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VARIABLES INFLUENCING HELP-SEEKING INTENTIONS FOR EARLY SYMPTOMS  
OF ALZHEIMER'S DISEASE IN AN AMERICAN INDIAN AND ALASKA NATIVE  
SAMPLE

by

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A Dissertation

Submitted to the Graduate Faculty of the

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December  
2020

This dissertation, submitted by Autumn Rose Arch in partial fulfillment of the requirements for the Degree of Doctor of Philosophy from the University of North Dakota, has been read by the Faculty Advisory Committee under whom the work has been done and is hereby approved.

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## PERMISSION

Title            Variables Influencing Help-Seeking Intentions for Early Symptoms of  
                  Alzheimer's Disease in an American Indian And Alaska Native Sample

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## TABLE OF CONTENTS

LIST OF TABLES.....	vii
ACKNOWLEDGMENTS.....	viii
ABSTRACT.....	ix
CHAPTER	
I. BACKGROUND AND REVIEW.....	10
Alzheimer’s Disease.....	11
Alzheimer’s Disease Risk Factors.....	12
Diagnosis and Treatment of Alzheimer’s Disease.....	12
Alzheimer’s Disease Among Racial/Ethnic Minority Populations.....	14
American Indian/Alaska Natives and Alzheimer’s Disease.....	16
Help-Seeking Intention.....	19
A Model for Evaluation Help-Seeking Intentions for Alzheimer’s Disease.....	20
American Indian/Alaska Native Cultural Considerations.....	21
Role of Alzheimer’s Disease Knowledge.....	22
Other Modifying Variables.....	23
Purpose of the Study.....	24
Hypotheses.....	26
Hypothesis 1.....	26
Hypothesis 2.....	26

Hypothesis 3.....	26
Hypothesis 4.....	27
II. METHOD.....	28
Participants.....	28
Recruitment.....	28
Study Sample Characteristics.....	29
Measures.....	30
Background Characteristics.....	30
Cultural Identity.....	31
Health System Barriers.....	31
Alzheimer’s Disease Factual Knowledge.....	33
American Indian/Alaska Native Cultural Beliefs of Alzheimer’s Disease.....	33
Health Belief Model Variables.....	34
Help-Seeking Intentions for Alzheimer’s Disease.....	34
Procedure.....	35
Data Analysis.....	36
III. RESULTS.....	38
Preliminary Analysis.....	38
Descriptive Statistics and Bivariate Correlations.....	38
Hypothesis 1: Predicting Informal Help-Seeking Intentions.....	43
Hypothesis 2: Predicting Intentions to Seek Help from Biomedical Sources.....	45
Hypothesis 3: Predicting Intentions to Seek Help from Traditional Sources.....	47
Hypothesis 4: Moderation Analysis.....	48

IV. DISCUSSION.....	52
Limitations and Considerations.....	56
Clinical Implications and Future Directions.....	58
REFERENCES.....	60
APPENDICIES.....	73

## LIST OF TABLES

Table 1: Demographic Characteristics.....	30
Table 2: Descriptive Statistics of Predictor Measures.....	39
Table 3: Descriptive Statistics of the Help-Seeking Intention Questionnaire.....	40
Table 4. Bivariate Correlations Between Measures.....	42
Table 5. Hierarchical Regression Analysis for Prediction of Informal Help-Seeking Intentions.....	44
Table 6. Hierarchical Regression Analysis for Prediction of Biomedical Help-Seeking Intentions.....	46
Table 7. Hierarchical Regression Analysis for Prediction of Traditional Help-Seeking Intentions.....	48
Table 8. Regression Analysis of Moderator Effects on Alzheimer’s Disease Knowledge Scores.....	49
Table 9. Regression Analysis of Moderator Effects on Cultural Beliefs of Alzheimer’s Disease Scores .....	50
Table 10. Regression Analysis of Moderator Effects on Health Barriers Scores.....	51



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## ABSTRACT

Guided by the Sociocultural Health Belief Model (SHBM) of dementia care-seeking, this study aimed to evaluate the role of several factors, including health system barriers, cultural beliefs and knowledge of Alzheimer's disease, in predicting help-seeking intentions for early symptoms of Alzheimer's disease among American Indians/Alaska Natives (AI/ANs). Participant recruitment and study procedures took place online. Participants completed a series of online surveys designed to assess predictor variables from the proposed model and help-seeking intentions from several care sources (i.e., informal, traditional, and biomedical). A total of 118 participants were included in the final sample. Three-step hierarchical regressions were conducted to evaluate the ability of the proposed model to predict help-seeking intentions for each type of care source. Results found the proposed model was significant in predicting help-seeking intentions for biomedical sources, but for predicting help-seeking intentions from informal or traditional sources. Alzheimer's disease factual knowledge was found to be a significant predictor in biomedical help-seeking intentions. Results from this study contributed to our knowledge of how Alzheimer's disease is understood by AI/ANs and may be useful for guiding future research and interventions related to timely recognition and care of Alzheimer's disease in AI/ANs communities.

*Keywords:* American Indians/Alaska Natives, Alzheimer's disease, help-seeking intentions, Sociocultural Health Belief Model

## **CHAPTER I**

### **BACKGROUND AND REVIEW**

Dementia refers to a group of neurocognitive disorders characterized by decline in cognitive functioning across multiple domains, including memory, language, complex attention, perceptual motor, and executive functions. The term dementia falls under the category of Neurocognitive Disorders (NCD) in the DSM-V. There are numerous etiological subtypes of NCDs, the most common of which is Alzheimer's disease (60% to 90% of cases), followed by vascular disease. Other etiological subtypes include Lewy body disease, frontotemporal lobar degeneration, Parkinson's disease, Huntington's disease, substance/medication use, and NCD due to mixed pathologies. Associated symptoms vary by etiological subtype. Generally, mild stages of NCD are associated with modest cognitive decline in one or more domains with relatively preserved independence in performing instrumental activities of daily living (IADLs), although individuals may require greater effort or assistance to maintain independence and safety. Decline in cognition and functioning in earlier stages is often subtle and may be difficult to detect. As the disease progresses, more substantial cognitive decline across multiple domains is observed along with reduced capacity to perform IADLs independently. Changes in mood, personality, and behavior may also occur (Alzheimer's Association, 2020; American Psychiatric Association [APA], 2013).

## **Alzheimer's Disease**

Alzheimer's disease (AD) results from abnormal changes in the brain, including accumulation of beta-amyloid plaques and tau tangles, which contribute to neurodegeneration and brain atrophy. Other changes include inflammation and reduced glucose metabolism in the brain. Previous research has indicated changes in the brain related to AD may begin several years prior to symptom onset (about 22 years for beta-amyloid accumulation and 18 years for decreased glucose metabolism; Gordon et al., 2018).

The typical course of AD includes an insidious onset with gradual progression of cognitive decline and functioning. Symptom presentation typically follows an amnesic pattern (i.e., decline in learning and memory). Other symptoms may include deficits in executive functioning and social cognition. As symptoms progress, deficits in visuospatial/perceptual ability, and language may also present. Psychological and behavioral disturbances may also occur, including depression and/or apathy in the earlier stages, with irritability, agitation, combativeness, psychotic features, and wandering commonly presenting in moderate to severe stages. (APA, 2013). As AD related cognitive decline continues to progress, symptoms begin in to interfere with independent functioning in daily life (Alzheimer's Association, 2020).

One of the earliest warning signs of AD may be subjective cognitive decline. Subjective cognitive decline has been defined as self-perceived decline in memory or increased confusion with the previous 12 months (C. Taylor et al., 2018). These worsening cognitive difficulties may not be observed by others or present on objective testing. Not all individuals who experience subjective cognitive decline develop mild cognitive impairment (MCI) or AD, however, a higher risk for developing AD in those with subjective cognitive decline has been indicated (Reisberg et al., 2010; Wolfsgruber et al., 2016). About 11% of individuals age 45 years and older experience

subjective cognitive decline (Alzheimer's Association, 2020). Of those, only about 45% report consulting with a health care professional about their memory and cognitive concerns (Alzheimer's Association, 2020; Center for Disease Control and Prevention [CDC], 2018b). Among AI/ANs, one in six aged 45 years and older reported experiencing symptoms of subjective cognitive decline between 2015 to 2017. Of those reporting subjective cognitive decline, about two-thirds indicated their symptoms have interfered with their functioning in daily life (CDC, 2018a).

### **Alzheimer's Disease Risk Factors**

Age is the greatest risk factor for late onset AD with most individuals diagnosed at age 65 or older. The percentage of people diagnosed with AD increases with age (3% between 65 and 74, 17% between 75 and 84, and 32% age 85 or older; Herbert et al., 2013). Other risk factors for dementia include genetic variables (e.g., apolipoprotein-e4 gene) and family history of AD. Modifiable risk factors for AD include cardiovascular disease, including hypertension, diabetes mellitus, and heart disease. Lifestyle factors associated with increased risk for cardiovascular disease such as smoking, chronic high alcohol consumption, lack of regular physical activity, and poor nutrition, may also increase risk of AD (Alzheimer's Association, 2020; APA, 2013). In addition to age, fewer years of formal education and lower SES have been linked to increased risk for AD and are associated with increased risk of cardiovascular risk disease, increased likelihood of experiencing poor nutrition, and reduced access to affordable health care (Alzheimer's Association, 2020; McDowell et al., 2007).

