

RESEARCH ARTICLE

Communication about Alzheimer's disease and research among American Indians and Alaska Natives

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Abstract

Introduction: American Indian and Alaska Native (AI/AN) people infrequently participate in Alzheimer's disease (AD) research, despite the rapidly increasing population of AI/AN people aged 65 and older.

Methods: We surveyed 320 adults who identified as AI/AN at two Native-focused events and used ordinary least squares regression and logistic regression models to test associations between demographic factors and perceived risk of AD, knowledge about AD, and willingness to participate in research, along with preferred source of AD information.

Results: Willingness to participate in research was highest among those living in a city versus reservation and associated with perceived personal risk for AD. Health professionals and the internet were preferred sources of information about AD.

Discussion: These hypothesis-generating results provide insight into perceptions of AD and willingness to participate in research. Conclusions could inform development of AD recruitment strategies for AI/ANs and influence participation in AD research.

KEYWORDS

Alzheimer's disease, communication, dementia, education, Indigenous, perception

1 | BACKGROUND

The American Indian and Alaska Native (AI/AN) population is increasing three times faster than the US population overall.¹ It is predicted that by 2050 the number of AI/ANs ages 65 and older will triple to 1,624,000, while the number ages 85 and older will increase 7-fold to 300,000.² The largest known risk factor for Alzheimer's disease (AD) is older age.³ The aging population, combined with a high prevalence of AD risk factors, has sparked growing concern about AD among AI/AN communities.⁴

Despite advances in AD research among non-Hispanic Whites, little is known about AD prevalence or risk in AI/ANs.^{5,6} This is partially due to low participation of AI/ANs in AD research.^{7,8} To increase

AI/AN participation in research studies, the Alzheimer's Association and the National Institute on Aging have issued calls to enhance the recruitment of minority older adults in research, and for research on effective strategies for communicating health messages to diverse populations.^{9,10} Numerous studies have examined the general public's perceptions and understandings of AD,¹¹⁻¹⁶ but few have examined AI/AN perceptions of AD, participation in research, or their preferred information sources. This omission is concerning because designing effective health messaging and increasing participation in research requires examining perceptions and knowledge of the topic of study, as well as preferences for information sources.¹⁷⁻²⁰

To address these needs, we surveyed AI/ANs in the Pacific Northwest to evaluate their perceived personal risk for AD, risk to their

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communities, levels of knowledge about AD, willingness to participate in AD research, and preferred formats for AD-related health communication. Our overarching goals are to provide insight into AI/ANs' perceptions of AD and willingness to participate in research. These hypothesis-generating results could be used to plan and test approaches to recruit AI/ANs into AD studies and develop culturally informed communication material.

2 | METHODS

2.1 | Population and procedures

We administered surveys in 2018 to 213 AI/ANs at the Seafair Pow Wow, and to 107 AI/ANs at the Gathering at the Falls Pow Wow. The Seafair Pow Wow, held in Seattle, Washington, is a 3-day event that attracts between 7000 and 10,000 attendees each year.²¹ The Gathering at the Falls Pow Wow, held in Spokane, Washington, attracts approximately 5000 attendees who represent more than 200 Tribes.²² Although these events are held in urban settings, pow wows attract AI/ANs from both urban and rural areas. They also reach AI/ANs who may not regularly use health-care services. In addition to celebrating culture, pow wows attract vendors and community organizations that offer information on employment opportunities and health and social services, most often at booths arranged in a circular formation around activities of drumming, singing, and dancing.

Partnerships for Native Health, a large education and research unit at Washington State University, hosted a booth at these two events to administer the survey to identify health needs and disseminate information on various health conditions prevalent among AI/ANs. Pow wow attendees were invited to approach the staff at the booth and learn about the survey. If they were interested in participating in the survey, two screening questions were asked to determine eligibility: (1) "Are you at least 18 years old?" and (2) "Do you identify as American Indian or Alaska Native?" Screen failure data were not recorded. Participants completed a paper-based survey that included items on health-related topics such as cancer screening, kidney disease, Parkinson's disease, AD, and demographic characteristics and were provided with a \$5 gift card to recognize their time and effort. Participants completed the survey in approximately 15 minutes. Our analysis used a total of 25 questions that focused on AD, participation in research, information preferences, and demographics. The study was determined exempt from review by the Washington State University Institutional Review Board. No identifying information was associated with the questionnaires and all data were collected anonymously so consent from participants was not necessary.

