

SHORT REPORT

Perceptions of cognitive decline among American Indian and Alaska Native elders

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Abstract

INTRODUCTION: American Indian and Alaska Native elders aged ≥ 65 years are experiencing increased life expectancy. Elders are critical to intergenerational knowledge, yet limited data exist on the health challenges faced by this group.

METHODS: This study engaged individuals attending the National Indian Council on Aging 2021 Annual Meeting in Reno, Nevada. A 19-question survey, designed to examine perceptions about cognitive decline and to identify comfort with potential risk and protective factors, was disseminated to 50 participants.

RESULTS: Participants indicated that they are concerned about cognitive decline, are willing to plan for their future care and cognitive testing, and articulated a desire for Tribally led long-term support services.

DISCUSSION: This study found similar results to studies on White individuals, which include a lack of knowledge, stigma around the aging process, and gaps in services available. More work is necessary to address the gap in literature and policy.

KEYWORDS

aging, Alaska Native, Alzheimer's disease, American Indian, long-term supports and services, older adults

Highlights

- American Indian and Alaska Natives (AI/ANs) are underrepresented in literature on Alzheimer's disease and related dementia (ADRD).
- AI/ANs believe that they will experience cognitive decline as they age.
- AI/ANs indicate a willingness to plan for future care and participate in future research on ADRD.

1 | BACKGROUND

American Indian and Alaska Native (AI/AN) people aged ≥ 65 years, hereafter referred to as Elders, are expected to triple to > 1.6 million by 2050, with those aged ≥ 85 years expected to increase

7-fold to just over 0.3 million. While status as an Elder is Tribally defined, a person aged ≥ 55 years is often considered to be a Tribal Elder.¹ As a group, Elders are critical to intergenerational knowledge and enable the resiliency of Indigenous peoples through their wisdom.²

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A particular exigency is to understand the prevalence of Alzheimer's disease and related dementias (ADRD), its precursor, mild cognitive impairment (MCI), and how best to provide ADRD health care for Elders.³ AI/AN people are the most underrepresented racial minorities in ADRD research. A recent PubMed search for the terms "dementia" or "Alzheimer's" in the title returned 123,931 results. Filtering for "American Indian[s]" reduced this number to just 17 publications, many of which did not contain original data. Even smaller numbers were returned when filtered for "Alaska Native[s]" (16 publications). The prevalence of dementia in AI/AN Elders is unknown; yet, because AI/AN people experience a disproportionate burden of ADRD risk factors, including hypertension and type 2 diabetes,^{4,5} this implies that AI/AN people may also experience a greater burden of ADRD. Because ADRD can impact memory, the potential for the loss of knowledge and culture is of great concern.

Of the literature that does exist on ADRD in elderly populations, the focus is on opportunities and challenges of working with AI/AN communities to understand ADRD.⁶⁻⁹ One study focusing on ADRD knowledge among AI/AN people in the Pacific Northwest revealed that culturally informed materials are still needed to address knowledge gaps concerning ADRD.¹⁰ Further, the literature specifically calls out the lack of infrastructure to serve Elders who may suffer from ADRD and its risk factors. This infrastructure, referred to as long-term supports and services (LTSS), comprises a broad set of services that help people with care needs in addition to activities of daily living.¹ Current LTSS for Elders is minimal, and national efforts to address this need often exclude Tribal communities.¹¹ Despite this, organizations such as the Alzheimer's Association, the Indian Health Service, Centers for Disease Control, and the National Indian Council on Aging (NICOA) have collaborated to raise awareness about ADRD through tools such as the "Road Map for Indian Country."¹²

Without accurate and reliable data that uplift the importance of Elders, pragmatic recommendations for both prevention and intervention will not be comprehensive.

However, scholars must consider the historical instances of conflict-laden, improper use of research, including "helicopter research," which is a term used by many AI/AN communities to define research in which investigators fly in and out, staying only long enough to collect the data.¹³⁻¹⁵ This project, therefore, kept a focus on not just answering a critical research question but on centering Indigenous methodologies.

2 | METHODS

2.1 | Respondents and setting

The project recruited from a convenience sample of AI/AN people attending the 2021 NICOA biannual conference. For nearly 50 years, NICOA has served as the nation's foremost advocate for Elders and includes members that are ≥ 18 , though a vast majority are 55+. Thus, the inclusion criteria were (1) self-identified AI and/or AN and (2) respondents aged ≥ 18 .