### **Diagnosis and Treatment of Alzheimer's Disease**

AD is diagnosed based on symptom presentation, family history of AD, and rule out of other potential causes of cognitive decline. Symptoms may be evaluated based on observation,

individual and collateral reports, and objective testing. Family history of AD and genetic testing may assist in revealing those at greater risk for developing AD. Assessment and testing for other potential causes of cognitive and functional decline are also utilized. This may include neurological exams, brain imaging, or blood and urine analyses. Use of brain positron emission tomography (PET) scans and tests of cerebrospinal fluid to evaluate the presences of beta-amyloid levels have also been utilized in some cases to assist in differential diagnosis (Johnson et al., 2013; Shaw et al., 2018).

Currently, there is no treatment that will slow or stop the progression of damage to neurons that causes AD. Pharmacologic treatments may temporarily improve cognitive symptoms for some individuals. Pharmacologic treatments may also be utilized to manage other associated symptoms of AD such as depression or behavioral disturbances. Other interventions are generally utilized to help maintain or improve existing functioning (e.g., compensatory strategies), ability to perform IADLs, and overall quality of life as well as provide support for family, friends, and caregivers. Services may include support groups, information and referral programs, adult day care, in-home respite, and long-term care facilities (Alzheimer's Association, 2020).

AD care practice guidelines emphasize the importance of early detection in the diagnosis and treatment of AD (Alzheimer's Association, 2020). Early evaluation of symptoms of cognitive decline allows assessment for other potential causes that may be reversible such as depression, medication side effects, thyroid problems, certain vitamin deficiencies, and excessive alcohol use (Alzheimer's Association, 2020). Early diagnosis allows patients and family members time to develop an understanding of the nature of AD and symptoms that can be expected to occur in the future. It allows the patient to be involved in making decisions about

future care and treatment, and address financial and legal considerations while still competent to do so. Referral information for support groups and other community resources may be provided to assist patients and their family in managing AD symptoms and address caregiving issues. Furthermore, interventions implemented at earlier stages of the disease process generally provide greater opportunity to maximize functioning and assist in preserving independence longer (Alzheimer's Association, 2020). Despite these benefits, research suggests that minority ethnic groups tend to present for initial evaluation of symptoms of AD at later stages of the disease process than Non-Hispanic Whites (Cooper et al., 2010).

### **Alzheimer's Disease Among Racial/Ethnic Minority Populations**

Prevalence estimates suggest AD and related dementia may be more prevalent among some ethnic minority groups including African Americans and Hispanic/Latinos, although this may vary across specific subgroups and geographic location (Alzheimer's Association, 2020; Gurland et al., 1999; Mehta & Yeo, 2017; Rajan et al., 2019). Some research has suggested genetic risk factors for AD and other dementias may differ across racial/ethnic groups, which may influence the differences in prevalence estimates across racial/ethnic groups. However, research has found that differences in prevalence estimates diminishes when AD risk factors are taken into account, and it may be this, rather than genetic factors that account for much of the difference in prevalence estimates across racial/ethnic groups (Alzheimer's Association, 2020; Kumar et al, 2017; Mayeda et al., 2016; Mehta & Yeo, 2017; Yaffe et al, 2013). Socioeconomic risk factors such as lower educational attainment, lower quality of education, and poverty are more prevalent among minority ethnic communities. Increased risk of cardiovascular disease and diabetes have also been associated with increased prevalence rates of AD and related dementia

among African Americans and Hispanic/Latino (Alzheimer's Association, 2020; Chin et al., 2011; Lines et al., 2014; Mehta & Yeo, 2017).

Despite higher prevalence estimates among some racial/ethnic minority groups, missed or delayed diagnosis is more likely among these groups (Alzheimer's Association, 2020; Cooper et al., 2010). There are several factors that have been identified in previous research as possible contributors to missed or delayed diagnosis of AD and related dementias among racial/ethnic minority groups. Factors impacting access to health services has been identified as one such contributor. Availability and cost of health care services may be barriers to accessing services for some minority communities in which poverty and limited public health resources are challenges (Bradford et al., 2010; Daker et al., 2002; Department of Health & Human Services, 2016; Stein et al., 2007; Werner, 2004). Additionally, lack of culturally appropriate assessment instruments may also contribute to misdiagnosis of AD and related dementias in minority populations. Many assessment tools for evaluating cognitive functioning have been developed and normed with non-Hispanic Whites, creating challenges for interpreting test results in individuals outside of this population (Verney et al., 2019).

Lack of awareness and knowledge of AD and care services has been associated with delays in seeking help for some minority populations (Daker et al., 2002; Kenning et al., 2017; Roberts et al., 2003). In one study evaluating differences in perceptions of AD between African Americans and Whites, researchers found African Americans to have less awareness of AD with fewer sources of AD information. They were also found to be less likely to perceive AD as a threat and more likely to consider AD to be a normal part of aging (Roberts et al., 2003). In another study higher levels of AD factual knowledge were also found to be associated with increased perceived threat and concern for risk of AD among a sample of older Chinese



Americans (Sun et al., 2013). Cultural beliefs about AD and related dementias, particularly those that attribute AD to normal aging, have also been associated with delays in seeking help for AD among racial/ethnic minority groups (Alzheimer's Association & CDC; Roberts et al., 2003; Sayegh & Knight, 2013). Given the benefits of early detection and intervention for AD and related dementias, it is important to understand the factors contributing to delayed and missed diagnosis for specific racial/ethnic minority populations.

### **American Indian/Alaska Natives and Alzheimer's Disease**

Approximately 5.2 million people in the United States (1.7% of the U.S. population) identified as American Indian or Alaskan Native (AI/AN) alone or in combination with another race per the U.S. 2010 Decennial Census. About 2.9 million identified as AI/AN alone, which is about 0.9% of the U.S. population (U.S. Census Bureau, 2012). This represents an increase of approximately 39% in the number of people in the U.S. identifying as AI/AN since the 2000 census (U.S. Census Bureau, 2012). There are 573 federally recognized AI/AN tribes and villages in the United States. There are also a number of other tribes that are recognized by states only or are in the process of seeking federal recognition. While about 60% of the AI/AN population (56% of AI/ANs aged 50 and older) live in urban areas, they are more likely than the rest of the population to live in rural areas. Only about 20% of the AI/AN population reside in AI/AN communities (U.S. Census Bureau, 2012).

To the best of this author's knowledge, no national prevalence data estimates of AD among AI/ANs currently exists. Several studies evaluating dementia rates among specific groups of AI/ANs are mixed. Some earlier studies indicate lower prevalence rates compared to other ethnic groups; however, more recent studies suggested AD and related dementias may be more prevalent (Hendrie et al., 1993; Jervis & Manson, 2002; Mayeda et al., 2016; Warren et al.,

2015). In one study examining dementia incidence rates among several different racial and ethnic groups from 14 years of data from a large Northern California health plan, the incidence of dementia among AIs was higher than that of non-Hispanic whites. Based on this study, it was estimated that, over the next 25 years, one in three AI adults over the age of 64 would be diagnosed with dementia (Alzheimer's Association & CDC, 2019; Mayeda et al., 2016). Results from another study evaluating the prevalence rates of physician-treated dementia among First Nation's people in Canada, indicated AD and related dementia rates increased at a faster rate than non-First Nations people from 1998 to 2009. This study also suggested that age of onset was approximately 10 years younger among First Nations people and found a higher prevalence rate in men compared with women (Jacklin et al., 2013). High prevalence rates of AD and related dementia risk factors in AI/AN populations (e.g., diabetes, heart disease, obesity, smoking, etc.) would suggest the rate of dementia would be similar to or higher than other ethnic groups with lower risk factor prevalence (Alzheimer's Association & CDC, 2019).

Differences in prevalence estimates across studies may be related to missed or delayed diagnosis of AD and related dementias in AI/AN populations (Alzheimer's Association & CDC, 2019; Jervis & Manson, 2002). Many individuals who meet criteria for Alzheimer's disease and other related dementias are not diagnosed by a physician. Per the CDC (2018a), of AI/ANs aged 65 years and older with reported memory loss, about 31% have reported discussing their memory concerns with their healthcare provider. Geographical, economic, and cultural barriers may also contribute to delayed or missed diagnosis of AD in AI/ANs. Older AI/ANs have greater difficulties accessing healthcare services than non-AI/ANs. Limited availability of healthcare services, particularly specialized care, transportation issues, and affordability of healthcare services have been noted as contributing factors in AI/ANs difficulties accessing care (Boccuti et

al., 2014). AI/ANs residing in urban areas may also have limited access to culturally- relevant health services and supports (Alzheimer's Association & CDC, 2019).

