms of Alzheimer's disease (TRUE)	62 (57-67)
When a person with Alzheimer's disease becomes agitated, a medical examination might reveal other health problems that caused the agitation (TRUE)	78 (73-82)
Disease Course Domain	
In rare cases, people have recovered from Alzheimer's disease (FALSE)	65 (60-70)
Eventually, a person with Alzheimer's disease will need 24-hour supervision (TRUE)	87 (83-90)
After symptoms of Alzheimer's disease appear, the average life expectancy is 6-12 years (TRUE)	57 (51-62)
A person with Alzheimer's disease becomes increasingly likely to fall down as the disease gets worse (TRUE)	68 (63-73)
Life Impact Domain	
It is safe for people with Alzheimer's disease to drive, as long as they have a companion in the car at all times (FALSE)	79 (75-84)
Most people with Alzheimer's disease live in nursing homes (FALSE)	54 (48-59)
People with Alzheimer's disease are particularly prone to depression (TRUE)	74 (69-79)
Treatment and Management Domain	
Alzheimer's disease cannot be cured (TRUE)	74 (69-79)
When a person has Alzheimer's disease, using reminder notes is a crutch that can contribute to decline (FALSE)	61 (55-66)
People whose Alzheimer's disease is not yet severe can benefit from psychotherapy for depression and anxiety (TRUE)	66 (61-71)
Poor nutrition can make the symptoms of Alzheimer's disease worse (TRUE)	72 (67-77)
Symptoms Domain	
Tremor or shaking of the hands or arms is a common symptom in people with Alzheimer's disease (FALSE)	50 (45-56)

(Continues)

TABLE 4 (Continued)

ADKS item	Provided correct response % (95% CI)
Most people with Alzheimer's disease remember recent events better than things that happened in the past (FALSE)	63 (58–68)
One symptom that can occur with Alzheimer's disease is believing that other people are stealing one's things (TRUE)	60 (55–65)
Trouble handling money or paying bills is a common early symptom of Alzheimer's disease (TRUE)	75 (70–79)
Risk Factor Domain	
Genes can only partially account for the development of Alzheimer's disease (TRUE)	68 (63–73)
Prescription drugs that prevent Alzheimer's disease are available (FALSE)	59 (54–64)
People in their 30s can have Alzheimer's disease (TRUE)	72 (67–77)
It has been scientifically proven that mental exercise can prevent a person from getting Alzheimer's disease (FALSE)	44 (39–49)
Having high blood pressure may increase a person's risk of developing Alzheimer's disease (TRUE)	53 (48–59)
Having high cholesterol may increase a person's risk of developing Alzheimer's disease (TRUE)	47 (42–52)
Caregiving Domain	
People with Alzheimer's disease do best with simple instructions giving one step at a time (TRUE)	84 (80–88)
When people with Alzheimer's disease repeat the same question or story several times, it is helpful to remind them that they are repeating themselves (FALSE)	49 (44–55)
If a person with Alzheimer's disease becomes alert and agitated at night, a good strategy is to try to make sure that the person gets plenty of physical activity during the day (TRUE)	75 (70–80)
Once people have Alzheimer's disease, they are no longer capable of making informed decisions about their own care (FALSE)	38 (33–44)
When people with Alzheimer's disease begin to have difficulty taking care of themselves, caregivers should take over right away (FALSE)	28 (23–33)

4 | DISCUSSION

Our study findings indicate a moderate level of knowledge about AD among AI/ANs residing in the Pacific Northwest of North America, given the average ADKS score of 19 and the overall average of 63% correct responses. These averages are slightly lower than those reported in another study that included U.S. minority groups.^{22,31} Yet, they are generally consistent with the results of a recent systematic review, which found that knowledge of dementia is often poor to moderate among racial and ethnic minorities.³² Like others,²⁴ we found that knowledge about AD was positively associated with higher levels of education but did not vary by age, sex, or place of residence. Carpenter et al., who developed the ADKS, also found that knowledge about AD was more extensive in two categories of respondents: those who had attended a dementia support group (mean score = 26 vs 21 for non-attendees), and those who had completed a class or educational program about dementia (mean score = 24 vs 21 for non-attendees).^{22,31} We did not ask additional questions about these characteristics in our pow-wow survey.