RESEARCH IN CONTEXT

1. **Systematic review:** The authors reviewed literature on cognitive decline, Alzheimer's disease and related dementias (ADRD), and long-term support services among American Indians and Alaska Natives (AI/ANs) using traditional sources (e.g., PubMed). Relevant references are cited appropriately.
2. **Interpretation:** The article addresses a gap in scholarly literature on the topic of aging and cognitive decline among AI/ANs. The article finds that AI/AN Elders have a lack of knowledge and stigma around aging and cognitive decline, are willing to plan for their future care and cognitive testing, and have a desire for Tribally led long-term support services.
3. **Future directions:** An Indigenous scholar outlines critical gaps in knowledge and identifies opportunities to engage AI/AN Elders on perceptions of cognitive decline including testing and the availability of long-term support services. Any future work on this topic must use Indigenous research methods and meaningfully engage Indigenous communities.

All recruitment, data collection, and analytic procedures were approved by the Washington State University and University of North Dakota Institutional Review Boards.

2.2 | Procedures

This project represents a direct response to an invitation to the lead author from leadership at NICOA to host a breakout session. The survey was disseminated to the first 50 respondents to attend the session, and to receive their \$50 gift card for participating, respondents were allowed to return their survey at any point after the session. A brief 19-question survey was created to better understand Elders' perceptions about cognitive decline, cognitive testing, living assistance, and demographics. A copy of the survey is provided in the supporting information.

2.3 | Data analysis

A total of 39 of 50 invited individuals (78%) completed the survey. Incomplete or ambiguous responses were coded as missing. Missingness for a given question ranged from 0.0% to 10.3%. Records were entered into Qualtrics and exported into Microsoft Excel for analysis of descriptive statistics.

TABLE 1 Likelihood of preventive activities and seeking cognitive evaluation.

	Very likely	Somewhat likely	Not very likely	I already do these activities	Missing
Likelihood of incorporating preventive activities					
Engaging in mentally stimulating activities	24 (61.5%)	10 (25.6%)	1 (2.6%)	3 (7.7%)	1 (2.6%)
Eating a healthy diet	29 (74.4%)	4 (10.3%)	3 (7.7%)	2 (5.1%)	1 (2.6%)
Getting enough restful sleep	30 (76.9%)	5 (12.8%)	1 (2.6%)	2 (5.1%)	1 (2.6%)
Managing stress	28 (71.8%)	6 (15.4%)	2 (5.1%)	2 (5.1%)	1 (2.6%)
Socializing with family and friends	26 (66.7%)	6 (15.4%)	2 (5.1%)	4 (10.3%)	1 (2.6%)
Getting regular physical exercise	29 (74.4%)	5 (12.8%)	1 (2.6%)	3 (7.7%)	1 (2.6%)
Reasons to seek cognitive evaluation					
If my doctor or another health-care professional recommended an evaluation	19 (48.7%)	7 (18.0%)	12 (30.8%)	0 (0.0%)	1 (2.6%)
If a family member recommended an evaluation	13 (33.3%)	14 (35.9%)	10 (25.6%)	1 (2.6%)	1 (2.6%)
Wanting to check if my memory was normal for my age	13 (33.3%)	14 (35.9%)	10 (25.6%)	1 (2.6%)	1 (2.6%)
Forgetting appointments	10 (25.6%)	14 (35.9%)	14 (35.9%)	0 (0.0%)	1 (2.6%)
If people were telling me that I repeat myself frequently	9 (23.1%)	14 (35.9%)	14 (35.9%)	1 (2.6%)	1 (2.6%)
Forgetting to pay my bills	9 (23.1%)	6 (15.4%)	22 (56.4%)	1 (2.6%)	1 (2.6%)
Feeling that my mental sharpness has declined	7 (18.0%)	18 (46.2%)	9 (23.1%)	2 (5.1%)	3 (7.7%)
Having difficulty focusing, paying attention	7 (18.0%)	14 (35.9%)	15 (38.5%)	1 (2.6%)	2 (5.1%)
Feeling I am forgetting more often than usual	5 (12.8%)	19 (48.7%)	12 (30.8%)	2 (5.1%)	1 (2.6%)
Having someone tell me that I am forgetting more than usual	5 (12.8%)	17 (43.6%)	16 (41.0%)	0 (0.0%)	1 (2.6%)

3 | RESULTS

3.1 | Demographics

Among 38 respondents providing demographic data, most were women (85%) and had completed some college or more (92%). The mean age was 66 years old, and ages ranged from 37 to 83 years. Respondents were largely rural or reservation based (69%) and two (5.1%) respondents listed that they were members of their community's Tribal leadership.

3.2 | Cognitive decline

A majority of respondents (75%) reported that they believe cognitive decline is inevitable as people get older with a slightly larger majority (82%) indicating that they were somewhat or very likely to experience cognitive decline. Most respondents indicated they are either very concerned or somewhat concerned about a range of personal situations (63%–87%). Respondents reported that they were very likely to engage in a range of preventative activities (Table 1).