Mistrust of the western biomedical health care system related to historical abuses against AI/AN people may also present as a barrier to accessing care. Perceptions and experiences with the western biomedical health care system may influence utilization of these health care services. In one study evaluating racial and cultural minority health care experiences, AI/ANs, were found to report experiencing racism and discrimination in health care settings, and poor treatment from health care providers. These experiences were associated with greater fear and apprehension of future health care utilization (Shepherd et al., 2018).

Limited awareness and knowledge of dementia within AI/AN communities and their health care providers may also contribute to delayed and missed diagnosis of AD and related dementias in AI/AN communities (Alzheimer's Association & CDC, 2019). Cultural understandings and beliefs regarding aging may result in misattribution of cognitive decline as a normal part of the aging process, inhibiting help seeking for cognitive decline (Griffin-Pierce et al., 2008; Jervis & Manson, 2002; Garrett et al., 2015; Mayeda et al., 2016). Cultural values about older adults and stigma of AD and related dementia may also present as barriers to seeking care among AI/ANs (Alzheimer's Association & CDC, 2019).

The proportion of older AI/AN adults in the US is expected to increase within the next 20 years (Vincent & Velkoff, 2010). With this increase in life expectancy, the number of AI/ANs with AD and related dementias is also expected to grow (Matthews et al., 2019) and become an increasing problem impacting AI/AN communities. If AD and related dementias are underdiagnosed in AI/AN populations, it may be important to understand the factors contributing to delayed recognition and care seeking for dementia.

## **Help-Seeking Intention**

Help-seeking intention refers to an individual's intent to engage in an action that is perceived to address a problem or reduce distress. This may include actions taken to gain understanding, advice, information, treatment, or support for a particular problem (Rickwood et al., 2005; Wilson et al., 2005). The source of help an individual chooses to pursue may vary as a function of their level of distress, beliefs, and attributions about the cause of their distress, as well as their perceptions about the benefits of seeking help (Rickwood et al., 2005). Sources of help may include informal sources (e.g., family member, friend), professional biomedical sources (e.g., doctor, mental health provider), or culturally bound sources of help such as traditional healers (Begum et al., 2012; Sayegh & Knight, 2012; Wills & DePaulo, 1991; Wilson et al., 2005). Evaluation of help-seeking intention is often used in help-seeking research and has been demonstrated to be a strong predictor of help-seeking behaviors (Ajzen, 1991; Armitage & Connor, 2003; Sutton, 1998; Wilson et al., 2005).

There have been numerous models developed for the purpose of describing and predicting health-related behaviors. The majority of models broadly propose that health behavior is a complex process involving social, cultural, individual, and health services factors (Begum et al., 2012; Kleinman et al., 1978). One model often used in research is The Health Belief Model (HBM). The HBM was initially developed to help understand underutilization of preventative health services (Becker & Maiman, 1975; Rosenstock et al., 1988). It has since been adapted to evaluate other health-related behaviors. The HBM proposes that several factors influence an individual's decision to engage in a health-related action or initiate health services. These include perceptions of one's self as vulnerable or susceptible to a particular health problem and beliefs that that health problem is likely to have serious consequences on the individual's life (together

termed “perceived threat”). Expectations about the outcome of engaging in a health behavior, including the perceived benefits and costs of the behavior, are also an important factor (Rosenstock et al., 1988).

Several criticisms of the HBM have been noted by researchers. The HBM does not specify the relationship or structure between its components or how they may interact to influence health behaviors (Johns et al., 2015). It does not account for individual determinants that may impact health behavior. These include health beliefs and attitudes, ability to access health care services, and degree of understanding and knowledge of the symptoms and treatment of a particular health problem (D. Taylor et al., 2006). Social and cultural factors that may influence an individual’s engagement in a particular health behavior are also not addressed by the HBM (Sayegh & Knight, 2013).

#### **A Model for Evaluating Help-Seeking Intentions for Alzheimer’s Disease**

The Sociocultural Health Belief Model (SHBM) was developed to expand on the HBM by accounting for the effects of social and cultural variables on health-related behaviors within the context of dementia help-seeking. These cultural variables include family-centered cultural values, cultural identity and level of acculturation, culturally associated beliefs of dementia, and knowledge about dementia. The SHBM model proposes that the decision to seek care or help for symptoms of AD or other dementia is directly influenced by views of oneself as susceptible to dementia, belief that dementia may have potentially serious consequences to the individual’s life, belief that seeking care may reduce the severity or their susceptibility of dementia, and anticipation of few negative attributes of seeking care. These perceptions are suggested to be influenced by cultural beliefs and factual knowledge about dementia. Cultural beliefs and

knowledge of dementia is then proposed to be influenced by family-centered values and level of acculturation (Sayegh & Knight, 2013).

### **American Indian/Alaska Native Cultural Considerations**

Cultural values and the beliefs individuals hold about a disorder can shape the way the disorder is conceptualized and the personal and social meanings they attach to the disorder. These beliefs may include explanations about the cause of the disorder, expectations about the disease course and symptoms, and the level and type of help to seek (Dilworth-Anderson et al., 2002; Sayegh & Knight, 2013). Several researchers have evaluated the cultural values and beliefs associated with aging and dementia among AI/ANs. These studies have primarily been qualitative in nature utilizing semi-structured interviews and focus groups or talking circles with AI/ANs from a specific tribe to identify cultural themes related to dementia. These studies suggest, AI/ANs are more likely to conceptualize AD-related memory loss differently from the western biomedical model of AD. Although AI/ANs are a heterogenous group and cultural beliefs, norms, values, and practices vary across tribes, several common, broad themes have been identified across studies. These themes include: (1) views of dementia as a normal part of the aging process, (2) dementia symptoms resulting from changes in culture and loss of traditional values and way of life, and (3) attribution of dementia symptoms to spiritual and religious constructs (Griffin-Pierce et al., 2008; Henderson & Henderson, 2002; Hulko et al., 2010; Jacklin & Walker, 2019; Lanting & Crossley, 2011; O'Connor et al., 2010; Garrett et al., 2015). Although these themes are related to important cultural values among AI/AN communities, they may lead to delays or avoidance of seeking help for AD-related symptoms (Alzheimer's Association & CDC, 2019).

There are several other AI/AN cultural values and beliefs that may impact help-seeking for symptoms of memory loss. AI/AN older adults are often respected and honored for their wisdom, knowledge, and spiritual leadership. In general, AI/AN communities traditionally value family caregiving of the elderly and emphasize respect and honor of older adults for their wisdom and spiritual leadership (Alzheimer's Association & CDC, 2019). These values may contribute to reluctance of family members to express concerns about symptoms of cognitive decline or seek outside care and support (Griffin-Pierce et al., 2008; Lanting & Crossley, 2011).

### **Role of Alzheimer's Disease Knowledge**

Accurate scientific knowledge and understanding of AD and related dementia including the cause, risk factors, symptoms, and course, as well as diagnostic and treatment services, impacts decisions to seek evaluation or treatment (Kenning et al., 2017; Morhardt et al., 2010). Research has found that knowledge about the symptoms of AD and related dementia accounts for a greater amount of variance in help-seeking intentions (Devoy & Simpson, 2017). Several studies have found higher knowledge of AD symptoms and treatment to be associated with increased screening for AD and related dementias and intentions to seek help from professional sources (Galvin et al., 2008; Helmes et al., 2010; Werner, 2003a). Inaccurate illness representations or misattribution of AD-related symptoms has also been suggested to prevent help-seeking for symptoms of AD and related dementia (Hamilton-West et al., 2010; Muckadam et al., 2011). Greater knowledge of AD has also been found to be associated with increased perceptions that AD symptoms are severe and are likely to have more serious consequences for the individual (Begum et al., 2012; Hamilton-West et al., 2010).

Individuals who have had less exposure to information about AD and related dementia are more likely to rely on alternative explanations for the meaning of the illness, including

culturally based ideas and beliefs, which may contribute to delays in care seeking (Dilworth-Anderson et al., 2002). Results from previous research suggest that the conceptualization of memory loss as part of the normal aging process may be one of the most important barriers to the recognition of dementia as a neurological disorder and seeking care (Botsford et al., 2011; Mukadam et al., 2011; Bradford et al., 2010). Beliefs of AD and related dementia as resulting from psychological, environmental, social, or spiritual causes or misattributing symptoms of dementia to another illness (e.g., diabetes) may also pose a barrier to seeking care or treatment for the memory loss and cognitive impairment resulting from the disease (Kenning et al., 2017; Mukadam et al., 2011). Alzheimer's disease in AI/ANs has been described as a serious concern among AI/AN communities, however, concerns about limited knowledge of AD and related dementia and lack of awareness among tribal members and AI/AN community providers has been reported (Alzheimer's Association & CDC, 2019). While limited factual knowledge or awareness of AD and related dementia is present across many communities throughout the U.S., it may be more prevalent in AI/AN communities in which AD outreach and education interventions have been limited (Alzheimer's Association & CDC, 2019).