Empirical studies of the cultural understanding of dementia among Native people are rare,³³ but extant literature suggests that cognitive impairment and dementia might be viewed differently among AI/ANs relative to other U.S. populations.^{23,34,35} For example, Choctaw elders embraced three different views of dementia.³⁶ In one view, dementia reflected normal aging; in the second, it accompanied the transition to the next world; and in the third, it reflected a combination of various explanations. Another small study noted that Northern Plains elders also expressed a range of views on dementia, with many stating that AD was rare in their tribe. Mental acuity was judged primarily in relation to an elder's ability to recall details about the distant past, which can remain intact well into the later stages of dementia.³³ Another report found that Pueblo family caregivers were less embarrassed than researchers expected by the inappropriate behavior of their "confused" elders.³⁷ In another study involving a series of sharing circles and interviews with elders, memory loss was attributed both to going through the full circle of life and to living in the way of White people.²³

Collectively, these studies suggest that recognition of dementia as a disease is infrequent among AI/ANs, and that a consistent explanatory model of dementia is not available in tribal traditions.³⁸ Such variations in the cultural recognition and interpretation of declining cognitive ability will pose barriers to the kinds of programs we envision. This includes community education programs that raise awareness of AD which aim to change widespread perceptions that memory loss is part of normal aging. Barriers created by a lack of knowledge among Native community members have been cited by elders to negatively impact dementia care and seeking treatment.³⁹ Explanatory models in AI/AN cultures attribute dementia variously to "naturalization" (eg, dementia is the Creator's plan for ultimate learning); to an imbalance in the patient's spiritual, emotional, or social environment (eg, dementia results from breaking a cultural taboo); to a spiritual transition (eg, the patient's spirit has already crossed over into the next world); or to the stress of living simultaneously in traditional and White society.³⁶ As

long as AD symptoms are not regarded as a cause for concern, declines in memory will not be reported to health-care providers, further hindering diagnosis.^{40,41}

Disparities in health-care access among AI/ANs will also present formidable barriers to community education about AD. Such disparities include lack of a regular primary care physician,¹³ inadequate health education,¹⁵ and the need to travel long distances for clinical services.¹⁶ Demographic and institutional factors present further complications. Between 1940 and 1996, AI/AN life expectancy increased from 51 to 71 years.⁴² Despite subsequent improvements, nevertheless, life expectancy is still 5.5 years shorter in AI/ANs than in the U.S. all-races population (73 vs 78.5 years).⁴³ Unfortunately, the health-care systems that serve the aging AI/AN population are unprepared for the economic and social burdens associated with AD. Many AI/ANs receive care through the Indian Health Service,⁴⁴ which is perennially underfunded. Recent data provided by this institution indicate that rates of mortality due to AD in AI/ANs are lower than corresponding rates in the all-races population.⁴³ However, the experience of Indian Health Service clinicians suggests that the reported prevalence of AD in Native people does not accurately reflect its true prevalence, because dementia in AI/ANs is under-identified.² Meanwhile, competing health-care and social priorities in AI/AN communities divert attention from dementia, impeding timely detection and treatment.^{33,34,45} Given the shortage of health-care professionals working in Native health,⁴⁶ the rapidly aging AI/AN population will place additional demands on an already overburdened and underfunded health system.

Specific knowledge gaps highlighted by the present study are especially troubling, as the lowest percentages of correct ADKS items appeared in the domains of caregiving and risk factors. Similarly, the study by Carpenter et al., with a sample size of 763, reported that respondents knew the most about assessment, treatment, and management of AD and the least about risk factors and prevention.³¹ In that study, respondents had an average of 74% correct items in the caregiving domain. Others have observed notably lower scores for individual items across multiple domains,²⁴ including caregiving and risk factors. Because the traditional caretaking unit in AI/AN cultures is the family, caregivers for AI/AN elders with dementia are commonly family members.⁴⁷ Our results therefore underscore the need for educational materials designed specifically for potential family members who are caregivers. This is particularly true for the two lowest scoring individual caregiving items: 62% believed that once people have AD, they are no longer capable of making informed decisions about their own care, and 72% believed that when people with AD begin to have difficulty taking care of themselves, caregivers should take over right away. Educational material could be specifically designed to provide information about the stages of AD, when care should be provided and if further treatment or help is necessary. Knowledge about AD may not directly translate to behavior change or adoption of preventative measures (eg, exercise, social engagement). However, having accurate knowledge and risk perceptions about a health issue is often a prerequisite for behavior change and positive health behaviors.⁴⁸