2.2 | Measures

2.2.1 | Personal perceived risk of AD

Three items were used to examine personal perceived risk of AD. These items were previously used in two surveys on AD in the US general

RESEARCH IN CONTEXT

- 1. Systematic Review:** The authors reviewed studies on knowledge of Alzheimer's disease (AD) and barriers to participation in research among American Indian and Alaska Native (AI/AN) populations. They cite extant research aimed to increase the recruitment of minority populations into AD research and call for greater understanding of perceptions of AD among AI/ANs.
- 2. Interpretation:** Having a 2-year college degree or higher was associated with higher perceived risk of AD and greater AD knowledge. Perceived personal risk was positively associated with willingness to participate in research. Respondents would like to receive information about AD from health professionals or the internet.
- 3. Future Directions:** Results can be used to develop AD research recruitment and communication strategies for AI/ANs. Future research could examine AI/AN populations across the United States and test our findings in research settings. Together our findings may influence participation in AD research.

HIGHLIGHTS

- Three hundred twenty American Indian and Alaska Native (AI/AN) adults were surveyed on perceptions of Alzheimer's disease (AD) and participation in trials.
- Having a family member with AD was positively associated with perceived risk and AD knowledge.
- Perceived personal risk of AD was associated with willingness to participate in trials.
- Respondents showed a preference for health professionals and the internet as AD information sources.
- Results could inform development of AD recruitment and messaging strategies for AI/ANs.

population.^{11,23} Participants indicated their level of agreement on a four-category Likert scale with three statements about possibly getting AD: (1) "You would like to know your chances of someday getting Alzheimer's disease," (2) "You believe you will get Alzheimer's disease someday," and (3) "You worry about getting Alzheimer's disease someday." The items were assessed for similarity and transformed into one standardized, continuous score (Cronbach's alpha = 0.7).¹¹

2.2.2 | General perceived risk of AD

Two items assessed general perceived risk of AD. Items were adapted from a survey on perceptions of health risks²⁴ and also have been used

by our group.²⁵ Items included (1) “Alzheimer’s disease is a large health problem for American Indians and Alaska Natives” and (2) “Alzheimer’s disease is a large health problem for Americans in general.” These were similarly combined from three-category Likert scales into one standardized score (Cronbach’s alpha = 0.7; Spearman’s rho = 0.5, *P* value < .0).

2.2.3 | Knowledge about selected AD risk and protective factors

Two true–false items from the validated Alzheimer’s Disease Knowledge Scale²⁶ and previously used on a short survey of AD knowledge¹¹ ascertained understanding of specific risk and protective factors for AD. Items included (1) “Prescription drugs that prevent Alzheimer’s disease are available” (correct answer = false) and (2) “Having a parent or sibling with Alzheimer’s disease increases the chance of developing it” (correct answer = true).

2.2.4 | Willingness to participate in research

Participants were first asked to respond “yes” or “no” to the general question: “Would you consider participating in a research program designed to test a medical treatment or therapy.” This question was followed by a second more specific question: “Would you consider participating in a research program designed to test a medical treatment or therapy for Alzheimer’s disease?”

2.2.5 | Reasons for participation in research

Nine questions with a yes/no response set examined reasons for participation in AD research. Questions were previously used in a study to examine willingness to participate in clinical treatment research among older Blacks and Whites.²⁷ All participants were asked: “To help researchers find the cause and develop treatments for Alzheimer’s disease, would you participate in a research program...”: (1) “if you received payment,” (2) “if a doctor recommended it,” (3) “if it may help someone or cure an illness,” (4) “if you received some free medical care,” (5) “if it helped scientists learn more,” (6) “if you knew someone who participated,” (7) “if there were no side effects,” (8) “if there was no cost,” and (9) “if a friend or family member recommended it.” In addition, participants answered “yes,” “no,” or “don’t know” to: (1) “It is important for American Indians and Alaska Natives to participate in research programs to test medical treatments” and (2) “It is important for Americans in general to participate in research programs to test medical treatments for Alzheimer’s disease.”

2.2.6 | Sources of information about AD

To assess exposure to information about AD, we asked whether respondents had “seen, heard or read information about AD in the past year?” and what sources they would like to get information from about AD. Response options included: television, newspaper, radio, magazines, brochures, health professionals including your doctor, health professionals other than your doctor, friends and relatives, internet sources including social media, and internet sources other than social media.