### **Other Modifying Variables**

Healthcare system barriers are also likely to impact decisions to obtain evaluation and treatment for AD and related dementia. These include negative past experiences or anticipation of negative experiences with the health care system, including discrimination or racism and lack of culturally appropriate services. Mistrust of research and biomedicine, related to historical abuses and trauma, has also been suggested as barriers to health care for AI/ANs. Additionally, lack of available services and difficulties accessing services (e.g., lack of transportation or cost of services) have been shown in previous research to predict greater illness and lower health



services use (Stein et al., 2007; Werner, 2003b) and impede timely evaluation and treatment of AD and related dementia (Bradford et al., 2010; Department of Health & Human Services, 2016; Garrett et al., 2015; Griffin-Pierce et al., 2008; Mukadam et al., 2010). Lower educational attainment, lower SES, and rural residential status likely contribute to accessibility issues (Department of Health & Human Services, 2016; Bradford et al., 2010; Mukadam et al., 2010).

Age and gender have also been identified as other possible modifying variables in previous research as potentially impacting AD and related dementia help-seeking. Older age has been associated with greater fear of AD or dementia diagnosis (Brunet et al., 2012). While older age is associated with greater willingness to seek professional help in general (Begum et al., 2012), greater perceptions of AD as having serious personal consequences (e.g., decline in status, job loss, changes in social relationships), may be associated with reduced likelihood of seeking help (Alzheimer's Association, 2020; Brunet et al., 2012). Female gender has been associated with more reported worry about developing AD or related dementia. Female gender may also be associated with greater likelihood of seeking help for symptoms of memory loss (Tang et al., 2018).

### **Purpose of the Study**

A review of the literature suggested a need to examine factors that may impact intentions to seek help for early symptoms of AD to help facilitate early diagnosis and intervention among AI/ANs. To advance knowledge in this field, this study, guided by the SHBM (Sayegh & Knight, 2013) and previous research, focused on the relationship between age, gender, AI/AN cultural identity, health system barriers (negative perceptions and experiences of the health care system and barriers accessing health care), AI/AN cultural beliefs about AD-related memory loss, factual knowledge of AD, perceived threat of AD, and perceived benefits and barriers of seeking

help for AD on help-seeking intentions. AD help-seeking was evaluated in terms of intent to seek help for mild symptoms of AD described in a vignette from informal sources (e.g., family, friends), biomedical sources (e.g., doctor/physician, mental health provider), and AI/AN traditional help sources (e.g., medicine person, traditional healer).

Based on the SHBM, the model for the present study proposed that cultural beliefs of AD, AD factual knowledge, and health system barriers would predict perceived threat and perceived benefits minus barriers of seeking help, and thereafter, intentions toward seeking help. Age, gender, and residential status were evaluated as distal determinants of help-seeking intentions within the proposed model. The degree to which an individual identifies with AI/AN culture was proposed as indirectly influencing perceived threat and benefits/barriers to seeking help for AD through its effect on health system barriers, cultural beliefs, and knowledge of AD. However, as noted previously, limited AD knowledge and awareness is not uncommon among other non-AI/AN communities in the U.S., particularly those in more rural areas (Alzheimer's Association & CDC, 2019). Given that AI/ANs live in more rural areas compared with the rest of the U.S. population and that many tribal communities are located within rural areas (U.S. Census Bureau, 2012) it is possible that rural residential status may also contribute to limited AD knowledge and awareness and subsequently higher levels of cultural beliefs of AD. Similarly, while AI/ANs experience disproportionately higher rates of health disparities and barriers accessing health care (Adakai et al., 2018; Monique et al., 2018), those residing in more rural areas also experience greater barriers accessing care. Since it was unclear how AI/AN cultural identity may influence cultural beliefs and knowledge of AD, another goal of this study was to explore the relationship between AI/AN cultural identity and residential status on AI/AN cultural

beliefs of AD, knowledge of AD, and barriers accessing health care. To evaluate the proposed model, the following hypotheses were tested.

### **Hypotheses**

**Hypothesis 1.** Intentions to seek help from informal sources would be predicted by: (a) greater age, female gender, rural residential status, and higher AI/AN cultural identity; (b) greater factual knowledge of AD, higher endorsement of AI/AN cultural beliefs about AD, and greater health care system barriers, after controlling for age, gender, and AI/AN cultural identity; and (c) greater perceived threat of AD and higher perceived barriers of seeking help after controlling for all previous variables.

**Hypothesis 2.** Intentions to seek help from biomedical sources would be predicted by (a) greater age, female gender, urban residential status, and lower AI/AN cultural identity; (b) greater factual knowledge of AD, lower endorsement of AI/AN cultural beliefs about AD, and fewer health system barriers, after controlling for age, gender, and AI/AN cultural identity; and (c) greater perceived threat of AD and higher perceived benefits of seeking help after controlling for all previous variables.

**Hypothesis 3.** Intentions to seek help from traditional sources would be predicted by (a) greater age, female gender, rural residential status, and higher AI/AN cultural identity; (b) lower factual knowledge of AD, higher endorsement of AI/AN cultural beliefs about AD, and greater health system barriers, when controlling for age, gender, and AI/AN cultural identity; and (c) higher perceived threat of AD, and higher perceived barriers of seeking help after controlling for all previous variables.

**Hypothesis 4:** Residential status would moderate the relationship between AI/AN cultural identity and (a) AD factual knowledge scores; (b) endorsement of AI/AN cultural beliefs of AD; and (c) barriers accessing health care.

## CHAPTER II

### METHOD

#### Participants

##### Recruitment

An a priori power analysis was conducted using G\*Power 3.1.9.2 software to estimate the number of subjects required to achieve a power of .80. The predictor variables were anticipated to account for a medium effect size (Cohen's  $f^2 = .15$ ). The analysis indicated that a sample size of 114 would be adequate to achieve a projected power level of .80 (Faul et al., 2009).

Participants were initially proposed to be recruited from multiple tribal communities in Minnesota with study procedures occurring in person. However, as a result of the COVID-19 pandemic, the study was transferred to an online survey platform in accordance with safety guidelines promoting social distancing. The surveys for this study were generated using the Qualtrics online survey platform (Qualtrics, Provo, UT). Participants were recruited through the Amazon Mechanical Turk (MTurk; Amazon Mechanical Turk, Inc., 2005) system. Individuals, called workers, within the MTurk program are able to review a listing of opportunities, called Human Intelligence Tasks (HITs). HITs for the present study contained a link to the Qualtrics Survey and requested potential subjects complete a series of surveys about care seeking for health concerns with the following keywords: *survey, demographics, health, culture, Native American Indian*. Access to HITs was limited to individuals registered with MTurk in the United States, those with a 90% or greater approval rating on prior HITs, and not those who had not previously been assigned a qualification code by the researchers indicating they had already

taken the survey once. IP blocking through Qualtrics was also utilized to prevent subjects from taking the survey more than once. Participants were given two hours to complete all surveys.

Participants aged 45 years and older and who identify as American Indian/Alaskan Native, alone or in combination with one or more other race or ethnicity, or as having American Indian/Alaskan Native ancestry were included in this study. Participants were excluded if they did not meet inclusion criteria or provide their tribal affiliation. Participants were compensated \$3.20. Those who were excluded from the study following completion of the demographic survey were compensated \$0.20.

### **Study Sample Characteristics**

A total of 1,833 MTurk workers responded to the HITs published for this study. Of those, 253, met initial screening criteria (i.e., age 45 years or older, identified as American Indian/Alaskan Native or as having AI/AN ancestry, and responded to the tribal affiliation question) and were routed to the remaining surveys. About half ( $n = 128$ ; 50.6%) of completed surveys were considered invalid and excluded from the study for failing to provide a recognized tribal affiliation. Examples of excluded tribal affiliation responses included: (a) providing a description or definition of the term “tribal affiliation,” (b) identifying their tribal affiliation as “American Indian” or similar, (c) identifying another race/ethnic background as their tribal affiliation (e.g., “Asian American,” “Black,” “White”), (d) and other inapplicable responses (e.g., “Christian,” “USA,” “no,” “good,” “5,” etc.). An additional seven participants who met qualification requirements were excluded for not completing the remaining surveys. The final sample included for analyses consisted of 118 participants. Demographic characteristics of the sample are presented in Table 1.

**Table 1***Sample Demographic Characteristics*

Variable	<i>n</i>	Mean ( <i>SD</i> ) or %
Age	118	51.1 (6.2)
45 to 49	60	50.8%
50 to 54	30	25.4%
55 to 59	15	12.7%
60 to 64	8	6.8%
65 and older	5	4.2%
Gender		
Male	71	60.2%
Female	47	39.8%
Race/Ethnicity		
AI/AN only	50	42.4%
AI/AN and 1 or more other race/ethnicity	26	22.0%
AI/AN ancestry	42	35.6%
Tribal Affiliation		
Northwest	11	9.3%
Southwest	10	8.5%
California/Pacific	7	5.9%
Northern Plains	21	17.8%
Southern Plains	10	8.5%
North Eastern	13	11.0%
South Eastern	37	31.4%
Alaska	9	7.6%
Residential Status		
Reservation or tribal community	16	13.6%
Rural area	40	33.9%
Urban area	62	52.5%

**Measures****Background Characteristics**

Background characteristics that were gathered included, age, gender, race/ethnicity, and tribal affiliation. Information regarding residential status was also gathered, although the question pertaining to this was included in the cultural identity questionnaire.