3.3 | Cognitive testing

Respondents' beliefs about when their cognitive function should be evaluated were spread out with the top choices being, "yearly starting at age 50" (26%), "when a family member requests it" (21%), and "when I request it" (21%). Table 1 shows the likelihood the respondents would seek a cognitive function evaluation based on a variety of symptoms and situations. As noted in the table, for some ($n = 1$ or 2) there are individuals already experiencing some symptoms or situations such as a decline in mental sharpness or forgetfulness. Most respondents felt that if they received a diagnosis of early-stage cognitive decline they would make a lifestyle change or plan for their future (Table 2).

3.4 | Living assistance

Respondents reported that they believe it is important for LTSS for Elders to come from a Tribal provider or organization, with 35 respondents (90%) indicating that it is "very important" and 4 respondents (10%) indicating that it is "somewhat important." More than half of the respondents (56%) indicated that LTSS should occur in their own homes.

TABLE 2 Feelings about early-stage diagnosis of cognitive decline.

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Missing
I would be motivated to have a healthier lifestyle	28 (71.8%)	7 (18.0%)	2 (5.1%)	0 (0.0%)	2 (5.1%)
I believe my chances for treatment would increase	26 (66.7%)	9 (23.1%)	1 (2.6%)	0 (0.0%)	3 (7.7%)
I could prepare my advanced directive or living will	26 (66.7%)	8 (20.5%)	3 (7.7%)	0 (0.0%)	2 (5.1%)
I would have more time to plan my future care	24 (61.5%)	12 (30.8%)	1 (2.6%)	0 (0.0%)	2 (5.1%)
I would have more time to plan my finances	23 (59.0%)	13 (33.3%)	0 (0.0%)	0 (0.0%)	3 (7.7%)
I would be more willing to participate in research about the disease	21 (53.9%)	10 (25.6%)	4 (10.3%)	1 (2.6%)	3 (7.7%)
I would do nothing differently	9 (23.1%)	9 (23.1%)	8 (20.5%)	11 (28.2%)	2 (5.1%)

4 | DISCUSSION

Generally, little research has been conducted on perceptions of cognitive decline by race and ethnicity. One national review that evaluated cognitive health and ADRD among the US population found similar gaps in research across all communities with people generally aware of ADRD but having limited knowledge.¹⁶ Despite a lack of existing literature on race and ethnicity this study did find similar results to studies on White individuals, which included a lack of knowledge, stigma around the aging process, and gaps in services available.

This study builds on this initial work to provide important cultural considerations, allow for deeper examination among AI/AN communities, and support important calls to action for both policy and research activities. The survey respondents provided perspectives of Tribal citizens from largely rural or reservation-based communities across eight states.

A majority of respondents believed that that they will likely experience cognitive decline as they age and are concerned with losing independence, being a burden, not having resources to pay for care, and needing to leave home. These findings reflect that some Elders face poverty, geographic isolation, and limited access to health care and other health services.¹¹ Almost half of respondents (49%) said they would be very likely to seek a cognitive evaluation if recommended by a doctor or health-care professional. In addition, respondents selected situations related to their doctors, family members, or their own personal decisions as the most likely reasons they would seek an evaluation. While these decisions are complex, there may be an opportunity to examine the relationship between shared decision making among patients, their providers, and their families.

Questions related to feelings about an early-stage diagnosis of cognitive decline illuminated a willingness of respondents to seek aging-related services to plan for future care, including creating a will/advanced directive, financial planning, and living a healthier lifestyle. These respondents also indicated a willingness to participate in research that relates to cognitive decline. This is a strong call to action and underscores the importance of including AI/AN people in research with respondents also clear on the importance of LTSS for AI/AN Elders coming from a Tribal entity.

4.1 | Implications

This study provides critical insights for future, larger-scale efforts to better understand perceptions of cognitive decline, including preferences for cognitive testing and LTSS. Any work must take into consideration a strong call for these services to be Tribally driven, and any future research or policy work must include these communities.

4.2 | Limitations and strengths

The number of respondents in this survey is small, limiting the ability to analyze associations among factors. In addition, conclusions drawn from this work are exploratory and should be confirmed by additional research. A second limitation is that the respondents came from a convenience sample and are likely not generalizable to the broader AI/AN community.

Despite these limitations, there are many strengths to this project including a high response rate, and a willingness to participate in future research and planning for their own future care needs.

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CONFLICT OF INTEREST STATEMENT

The author declares no conflicts of interest. Author disclosures are available in the [supporting information](#).

CONSENT STATEMENT

All human subjects provided informed consent.

HUMAN STUDY STATEMENT

This study was approved by the Washington State University Institutional Review Board (IRB#19003) and the University of North Dakota Institutional Review Board (IRB0005334) as exempt.

DEI STATEMENT

The author is an Indigenous scholar who uses Indigenous research methods in working with Indigenous communities. This article represents a community-driven project conducted as part of the author's PhD program in Indigenous health alongside Indigenous mentors and allies.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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