2.2.7 | Experience with AD

Two questions assessed personal experience with AD.¹¹ Participants were asked if they: (1) “Know anyone with Alzheimer’s disease” and (2) “If a doctor ever said that someone in their immediate family (defined as spouse/partner, parent, sibling, adult child) has Alzheimer’s disease.”

2.2.8 | Demographic variables

We collected information about age in years, sex (male, female, transgender, other), highest grade of school completed (less than high school, high school/GED/vocational school, some college, college graduate), and location of residence (reservation, rural area or town, large metropolitan area).

2.3 | Data analysis

We combined summary statistics and multivariate analyses to examine AI/AN perceptions of AD risk, knowledge about AD, and willingness to participate in AD research. Continuous outcomes were assessed with ordinary least squares regressions while binary outcomes were evaluated with logistic regressions. Our independent variables included age, sex, education, whether the respondent knows someone with AD, and location of residence (reservation, rural/town, city). In the willingness to participate in AD research, we included perceptions of AD risk and knowledge about AD as covariates. We then explored the frequency of preferred sources for AD-related health information with percentages. A total of 329 respondents attempted the survey, but only those who filled out both the demographic questions and outcome variables were included in the analysis for a sample size of 320. A complete case analysis approach was used for the regression analyses in which missing values (<7% for any one variable) were excluded. Thus, the sample sizes for each outcome vary. All statistical analyses were performed using Stata version 16.²⁸

TABLE 1 Demographics ($N = 320$)

	Seafair % (n) $n = 213$	Gathering at the Falls % (n) $n = 107$	Total	P value
Age				
<40	43 (91)	51 (55)	46 (146)	.2
40–64	44 (93)	41 (44)	43 (137)	
65 and over	14 (29)	8 (8)	12 (37)	
Sex				
Female	64 (133)	58 (61)	62 (194)	.2
Male	36 (74)	43 (45)	37 (119)	
Highest educational degree				
No degree/GED or high-school diploma	51 (108)	63 (67)	55 (175)	.04
≥ 2-year college degree	49 (105)	37 (40)	45 (145)	
Location of residence				
Reservation	20 (42)	50 (53)	30 (95)	<.01
Rural area/town	19 (41)	21 (22)	20 (63)	
City	61 (128)	29 (30)	49 (158)	

Notes: Group difference P values using Chi-squared to test for independence between samples. Sample size based on inclusion criteria (age and identify as AI/AN). Variables may not add up to total size/percent due to missingness and rounding.

Abbreviation: AI/AN, American Indian and Alaska Native.

3 | RESULTS

3.1 | Demographics

The final sample includes 320 adults aged 18 years and older (Table 1). The mean age was 44 years. About half of the participants were over the age of 40 at both the Seafair (58%) and the Gathering at the Falls (50%) and 64% and 58% were female, respectively. Seafair Pow Wow participants were more highly educated than their peers at the Gathering at the Falls Pow Wow (at least a 2-year college degree, 49% vs. 37%). Participants mainly reported living in cities (49%), followed by reservations (30%), then other rural areas or towns (20%).

3.2 | Personal and general risk of AD and AD knowledge

Most respondents ($n = 228$, 69%) wanted to know their chances of developing AD, 35% ($n = 114$) worried about getting AD someday, but only 16% ($n = 54$) believed they will get AD. More than 75% ($n = 254$) reported AD is a large health problem for Americans in general compared to 51% ($n = 169$) for AI/ANs specifically. For those who responded to the knowledge questions, 63% ($n = 189$) correctly identified that prescription drugs cannot prevent AD, and 67% ($n = 215$) correctly believed that having a parent or sibling with AD increased the chance of personally developing AD.

Table 2 illustrates the associations between participant characteristics and personal and general perceived risk, along with the two knowl-

edge outcomes. Compared to participants who do not know someone with AD, knowing someone was related to a higher perceived personal risk ($b = 0.2$, 95% confidence interval [CI]: 0.0, 0.4), general risk ($b = 0.3$, 95% CI: 0.1, 0.5), and knowing that AD in the family increases the risk of AD (1.8 odds ratio [OR], 95% CI: 0.9, 4.0). Having an immediate family member with AD was further associated with a higher perceived personal ($b = 0.5$, 95% CI: 0.2, 0.7) and general risk ($b = 0.5$, 95% CI: 0.2, 0.7), compared to not knowing someone with AD. At least a 2-year college degree was related to a higher perceived general risk ($b = 0.2$, 95% CI: 0.0, 0.4) and knowledge that AD in the family increased AD risk (1.9 OR; 95% CI: 1.2, 3.2) compared to the group with no degree or a GED/high school diploma.