The present study has several limitations. First, people attending community pow-wows represent a convenience sample. Nonetheless, pow-wows are an efficient way to survey a non-clinical population that is otherwise hard to reach. Second, it is possible that participants could have completed surveys at multiple pow-wows but that information was not collected and could not be accounted for in analysis. Due to potential correlations between multiple responses from the same individuals, confidence intervals may be too narrow; results should be interpreted with caution. Third, participants completed the questionnaire on clipboards at tables, hindering our ability to make sure participants answered all items. However, our analysis used multiple imputation to account for potential bias due to information missingness. Fourth, the exact number of attendees at the pow-wows is unknown, as well as the number of attendees invited to complete the survey. We are therefore unsure how representative the 438 survey respondents were of all those who attended the pow-wows. Fifth, cultural beliefs may affect interpretation of health information and constrain decisions to seek support for dementia among AI/ANs,³⁵ potentially influencing the performance of measures such as the ADKS. We recommend that a culturally sensitive assessment scale be developed and validated among AI/AN populations, because the ADKS may not adequately cover culturally specific misconceptions among these populations. Finally, our results may not be generalizable to other AI/AN populations, including those unable to attend pow-wows and those living outside the Pacific Northwest. In particular, almost a third of our participants were college graduates and more than 85% had a high school diploma, indicating that our sample was better educated than the overall AI/AN population ($\approx 80\%$ high school graduates, 14% bachelor's degree).⁴⁹ To participate in this study, respondents indicated that they were American Indian or Alaska Native. Because this is aggregated data we are unable to parse out specific information between the two populations (ie, American Indians vs Alaska Natives). Future research could examine dementia knowledge between American Indians and Alaska Natives as there could be meaningful differences between populations that could inform AD communication material.

Nonetheless, as the first study of AD knowledge among AI/ANs, this work can inform the development of culturally informed educational materials to raise community awareness. The authors have already used these results to develop a presentation on AD for AI/AN elders, illustrating how information gathered at community cultural events can be readily translated into health promotion and communication campaigns to expand public knowledge of AD.

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REFERENCES

1. Alzheimer's Association. 2019 Alzheimer's Disease Facts and Figures. <https://www.alz.org/media/Documents/alzheimers-facts-and-figures-2019-r.pdf>. Accessed May 13, 2019.
2. US Department of Health and Human Services on Alzheimer's Disease. A Big Sky Approach to a National Challenge before Committee