## **Cultural Identity**

The cultural identity questionnaire consisted of nine items designed to measure perceptions and behaviors of AI/AN cultural identity. Three items were adapted from a ‘cultural strength’ composite measure used in Shepherd and Colleagues (2018) study (“Are you proud of your cultural heritage?,” “Do you feel connected to your culture?,” and “How important is your culture to your everyday life.?”). Participants were asked to respond to these items in terms of their AI/AN identity. Questions were rated on a 5-point scale (1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = strongly agree).

Six items were developed from previous studies measuring cultural identity among AI/ANs and were designed to measure frequency of behavioral expressions of AI/AN identity. These questions were developed from previous studies involving evaluation of cultural identity among AI/ANs (Berry, 1999; Garrett & Pichette, 2000; Reynolds et al., 2011; Whitebeck, 2004; Winderowd et al., 2008). Questions were rated on a 5-point scale (1 = never, 2 = rarely, 3 = occasionally, 4 = often, and 5 = very often) and included asking participants how often they attend traditional activities and ceremonies, use of tribal language, social interactions with AI/AN relatives and friends, and residential status. Raw scores may range from 9 to 45 with higher scores reflecting higher levels AI/AN cultural identity. Internal reliability of the cultural identity questionnaire in this sample was  $\alpha = .88$ . The full list of items is presented in Appendix A.

## **Health System Barriers**

This questionnaire was divided into two parts measuring structural barriers to health care and health care expectations and experiences. The structural barriers to health care survey consisted of seven items evaluating how often participants have experienced problems accessing



health care services due to the following: lack of transportation, inability to find child care, not having health insurance or being unable to afford services, work or time constraints, needed health services are unavailable where they live, and difficulty navigating the health care system. Items are rated on a 4-point Likert scale (1 = never, 2 = sometimes, 3 = often, 4 = always). Higher scores indicated more barriers accessing health care services. The internal reliability of this subscale in this sample was  $\alpha = .86$  (see Appendix B).

Questions for the health care expectations and experiences questionnaire were developed from Shephard's and colleagues (2018) health experiences survey. Their survey consisted of 14-items designed to evaluate social, cultural, and health needs and expectations as health service users, experiences of discrimination in health care settings, and how well existing health services accommodate their needs (Shephard et al., 2018). Five items from this survey were adapted for use in this study. Since the purpose of the questionnaire for this study was to evaluate negative perceptions and experiences that may influence help-seeking intentions, only items pertaining to those topics were included. Two items measured perceptions of negative experiences (i.e., perceptions of having been poorly treated by health care providers because of the individual's cultural background, and perceptions that the individual's cultural beliefs or health practices were not respected). Three items evaluated fear and distrust of western health care services (i.e., fear of health care visits, distrust of the health care system, distrust of information from services providers). Participants were asked to answer questions regarding their experiences with western health care services only, not including traditional or cultural health practices. Each item was rated on a 5-point scale with 1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = strongly agree. Higher scores indicated more negative perceptions and experiences of western biomedical health care services. Higher scores reflected fewer negative health

experiences. The internal reliability of the health care expectations and experiences subscale in this sample was  $\alpha = .84$ . Participant scores on the two health system barriers subscales were combined to form a composite score for the main study analyses. The internal reliability of the health system barriers composite was  $\alpha = .89$  (see Appendix B).

### **Alzheimer's Disease Factual Knowledge**

Knowledge of AD was assessed by asking participants to identify accurate information about the symptoms, risk factors, and treatment for AD. The total scale contained 37 items with 12 items pertaining to symptoms of AD, 20 to risk factors for AD, and 4 to treatment and care for AD. Items were derived from previously validated AD knowledge questionnaires (Carpenter et al., 2009; Roberts & Connell, 2000). Response options included “agree,” “disagree,” and “unsure.” The number of correct responses was totaled. Scores may range from 0 to 37 with higher scores indicative of greater factual knowledge of AD. The internal reliability of the AD knowledge questionnaire in this sample was  $\alpha = .74$  (see Appendix C).

### **American Indian/Alaska Native Cultural Beliefs of Alzheimer's Disease**

Cultural beliefs of AD were measured by summing the scores on 10 items embedded within the knowledge of AD questionnaire. These items were developed from published literature evaluating explanatory models and beliefs regarding AD and related dementia in AI/AN groups. These beliefs generally attributed AD to normal aging, loss of culture, or other external causes. The 10 cultural beliefs items embedded within the AD knowledge questionnaire included attributions of AD to normal aging, part of the life cycle process, imbalance in spiritual, emotional, mental, or physical health, alcohol, unhealthy diet, pollution, gambling, side-effects or overuse of medications, loss of culture, not engaging in cultural practices, ceremonies, or traditions, and trauma. Response options were the same as the AD questionnaire (“agree,”

“disagree,” “unsure”). One point was awarded for each item endorsed with higher scores indicating greater endorsement of AI/AN cultural beliefs of AD. Internal reliability of the cultural belief scale in this study was  $\alpha = .69$ .

### **Health Belief Model Variables**

HBM variables included perceived threat of AD, and perceived benefits minus barriers to seeking help for AD. Items for these scales were drawn from scales used in previously published studies using the HBM to evaluate health behaviors pertaining to AD and other conditions (Boustaini et al., 2008; Connell et al., 2009; Roberts & Connell, 2000; Roberts et al., 2003; Werner, 2003b). Eleven items were developed to measure perceived threat of AD. These questions asked participants about their perceived susceptibility to AD and the impact they perceived developing AD would have on their life. These items were rated on a 5-point scale (1 = extremely disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, and 5 = extremely agree) with higher scores indicating greater perceived threat of AD. The internal reliability of the perceived threat questionnaire in this study was  $\alpha = .79$ .

The perceived benefits and barriers of seeking help for AD consisted of six items asking participants about their beliefs of the helpfulness and importance of seeking help for AD. Items were rated on the same 5-point scale as the perceived threat questions. Higher scores indicated greater perceived benefits to seeking help for AD while lower scores indicated greater perceived barriers to seeking help for AD. The internal reliability of this questionnaire in this sample was  $\alpha = .60$ . See Appendix D for a full list of the two HBM questionnaires items.

### **Help-Seeking Intentions for Alzheimer’s Disease**

The AD help-seeking intentions questionnaire used in this study was adapted from The General Help-Seeking Questionnaire (GHSQ; Wilson et al., 2005), which asked participants to

select how likely they would seek help for a given problem from several source options. The GHSQ was designed to allow for modification based on the purpose and need of sample characteristics and study requirements. The questionnaire developed for this study asked participants to read a vignette describing a person with early or mild symptoms of AD. The vignette was adapted from vignettes developed and used in previous research for use with members of the general public. A vignette describing mild AD was chosen given the focus of this study was on evaluating factors related to early recognition and help-seeking for AD (Oremus, Xie & Gaebel, 2016; Oremus, Xie, Pullenayegum et al., 2016). After reading the vignette participants were asked to indicate how likely they would be to seek care from 10 different sources using a 5-point scale (1 = extremely disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, and 5 = extremely agree). Sources included informal sources of help (i.e., intimate partner, parent, child or other relative, friend, and other religious or spiritual leader), biomedical sources of care (i.e., doctor/family physician and mental health provider,), and AI/AN traditional sources of care (i.e., traditional healer or medicine person and community elder, other religious leader). They were also asked if they would not seek help from anyone. Lastly, participants were asked to list what, if anything, they believed the person in the vignette may have been suffering from. Higher scores for each item indicated greater likelihood of seeking care from each source. Total scores were calculated for each of the three help source categories (i.e., informal, biomedical, and traditional). The internal reliability for the help-seeking intention questionnaire in this sample was  $\alpha = .75$  (see Appendix E).

### **Procedure**

Online surveys were administered through Qualtrics. Participants were recruited through the MTurk system which contained a link to the Qualtrics survey. After entering the Qualtrics

survey link, participants were presented with a cover letter consent form to review. They were provided contact information for the principle investigator, research advisor, and University of North Dakota (UND) Institutional Review Board (IRB) to contact should they have any questions about the study. They were then asked to select “I agree to participate” or “I do not agree to participate.” Those that consented to participate in the study were routed to the demographic form. After completing this form, those who qualified for the study were presented with the remaining surveys. The cultural identity survey was administered first, followed by the help-seeking intentions survey. The help-seeking intentions survey was administered prior to the remaining questionnaires to prevent participants from learning the study was investigating AD help-seeking prior to reading the vignette. The remaining surveys (health system barriers, AD knowledge, and HBM variable questionnaires) were presented in randomized order following the help-seeking intentions questionnaire to help control for order effects. With the exception of the demographic form, all other survey items were also presented in random order to control for order effects. All research procedures were approved by the UND IRB. Participants were compensated \$3.20. Those who were excluded from the study following completion of the demographic survey were compensated \$0.20.