3.3 | Willingness to participate in AD research

Less than half of participants ($n = 126$, 39%) reported that they were willing to participate in AD research. Table 3 shows the associations between the willingness to participate in AD research and experience with AD, risk perceptions, AD knowledge, and the demographic characteristics. Compared to not being willing to participate in research, willingness to participate was associated with a higher perceived personal risk, as well as living in a city compared to living on a reservation.

Figure 1 demonstrates the three most commonly cited reasons for participating in AD research were to help with a cure ($n = 258$, 83%), and if participation accrued no cost ($n = 239$, 77%) or side effects to the respondent ($n = 238$, 77%), followed closely by free medical care

TABLE 2 Participant characteristics associated with perceived AD risk and AD knowledge

	Perceived risk ^a		Knowledge ^b	
	Personal	General	AD prescription drugs are available	AD in family increases risk
Age (years)				
40–64	0.0 [–0.2 0.2]	–0.1 [–0.3 0.1]	1.2 [0.7 1.9]	0.9 [0.5 1.6]
65 and over	–0.2 [–0.5 0.0]	–0.2 [–0.5 0.0]	1.1 [0.5 2.5]	0.5 [0.2 1.1]
Sex				
Female	0.1 [–0.2 0.2]	0.0 [–0.2 0.2]	1.0 [0.6 1.6]	1.6 [1.0 2.7]
Highest educational degree				
≥2-year college degree	0.0 [–0.2 0.2]	0.2 [0.0 0.4]	1.1 [0.7 1.8]	1.9 [1.2 3.2]
Knows someone with AD				
Yes, but not immediate family	0.2 [0.0 0.4]	0.3 [0.1 0.5]	0.7 [0.4 1.2]	2.0 [1.0 3.3]
Yes, immediate family	0.5 [0.2 0.7]	0.5 [0.2 0.7]	1.0 [0.5 2.1]	1.8 [0.9 4.0]
Location of residence				
Reservation	–0.2 [–0.4 0.1]	0.1 [–0.2 0.3]	0.8 [0.5 1.5]	1.0 [0.5 1.8]
Rural area/town	–0.2 [–0.5 0.0]	–0.2 [–0.4 0.1]	0.9 [0.5 1.7]	0.7 [0.4 1.4]
Observations	308	309	287	304

Notes: 95% confidence intervals in brackets. Reference categories: <40 years old, male, < 2-year college degree, “does not know someone with AD,” and city residence.

Abbreviations: AD, Alzheimer’s disease; AI/AN, American Indian and Alaska Native.

^aOrdinary least squares of standardized dependent variables, centered on 0 with a standard deviation of 1. Personal perceived risk index includes three, four-category Likert scale questions—wanting to know chances of getting AD, believing you will get AD someday, and worrying about getting AD someday (Cronbach’s alpha = 0.7). General perceived risk includes two, three-category Likert scale questions—AD as a large problem for AI/AN people and for Americans in general (Cronbach’s alpha = 0.7; Spearman’s rho = 0.5, *P* value < .0).

^bLogistic regression with odds ratios.

(*n* = 227, 73%), a doctor recommends (*n* = 224, 72%), receive payment (*n* = 220, 71%), and to help science (*n* = 217, 70%). Recommendations from a friend/family (*n* = 197, 64%) and knowing other participants (*n* = 172, 55%) were cited least. Thirty-one (10%) participants would not participate in research studies for any reason.

3.4 | Preferences for AD information source

Figure 2 presents the results on the preferences for AD information sources. Respondents overwhelmingly preferred receiving information from a doctor (*n* = 273, 88%) or health professional (*n* = 226, 73%). Other important sources included a brochure (*n* = 216, 68%) and the internet (*n* = 204, 66%). Radio (*n* = 134, 43%) was the least cited information source.