- on Aging United States Senate. https://www.ihs.gov/sites/newsroom/themes/responsive2017/display_objects/documents/testimony/113/113th-August-13-2014.pdf. Accessed June 5, 2019.
3. Wang HX, Xu W, Pei JJ. Leisure activities, cognition and dementia. *Biochim Biophys Acta*. 2012;1822(3):482-491.
 4. Marden JR, Tchetgen Tchetgen EJ, Kawachi I, Glymour MM. Contribution of socioeconomic status at three life-course periods to late life memory function and decline: early and late predictors of dementia risk. *Am J Epidemiol*. 2017;186(7):805-814.
 5. Wilson RS, Boyle PA, Yu L, Barnes LL, Schneider JA, Bennett DA. Life-span cognitive activity, neuropathologic burden, and cognitive aging. *Neurology*. 2013;81(4):314-321.
 6. Wilson RS, Mendes De Leon CF, Barnes LL, et al. Participation in cognitively stimulating activities and risk of incident Alzheimer's disease. *JAMA*. 2002;287(6):742-748.
 7. Hall CB, Lipton RB, Sliwinski M, Katz MJ, Derby CA, Verghese J. Cognitive activities delay onset of memory decline in persons who develop dementia. *Neurology*. 2009;73(5):356-361.
 8. Ronnema E, Zethelius B, Lannfelt L, Kilander L. Vascular risk factors and dementia: 40-year follow-up of a population-based cohort. *Dement Geriatr Cogn Disord*. 2011;31(6):460-466.
 9. Debette S, Seshadri S, Beiser A, et al. Midlife vascular risk factor exposure accelerates structural brain aging and cognitive decline. *Neurology*. 2011;77(5):461-468.
 10. Launer LJ, Ross GW, Petrovitch H, et al. Midlife blood pressure and dementia: the Honolulu-Asia aging study. *Neurobiol Aging*. 2000;21(1):49-55.
 11. Ninomiya T, Ohara T, Hirakawa Y, et al. Midlife and late-life blood pressure and dementia in Japanese elderly: the Hisayama study. *Hypertension*. 2011;58(1):22-28.
 12. Pendlebury ST, Prevalence Rothwell PM. incidence, and factors associated with pre-stroke and post-stroke dementia: a systematic review and meta-analysis. *Lancet Neurol*. 2009;8(11):1006-1018.
 13. Loef M, Walach H. Midlife obesity and dementia: meta-analysis and adjusted forecast of dementia prevalence in the United States and China. *Obesity*. 2013;21(1):E51-55.
 14. Anstey KJ, Cherbuin N, Budge M, Young J. Body mass index in midlife and late-life as a risk factor for dementia: a meta-analysis of prospective studies. *Obes Rev*. 2011;12(5):e426-437.
 15. Anstey KJ, von Sanden C, Salim A, O'Kearney R. Smoking as a risk factor for dementia and cognitive decline: a meta-analysis of prospective studies. *Am J Epidemiol*. 2007;166(4):367-378.
 16. Rusanen M, Kivipelto M, Quesenberry CP Jr, Zhou J, Whitmer RA. Heavy smoking in midlife and long-term risk of Alzheimer's disease and vascular dementia. *Arch Intern Med*. 2011;171(4):333-339.
 17. Solomon A, Kivipelto M, Wolozin B, Zhou J, Whitmer RA. Midlife serum cholesterol and increased risk of Alzheimer's and vascular dementia three decades later. *Dement Geriatr Cogn Disord*. 2009;28(1):75-80.
 18. Meng XF, Yu JT, Wang HF, et al. Midlife vascular risk factors and the risk of Alzheimer's disease: a systematic review and meta-analysis. *J Alzheimers Dis*. 2014;42(4):1295-1310.
 19. US Census Bureau. The American Indian and Alaska Native Population. <https://www.census.gov/library/publications/2012/dec/c2010br-10.html>. Accessed May 4, 2020.
 20. US Census Bureau. The Native Hawaiian and Other Pacific Islander Population. <https://www.census.gov/about/partners/cic/resources/data-links/nhopi.html>. Accessed May 13, 2020.
 21. Ortman J, Velkoff V, Hogan H. An aging nation: the older population in the United States. *Current Population Reports*. 2014:P25-1140. <https://www.census.gov/prod/2014pubs/p25-1140.pdf>. Accessed November 22, 2018.
 22. Carpenter BD, Balsis S, Otilingam PG, Hanson PK, Gatz M. The Alzheimer's Disease Knowledge Scale: development and psychometric properties. *Gerontologist*. 2009;49(2):236-247.
 23. Hulko W, Camille E, Antifeau E, Arnouse M, Bachynski N, Taylor D. Views of First Nation elders on memory loss and memory care in later life. *J Cross Cult Gerontol*. 2010;25(4):317-342.
 24. Pollux PMJ, Elliot V, Howard M, Hudson JM. Distinguishing between knowledge gaps and misconceptions of Alzheimer's disease among caregivers in the UK. *J Aging ResHealthcare*. 2016;1(2):21-30.