### **Data Analysis**

Descriptive statistics were used to characterize the sample. Bivariate correlations were conducted to examine relationships among predictor variables. Three-step hierarchical multiple regression analyses were conducted to examine the extent to which background variables (age, gender, and residential status), cultural identity, health system barriers, AI/AN cultural beliefs of AD, factual knowledge of AD, perceived threat of AD, and perceived benefits minus barriers for seeking help collectively predict variation in help-seeking intentions. Three separate hierarchical

linear regression analyses were conducted to evaluate the predictive power of the set of variables in predicting intentions to seek help from informal, biomedical, and traditional sources of care. The predictor variables were entered into the analysis in accordance with the model discussed previously. Background variables and cultural identity were entered at stage one. Health system barriers, cultural beliefs of AD related memory loss, and factual AD knowledge, were entered at stage two. Perceived threat and perceived benefits minus barriers were entered at stage three. Three separate hierarchical regression analyses were conducted to evaluate the moderating effect of residential status on cultural identity in predicting AD factual knowledge, cultural beliefs, and barriers accessing health care. For each moderation analysis residential status and cultural identity were entered at step one. At step two, an interaction term for cultural identity and residential status was entered in the analysis. Pre-analysis and data-screening procedures were used to test for violation of multiple regression assumptions, multicollinearity, and outliers ( $\pm 3.00$  *SD* from mean). An  $\alpha$  level of .05 was maintained for all statistical analyses. SPSS (Version 26) was used to conduct all analyses for this study.

## **CHAPTER III**

### **RESULTS**

#### **Preliminary Analysis**

Preliminary analyses were conducted to ensure no violations of the assumptions for multiple regression. Predictor variables were evaluated for normality. Evaluation of the distribution of mean scores across all variables revealed skewness and kurtosis statistics less than  $\pm 1.00$ . Given this, data transformations were not considered necessary. Inspection of histogram and Q-Q plots of the studentized residuals indicated the assumption of normality was met for each of the four regression analyses. Linearity was indicated for all four analysis through inspection of partial regression plots and a plot of studentized residuals against the predicted values and partial regression plots. Visual inspection of plots of studentized residuals versus unstandardized predicted values were not suggestive of heteroscedasticity for the four analyses. Inspection of correlation coefficients did not reveal any correlations among predictor variables above a cutoff of  $r = .7$  (Tabachnick & Fidell, 2007), which was not suggestive of multicollinearity. Further analysis of tolerance values revealed no values below .10 providing further support that multicollinearity is not present. No outliers were identified (i.e., scores falling  $\pm 3.00$  *SD* from the mean).

#### **Descriptive Statistics and Bivariate Correlations**

Mean scores for the primary predictor measures are presented in Table 2. The mean score for the cultural identity total score fell about the mid-point. Scores on the cultural strength subscale of the cultural identity scale were above the mid-point falling between “agree” and

“strongly agree,” while scores on the external expressions subscale were below the mid-point falling between “rarely” and “occasionally.” On the health system barriers questionnaire, participants average endorsement on items evaluating barriers accessing health care fell between “sometimes” and “often.” The mean score on the health system experiences scale fell between “disagree” and “neither agree, nor disagree” indicating few negative experiences or perceptions of the western health system. Scores on the AD knowledge scale indicated participants answered about 51% of questions correctly. Participants endorsed on average 62% of items on the cultural beliefs questionnaire. Participants mean scores fell above the neutral midpoint on the perceived threat and the perceived benefits minus barriers questionnaires, each falling between “agree” and “neither disagree nor agree.”

**Table 2**

*Descriptive Statistics of Predictor Measures*

Measure	Scale	<i>M</i>	<i>SD</i>
Cultural Identity	1-5	3.1	0.8
Cultural Identity – Internal Perceptions	1-5	4.2	0.8
Cultural Identity – External Expressions	1-5	2.5	1.0
Health System Barriers - Access	1-4	2.1	0.7
Health System Barriers – Experiences	1-5	2.8	0.9
AD Factual Knowledge – Total Score	0-37	19.5	5.2
Cultural Beliefs - Total Endorsement	0-10	6.2	2.4
Perceived Threat	1-5	3.5	0.6
Perceived Benefits	1-5	3.5	0.6

Descriptive statistics for the help-seeking intentions questionnaire are presented in Table 3. On the help-seeking intentions questionnaire, participants endorsed they were most likely to seek help from biomedical sources, followed by informal sources, and traditional sources. Both informal and biomedical average scores were above the midpoint each falling between “likely” and “neither likely nor unlikely.” The mean traditional scores were below the midpoint, falling



between “neither likely nor unlikely” and “unlikely.” Among informal sources, seeking help from an intimate partner was rated the highest on average by participants. Among biomedical sources, seeking help from a doctor/family physician was rated higher on average than seeking help from a mental health provider. Traditional healer or medicine person was rated higher on average than community Elder.

**Table 3**

*Descriptive Statistics of the Help-Seeking Intentions Questionnaire*

Item	<i>M</i>	<i>SD</i>
Total	3.4	0.7
Informal	3.4	0.8
Intimate partner	4.0	1.2
Parent	3.2	1.4
Child or other family	3.4	1.3
Friend	3.5	1.5
Biomedical	3.6	1.1
Doctor/family physician	3.8	1.3
Mental health provider	3.4	1.3
Traditional	3.0	1.1
Traditional healer or medicine person	3.0	1.3
Community Elder	2.9	1.2

Bivariate correlations between primary variables are presented in Table 4. No significant correlations were found for age or gender between perceived threat of AD or help-seeking intentions scores, which is inconsistent with previous research. As anticipated, small to medium correlations were found between residential status and cultural identity and behavioral expressions of AI/AN cultural identity, indicating rural residential status was associated with higher AI/AN cultural identity scores. Residential status was also significantly correlated with scores on both health system barriers scales (access and experiences) as anticipated, indicating rural residential status was associated with higher endorsement of barriers accessing care and negative perceptions and experiences of the health system. In addition to residential status, a

medium correlation was found between cultural identity and both health system barriers scales, such that greater AN/AN identity was associated with higher endorsement of barriers accessing health care and negative perceptions and experiences of the health care system.

As anticipated, a small negative correlation was found between cultural belief and AD factual knowledge scores. AD factual knowledge scores were also positively correlated with both perceived threat and perceived benefits scores as hypothesized. A small positive correlation between cultural beliefs scores and perceived threat was observed, though not perceived benefits minus barriers of seeking help scores.

Regarding help-seeking intentions, small positive correlations were found for informal help-seeking intentions and cultural beliefs and perceived threat scores as hypothesized. Informal help-seeking intentions scores were not significantly correlated with health system barriers nor perceived benefits minus barriers as anticipated. As hypothesized a medium positive correlation was found between biomedical help-seeking intentions and AD factual knowledge scores. Biomedical help-seeking intentions were also significantly positively correlated with perceived threat of AD as expected, though not with perceived benefits minus barriers. Traditional help-seeking intentions scores were positively correlated with scores on the barriers accessing health care questionnaire, but not with scores on the perceptions and experiences of health system questionnaire. Traditional help-seeking intentions scores were also not correlated with cultural identity nor cultural beliefs scores as anticipated.

**Table 4***Bivariate Correlations Between Measures*

Measure	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1 Age	1.0														
2 Gender	.03	1.0													
3 Residential Status	-.05	-.08	1.0												
4 Cultural Identity	-.06	-.13	-.28**	1.0											
5 Internal	-.04	-.10	-.07	.66**	1.0										
6 External	-.05	-.12	-.31**	.95**	.41**	1.0									
7 HSB - Access	-.13	-.01	-.19*	.49**	.24*	.50**	1.0								
8 HSB - Exp	-.10	-.18	-.19*	.45**	.20*	.47**	.56**	1.0							
9 ADFK	-.06	-.07	-.09	-.09	-.21**	-.02	-.10	.11	1.0						
10 Cultural Beliefs	.07	-.04	-.13	.03	-.08	.07	-.01	-.11	-.22*	1.0					
11 HBM - Threat	-.08	-.56	-.15	-.02	-.07	.01	.01	-.06	.28**	.20*	1.0				
12 HBM - Benefits	-.04	-.03	-.13	.05	.07	.03	-.08	-.02	.24**	.14	.41**	1.0			
13 HSI - Informal	.01	.01	-.04	-.16	-.08	-.17	.09	-.05	.14	.18*	.22*	.17	1.0		
14 HSI - Biomedical	-.01	.07	.10	-.08	-.05	-.08	-.08	.15	.30**	.16	.29*	.09	.51**	1.0	
15 HSI - Traditional	-.05	.03	.03	.06	.02	.06	.19*	.04	-.12	-.08	-.04	.03	.41*	.09	1.0

*Note.*  $N = 118$ . \* $p < .01$ , \*\* $p < .001$  (2-tailed)

## Hypothesis 1: Predicting Informal Help-Seeking Intentions

Hierarchical multiple regression was conducted to examine the degree to which variables in the proposed model predict intentions to seek help from informal sources. It was hypothesized that intentions to seek help from informal sources would be predicted by: (a) greater age, female gender, rural residential status; and higher AI/AN cultural identity; (b) greater factual knowledge of AD, greater cultural beliefs about AD, and greater health system barriers, after controlling for age, gender, and AI/AN cultural identity; and (c) greater perceived threat of AD and greater perceived benefits of seeking help after controlling for all previous variables. Variables were entered in three steps as described above. Results of the hierarchical regression analysis predicting total help seeking intentions scores are presented in Table 5.