4 | DISCUSSION

Organizations such as the Alzheimer’s Association and the National Institute on Aging have called for efforts and communication strategies to increase recruitment of minority and diverse populations into AD and other research.^{9,10} Our study answers this call by contributing to a scarcity of publications concerning perceptions and knowledge of AD, preferences for information sources, and factors influencing AI/AN participation in AD research. To summarize our results, participants had low risk perceptions of AD with approximately half stating that AD was a major health problem for AI/ANs. They also had a moderate level of AD knowledge. Willingness to participate in research was highest among those living in a city versus reservation and associated with perceived personal risk for AD. Participants preferred receiving information about AD from doctors and health professionals, along with for-

TABLE 3 Participant characteristics associated with willingness to participate in AD research ($n = 285$)

	Willingness to participate in AD research
Age	
40–64	1.6 [0.9 2.8]
65 and over	1.1 [0.5 2.6]
Sex	
Female	0.7 [0.4 1.2]
Highest educational degree	
>2-year college degree	1.4 [0.8 2.3]
Knows someone with AD	
Yes, but not immediate family	0.8 [0.5 1.5]
Yes, immediate family	1.3 [0.6 2.8]
Location of residence	
Reservation	0.5 [0.3 0.9]
Rural area/town	0.8 [0.4 1.6]
Personal risk	
	1.9 [1.3 2.8]
General risk	
	1.1 [0.7 1.5]
AD prescription drugs are available	
Correct (False)	1.2 [0.7 1.5]
AD in family increases risk	
Correct (True)	1.4 [0.7 1.2]

Notes: 95% confidence intervals in brackets. Reference categories: <40 years old, male, < 2-year college degree, “does not know someone with AD,” city residence, and incorrect knowledge response (“AD prescription drugs are available” and “AD in family does not increase risk”). Personal perceived risk index includes three, four-category Likert scale questions—wanting to know chances of getting AD, believing you will get AD someday, and worrying about getting AD someday (Cronbach's alpha = 0.7). General perceived risk includes two, three-category Likert scale questions—AD as a large problem for AI/AN people and for Americans in general (Cronbach's alpha = 0.7; Spearman's rho = 0.5, P value < .0). Logistic regression with odds ratios.

Abbreviations: AD, Alzheimer's disease; AI/AN, American Indian and Alaska Native.

mats such as brochures and the internet. The following provides discussion of the results, limitations of the study, and recommendations for future research.

We found lower and misaligned perceptions of AD risk existed in a substantial portion of the respondents. Only half (51%) stated that AD was a major health problem for AI/ANs and three-quarters (77%) stated that AD was a major health problem for the general US population. Furthermore, only 35% were concerned about getting AD one day. To design effective health communication strategies, it is crucial to understand a population's perceptions of a hazard or risk.²⁹ Studies show that if people are not concerned about a hazard, they may not act to prevent it.³⁰ A study of AI/AN risk perceptions observed that participants correctly identified that cardiovascular disease was a major health problem for both AI/ANs (84%) and for the general US population (86%).³¹ Thus, the modest personal concern and a relative lack of awareness of the major impact of AD on the rapidly growing population of older adults, especially AI/ANs, may account for lower interest in AD research or perceived need to act to reduce risk.

Of equal importance to examining risk perceptions is understanding a population's knowledge of risk. This information provides the context needed to develop impactful health communication strategies.³² These results are consistent with our recent study that found a moderate level of knowledge about AD among AI/AN adults. We administered the 30-item Alzheimer's Disease Knowledge Scale²⁶ to 428 AI/ANs who answered approximately 19 (63%) items correctly.²⁵ Consistent with the present findings, higher education levels were associated with greater knowledge about AD; low knowledge was for the caregiving and risk factor domains. Our study did not use the full 30 items so we are unable to address how knowledge in different domains could influence interest in research participation. Similar to another study on the general public's knowledge of AD,¹¹ we noted many AI/ANs recognize that medications to prevent AD are not available (61%¹¹ vs. 63%) and that having an affected close relative was associated with increased personal risk (68%¹¹ vs. 67%). Our findings that the perception of great personal risk of AD has the greatest influence on willingness to participate in research is aligned with studies that document willingness to participate in research is associated with perceived risk of contracting a specific disease.³³ Perceived personal risk, in turn, appears to be influenced by whether respondents knew a person with AD. Furthermore, AI/ANs who live in cities are more likely to participate in research than those who live on reservations. This could be due to the lack of geographically convenient clinical trial sites that hinder study participation, particularly for those who live in rural areas.³⁴

Of interest, in contrast to studies of Blacks and Whites²⁷ in which only a minority of respondents would be willing to participate in trials if it helped others, 83% of AI/ANs surveyed here would be willing to participate in research for this reason. Although research is needed into motivational differences between AI/AN people and other populations, given their community orientation,³⁵ AI/AN people may be persuaded to participate in trials to benefit community rather than individual health. This perspective is congruent with the frequently cited reason to participate to “help with a cure.” The advantages of appealing to people's sense of community to engender positive behavior change