 25. Smyth W, Fielding E, Beattie E, et al. A survey-based study of knowledge of Alzheimer's disease among health care staff. *BMC Geriatr*. 2013;13:2.
 26. Rios M. UW Presents 46th Annual Spring PowWow. Tulalip News. <https://www.tulalipnews.com/wp/2017/04/12/uw-presents-46th-annual-spring-powwow/>. Accessed April 24, 2019.
 27. Williams R. Using the margins command to estimate and interpret adjusted predictions and marginal effects. *Stata J*. 2012;12(2):308-331.
 28. Eekhout I, de Vet HC, Twisk JW, Brand JP, de Boer MR, Heymans MW. Missing data in a multi-item instrument were best handled by multiple imputation at the item score level. *J Clin Epidemiol*. 2014;67(3):335-342.
 29. White IR, Royston P, Wood AM. Multiple imputation using chained equations: issues and guidance for practice. *Stat Med*. 2011;30(4):377-399.
 30. Stata Statistical Software: Release 15. StataCorp LLC; 2017.
 31. Carpenter BD, Zoller SM, Balsis S, Otilingam PG, Gatz M. Demographic and contextual factors related to knowledge about Alzheimer's disease. *Am J Alzheimers Dis Other Dement*. 2011;26(2):121-126.
 32. Cahill S, Pierce M, Werner P, Darley A, Bobersky A. A systematic review of the public's knowledge and understanding of Alzheimer's disease and dementia. *Alzheimer Dis Assoc Disord*. 2015;29(3):255-275.
 33. Jervis LL, Cullum CM, Manson SM. American Indians, cognitive assessment, and dementia. In: Yeo G, Gallagher-Thompson D, eds. *Ethnicity and the dementias*. 2nd ed. New York, NY: Taylor & Francis; 2006:87-101.
 34. Griffin-Pierce T, Silverberg N, Connor D, et al. Challenges to the recognition and assessment of Alzheimer's disease in American Indians of the southwestern United States. *Alzheimer's Dement: J Alzheimer's Assoc*. 2008;4(4):291-299.
 35. Jervis LL, Manson SM. American Indians/Alaska natives and dementia. *Alzheimer Dis Assoc Disord*. 2002;16(Suppl 2):S89-95.
 36. Henderson JN, Henderson LC. Cultural construction of disease: a "supernormal" construct of dementia in an American Indian tribe. *J Cross Cult Gerontol*. 2002;17(3):197-212.
 37. Hennessy CJ. R. The interpretation of burden among Pueblo Indian caregivers. *J Aging Studies*. 1995;9(3):215-229.
 38. Kleinman A. *Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine, and psychiatry*. Oakland, CA: University of California Press; 1980.
 39. Finkelstein SA, Forbes DA, Richmond CA. Formal dementia care among first nations in southwestern Ontario. *Can J Aging*. 2012;31(3):257-270.
 40. Ferraro FR. Assessment and evaluation issues regarding Native American elderly adults. *J Clin Geropsychol*. 2001;7:311-318.
 41. Finke B. How do we screen for and diagnose dementia in AI/AN elders?. *IHHS Provider*. 2003;28:7-8.
 42. John R. Health status and health disparities among American Indian elders. In: Whitfield KE, ed. *Closing the gap: Improving the health of minority elders in the new millennium*, Washington, DC: Gerontological Society of America; 2004:27-44.
 43. Indian Health Service. IHS Fact Sheets: Indian Health Disparities. U.S. Department of Health and Human Services. <https://www.ihs.gov/newsroom/factsheets/disparities/>. Accessed January 9, 2019.
 44. Indian Health Service. The Federal Health Program for American Indians and Alaska Natives. U.S. Department of Health and

- Human Services. <https://www.ihs.gov/>. Accessed October 21, 2019.
45. Jervis LL, Gray JS, Cox DWI. In: Teaster PH JE, ed. *American Indian perspectives, challenges, and approaches to elder mistreatment*. New York, NY: Elder Mistreatment and the Public's Health; 2015.
46. US Government Accountability Office. Indian Health Service: Agency Faces Ongoing Challenges Filling Provider Vacancies 2018. GAO-18-580. <https://www.gao.gov/assets/700/693940.pdf>. Accessed August 5, 2019.
47. Jacklin K, Pace JE, Warry W. Informal dementia caregiving among indigenous communities in Ontario, Canada. *Care Manag J*. 2015;16(2):106-120.
48. Kreuter MW, Strecher VJ. Changing inaccurate perceptions of health risk: results from a randomized trial. *Health Psychol*. 1995;14(1):56.
49. US Census Bureau. Educational Attainment: 2013-2017 American Community Survey. https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_17_5YR_S1501&src=pt. Accessed October 21 2019.

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