In the first step, age, gender, residential status, and cultural identity were entered into the model, which explained 3.5% of the variance in informal help seeking scores,  $F(4,113) = 1.03$ ,  $p = .393$ . AI/AN cultural identity uniquely predicted a significant proportion of variance in informal help seeking scores at step one,  $t(110) = -2.00$ ,  $p = .047$ , CI [-.23, -.01],  $s^2 = -.03$ .

In the second step, health care barriers composite, cultural beliefs, and AD factual knowledge were entered into the prediction model contributing an additional 5.8% of variance in informal help-seeking intentions scores,  $F(3,110) = 2.34$ ,  $p = .078$ . AI/AN cultural identity uniquely predicted a significant proportion of variance in informal help-seeking scores at step two,  $t(110) = -2.36$ ,  $p = .020$ , CI [-.29, -.03],  $s^2 = -.05$ .

At step three, perceived threat of AD and perceived benefits minus barriers to seeking help were entered, explaining an additional 3.6% of variance in informal help-seeking scores,  $F(2,108) = 2.23$ ,  $p = .113$ . AI/AN cultural identity was the only individual predictor that

uniquely predicted a significant proportion of variance in informal help-seeking scores at step three  $t(108) = -2.43, p = .017, CI [-.29, -.03], sr^2 = -.05$ .

The full model of age, gender, residential status, cultural identity, health system barriers, cultural beliefs of AD, AD factual knowledge, perceived threat of AD, and perceived benefits minus barriers to seeking help, to predict informal help-seeking intentions scores was not statistically significant  $F(9,108) = 1.78, p = .081$ .

**Table 5**

*Hierarchical Regression Analysis for Prediction of Informal Help-Seeking Intentions*

Variable	$R^2$	Adj $R^2$	$\Delta R^2$	$B$	$SE B$	$\beta$
Step 1	.03	.01	.04			
Age				-.01	.06	-.02
Gender				-.05	.79	-.01
Residential Status				.84	.83	.10
Cultural Identity				-.12*	.06	-.20
Step 2	.09	.04	.06			
Age				-.01	.06	-.01
Gender				.08	.78	.01
Residential Status				.34	.84	.04
Cultural Identity				-.16*	.06	-.27
HSB Composite				.09	.06	.17
ADFK				.06	.08	.07
Cultural Beliefs				.31	.16	.18
Step 3	.13	.06	.04			
Age				.01	.06	.02
Gender				.12	.77	.02
Residential Status				.09	.84	.01
Cultural Identity				-.16*	.07	-.27
HSB Composite				.10	.06	.19
ADFK				.02	.08	.02
Cultural Beliefs				.27	.16	.16
Perceived Threat				.09	.07	.14
Perceived Benefits/Barriers				.13	.12	.11

*Note.* A significant  $B$ -weight indicated the  $\beta$ -weight was also significant. \* $p \leq .05$ , \*\*  $p \leq .01$

**Hypothesis 2: Predicting Intentions to Seek Help from Biomedical Sources**

Hierarchical multiple regression was conducted to examine the degree to which variables in the proposed model predict intentions to seek help from biomedical help sources. It was hypothesized that intentions to seek help from biomedical sources would be predicted by (a) greater age, female gender, urban residential status, and lower AI/AN cultural identity; (b) greater factual knowledge of AD, fewer cultural beliefs about AD, and fewer health system barriers, after controlling for age, gender, and AI/AN cultural identity; and (c) greater perceived threat of AD and greater perceived benefits of seeking help after controlling for all previous variables. Variables were entered in three steps as described above. Results of the hierarchical regression analysis predicting total help-seeking intentions scores are presented in Table 6.

In the first step, age, gender, residential status, and cultural identity were entered into the model, which explained 4.0% of the variance in biomedical help-seeking scores,  $F(4,113) = 1.18, p = .097$ . None of the individual predictor variables uniquely predicted a significant proportion of variance in biomedical help-seeking intentions scores at this step.

In the second step, health care barriers composite, cultural beliefs, and AD factual knowledge were entered into the prediction model contributing a significant additional amount of variance (11.8%) in biomedical help seeking intention scores,  $F(3,110) = 5.16, p = .002$ . Both AD factual knowledge  $t(110) = 2.70, p = .008, CI [.03, .19], sr^2 = .06$  and the health system barriers composite  $t(110) = 2.34, p = .021, CI [.01, .13], sr^2 = .04$  uniquely predicted a significant proportion of variance in biomedical help-seeking scores at step two.

At step three, perceived threat of AD and perceived benefits minus barriers to seeking help were entered, explaining an additional 1.9% of variance in biomedical help-seeking scores,  $F(2,108) = 1.37, p = .258$ . Both AD factual knowledge  $t(110) = 2.26, p = .026, CI [.01, .18], sr^2 = .04$  and the health system barriers composite  $t(110) = 2.37, p = .019, CI [.01, .13], sr^2 = .04$

uniquely predicted a significant proportion of variance in biomedical help-seeking scores at step three.

The full model of age, gender, residential status, cultural identity, health system barriers, cultural beliefs of AD, AD factual knowledge, perceived threat of AD, and perceived benefits minus barriers to seeking help, to predict biomedical help-seeking intentions scores was statistically significant  $F(9,108) = 2.62, p = .009$ .

**Table 6**

*Hierarchical Regression Analysis for Prediction of Biomedical Help-Seeking Intentions*

Variable	$R^2$	Adj $R^2$	$\Delta R^2$	$B$	$SE B$	$\beta$
Step 1	.04	.01	.04			
Age				-.01	.03	-.02
Gender				.34	.43	.07
Residential Status				.77	.42	.17
Cultural Identity				-.02	.03	-.07
Step 2	.16	.11	.12**			
Age				.01	.03	.02
Gender				.45	.41	.10
Residential Status				.30	.43	.07
Cultural Identity				-.06	.03	-.18
HSB Composite				.07*	.03	.25
ADFK				.11**	.04	.25
Cultural Beliefs				.10	.09	.11
Step 3	.18	.11	.02			
Age				.01	.03	.03
Gender				.48	.41	.10
Residential Status				.27	.43	.06
Cultural Identity				-.06	.03	-.18
HSB Composite				.07*	.03	.25
ADFK				.09*	.04	.22
Cultural Beliefs				.08	.09	.09
Perceived Threat				.06	.03	.16
Perceived Benefits/Barriers				-.01	.06	-.02

Note. A significant  $B$ -weight indicated the  $\beta$ -weight was also significant. \* $p \leq .05$ , \*\*  $p \leq .01$

**Hypothesis 3: Predicting Intentions to Seek Help from Traditional Sources**

Hierarchical multiple regression was conducted to examine the degree to which variables in the proposed model predict intentions to seek help from traditional help sources. It was hypothesized that intentions to seek help from traditional sources would be predicted by (a) greater age, female gender, rural residential status, and higher AI/AN cultural identity; (b) lower factual knowledge of AD, greater cultural beliefs about AD, and greater health system barriers, after controlling for age, gender, and AI/AN cultural identity; and (c) higher perceived threat of AD and higher perceived barriers of seeking help after controlling for all previous variables. Variables were entered in three steps as described above. Results of the hierarchical regression analysis predicting total help-seeking intentions scores are presented in Table 7.

In the first step, age, gender, residential status, and cultural identity were entered into the model, which explained 0.9% of the variance in traditional help-seeking scores,  $F(4,113) = .24, p = .913$ . In the second step, health care barriers composite, cultural beliefs, and AD factual knowledge were entered into the prediction model contributing an additional 2.9% variance in traditional help-seeking intentions scores,  $F(3,110) = 1.09, p = .356$ . At step three, perceived threat of AD and perceived benefits minus barriers to seeking help were entered, explaining an additional 0.6% of variance in traditional help-seeking scores,  $F(2,108) = .35, p = .705$ . None of the individual predictors were significant at any step. The full model of age, gender, residential status, cultural identity, health system barriers, cultural beliefs of AD, AD factual knowledge, perceived threat of AD, and perceived benefits minus barriers to seeking help, to predict traditional help-seeking intentions scores was not statistically significant  $F(9,108) = .55, p = .839$ .