FIGURE 1 Summary of reasons for participating in research of those who responded to the question ($n = 285$)

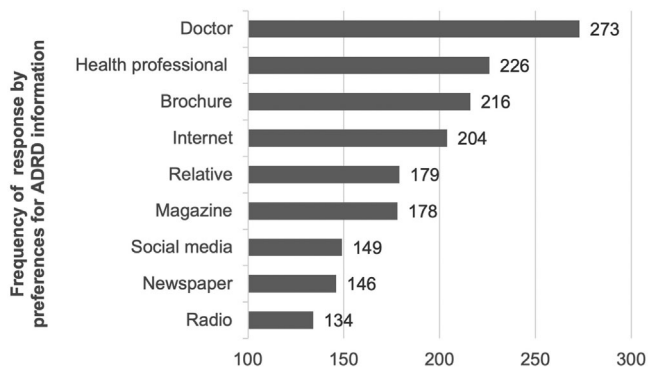
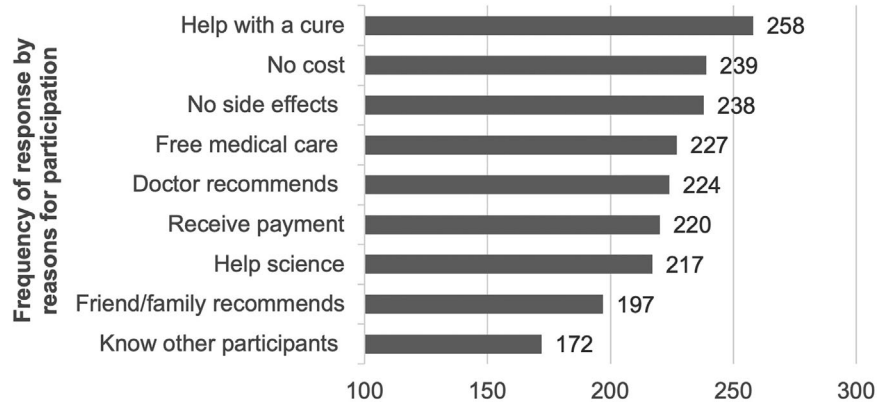


FIGURE 2 Number of respondents with preferences for sources of Alzheimer's disease information ($n = 310$). ADRD, Alzheimer's disease and related dementias

have been identified in other studies of health communication with Indigenous communities.³⁶

Consistent with other studies on information seeking, we found AI/AN respondents preferred receiving information about AD from doctors and health professionals, along with formats such as brochures and the internet. In one study, doctors and the internet were among the most preferred sources for information.³¹ Results from another study in the US mid-west found that AI/ANs commonly use computers to seek health information.^{37,38} Future research might focus on disseminating AD brochures or websites that contain information explicitly drawn from and featuring AI/AN doctors and health professionals working in the field of AD research.

This study has several limitations. We collected data from a convenience sample attending pow wows in Washington State, which is unlikely to be representative of the larger AI/AN population. Nevertheless, our study sample was recruited from two large cultural events that attracted AI/ANs from across the Pacific Northwest and beyond. Our results are likely more applicable to the general population of AI/ANs than a study limited to a single tribal community. It is also possible that several household members completed surveys, which could result in correlations between responses and overly narrow confidence intervals. In addition, questions related to risk perceptions and reasons for participation in research have not been previously validated in AI/ANs.

Despite these limitations, this study provides insight into AI/AN perceptions of AD and participation in research, preferences for information sources, and factors influencing participation in AD research. Our initial regression results and summary statistics provide direction to generate additional hypotheses, develop research designs that evaluate causal relationships between identified variables and acknowledge potential confounding and mediating relationships, as well as to plan and test approaches to recruit AI/ANs into larger and more representative studies of AD. Future research should examine knowledge of AD further, as specific knowledge domains could impact participation in related research. Research could further explore reasons for participating in AD-related research beyond the results of this study. While we examined nine reasons that may impact research participation, additional culturally specific motivations may exist among AI/AN populations. Finally, establishing whether AD knowledge among AI/AN populations differs from other groups may help tailor campaigns aimed at informing AI/AN older adults. A focus of such campaigns might simultaneously enhance the visibility of AI/AN people living with AD within their communities.

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CONFLICTS OF INTEREST

The authors declare that there are no conflicts of interest.

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