## **Table 7**



*Hierarchical Regression Analysis for Prediction of Help-Seeking Intentions from Traditional Sources*

Variable	$R^2$	Adj $R^2$	$\Delta R^2$	$B$	$SE B$	$\beta$
Step 1	.01	-.03	.01			
Age				-.01	.03	-.04
Gender				.18	.43	.04
Residential Status				.11	.24	.05
Cultural Identity				.02	.03	.07
Step 2	.04	-.02	.03			
Age				-.01	.03	-.03
Gender				.16	.43	.03
Residential Status				.10	.24	.04
Cultural Identity				-.01	.04	-.07
HSB Composite				.04	.03	.15
ADFK				-.05	.04	-.11
Cultural Beliefs				-.03	.09	-.03
Step 3	.04	-.04	.01			
Age				-.01	.04	-.03
Gender				.16	.44	.03
Residential Status				.11	.25	.05
Cultural Identity				-.01	.04	-.03
HSB Composite				.04	.03	.16
ADFK				-.05	.04	-.12
Cultural Beliefs				-.03	.09	-.04
Perceived Threat				-.10	.04	-.03
Perceived Benefits/Barriers				.06	.07	.09

*Note.* A significant  $B$ -weight indicated the  $\beta$ -weight was also significant. \* $p \leq .05$ , \*\*  $p \leq .01$

**Hypothesis 4: Moderation Analysis**

Moderation analyses were conducted to evaluate the hypothesis that residential status would moderate the relationship between AI/AN cultural identity and (a) AD factual knowledge scores; (b) endorsement of AI/AN cultural beliefs of AD; and (c) barriers accessing health care. Prior to running the moderation analysis, the predictor variable (AI/AN cultural identity) was mean centered to zero to allow for meaningful interpretation in the presence of interaction (Cohen et al., 2003; Aiken & West, 1991). After centering the cultural identity variable, an

interaction term for cultural identity and rural residential status were created by multiplying their scores.

A hierarchical multiple regression was conducted with cultural identity, residential status, and the interaction term as predictors of AD knowledge was performed. At step 1, residential status and cultural identity were entered, which did not explain a significant proportion of variance (2.4%) in AD knowledge scores  $F(2,115) = 1.43, p = .244$ . At step 2, the interaction term was entered, which explained less than 0.01% of variance in AD knowledge scores  $F(1,114) = .02, p = .887$ . These results indicated that rural residential status did not moderate the effect of AI/AN cultural identity on AD knowledge scores. Results are presented in Table 8.

**Table 8**

*Regression Analysis of Moderator Effects on Alzheimer's Disease Knowledge Scores*

Variable	$R^2$	Adj $R^2$	$\Delta R^2$	$B$	$SE B$	$\beta$
Step 1	.02	.01	.02			
Cultural Identity				-.07	.07	-.09
Residential Status				-1.39	1.01	-.13
Step 2	.02	-.01	>.01			
Cultural Identity				-.06	.09	-.08
Residential Status				-1.40	1.01	-.13
Cultural Identity x Residential Status				-.02	.14	-.02

*Note.* A significant  $B$ -weight indicated the  $\beta$ -weight was also significant. \* $p \leq .05$ , \*\*  $p \leq .01$

A hierarchical multiple regression was conducted with cultural identity, residential status, and the interaction term as predictors of cultural beliefs of AD was performed. At step 1, rural residential status and cultural identity were entered, which explained a significant proportion of variance (5.1%) in cultural belief scores  $F(2,115) = 3.09, p = .048$ . At step 2, the interaction term was entered, which explained an additional 0.3% of variance in cultural belief scores  $F(1,114) = .344, p = .559$ . These results indicated that rural residential status did not moderate the effect of AI/AN cultural identity on cultural beliefs. Results are presented in Table 9.

**Table 9***Regression Analysis of Moderator Effects on Cultural Beliefs of Alzheimer's Disease Scores*

Variable	$R^2$	Adj $R^2$	$\Delta R^2$	$B$	$SE B$	$\beta$
Step 1	.14	.13	.14			
Cultural Identity				.01	.03	.03
Residential Status				-1.14*	.46	-.22
Step 2	.16	.19	.02			
Cultural Identity				.03	.04	.07
Residential Status				-1.14*	.46	-.22
Cultural Identity x Residential Status				-.04	.06	-.07

Note. A significant  $B$ -weight indicated the  $\beta$ -weight was also significant. \* $p \leq .05$ , \*\*  $p \leq .01$

A hierarchical multiple regression was conducted with cultural identity, residential status, and the interaction term as predictors of barriers accessing health care was performed. At step 1, residential status and cultural identity were entered, which explained a significant proportion of variance (2.5%) in barriers accessing health care scores  $F(2,115) = 19.09, p < .001$ . At step 2, the interaction term was entered, which explained an additional 2.2% of variance in AD knowledge scores  $F(1,114) = 3.50, p = .064$ . These results indicate that rural residential status did not moderate the effect of AI/AN cultural identity on barriers accessing health care scores. Results are presented in Table 10.

Table 10

*Regression Analysis of Moderator Effects on Barriers Accessing Health Care Scores*

Variable	$R^2$	Adj $R^2$	$\Delta R^2$	$B$	$SE B$	$\beta$
Step 1	.25	.24	.25			
Cultural Identity				.33**	.05	.49
Residential Status				.85	.81	.09
Step 2	.27	.25	.03			
Cultural Identity				.25**	.07	.37
Residential Status				.84	.80	.08
Cultural Identity x Residential Status				.21	.11	.19

*Note.* A significant  $B$ -weight indicated the  $\beta$ -weight was also significant. \* $p \leq .05$ , \*\*  $p \leq .01$

## **CHAPTER IV**

### **DISCUSSION**

The purpose of this study was to evaluate factors that may impact intentions to seek help for early symptoms of AD among AI/ANs. Utilizing the framework of the SHMB (Sayegh & Knight, 2013) and results from previous research, this study evaluated the relationship between AI/AN cultural identity, AI/AN cultural beliefs of AD-related memory loss, AD factual knowledge, health care system barriers, perceived threat of AD, and benefits of seeking help for AD, on help-seeking intentions. Age, gender, and residential status were also included in the model as distal factors that may influence help-seeking intentions. Additionally, this study also sought to explore the possible moderating role of residential status in the relationships between AI/AN cultural identity and cultural beliefs of AD, AD factual knowledge, and barriers accessing health care.

Correlations were found between several variables that were expected to be related to each other based on previous research, however, there were also several hypothesized correlations that were not supported. Regarding background variables, unexpectedly, no significant correlations were found for age or gender between perceived threat of AD or help-seeking intention scores. Previous research has found older age to be associated with more willingness to seek care from professional sources (Begum et al., 2012) and greater perceptions of AD as having serious personal consequences (Alzheimer's Association, 2020; Brunet et al., 2012). Additionally, female gender has been found to be associated with perceived threat and greater willingness to seek help for symptoms of memory loss in previous studies (Tang et al.,

2018). Small to medium correlations were found between residential status and cultural identity and behavioral expressions of AI/AN cultural identity, indicating rural residential status was associated with higher AI/AN cultural identity scores. This was anticipated given that AI/ANs tend to reside in more rural locations than the rest of the U.S. population (U.S. Census Bureau, 2012). The correlation between residential status and behavioral expressions of AI/AN cultural identity may be related to the possibility of increased opportunities for engagement in AI/AN cultural activities in more rural areas as a large proportion of AI/AN communities are located in more rural areas within the U.S. (U.S. Census Bureau, 2012). As hypothesized residential status was also significantly correlated with scores on both health system barriers scales (access and experiences), indicating rural residential status was associated with higher endorsement of barriers accessing care and negative perceptions and experiences of the health care system.

Cultural identity was positively correlated with scores on barriers accessing health care and negative perceptions and experiences of the health care system as hypothesized.

Unexpectedly, correlations were not found between cultural identity scores and cultural beliefs or knowledge of AD. Analyses conducted to evaluate the role of residential status in moderating the relationship between AI/AN cultural identity and knowledge of AD, cultural beliefs, and barriers accessing care were also not significant.

AD factual knowledge was negatively correlated with cultural beliefs and positively correlated with perceived threat and perceived benefits minus barriers of seeking help as hypothesized. Cultural beliefs were positively correlated with perceived threat, though not perceived benefits minus barriers of help-seeking. While cultural beliefs were hypothesized to contribute to increased concern and worry of AD (e.g., perceived threat), cultural beliefs about the cause of AD were hypothesized to contribute to lower perceived benefits of seeking care. In

general, cultural beliefs about AD primarily attributed causes of to normal aging, or other external factors (e.g., loss of culture, pollution) that are not perceived has controllable or treatable through health care, which may explain the lack of correlation with perceived benefits of seeking care of AD specifically.

Perceived threat of AD was correlated with intentions to seek help from informal and biomedical sources as hypothesized, though not with traditional sources as expected. Perceived benefits minus barriers of seeking help for AD were not correlated with help-seeking intentions for informal or biomedical sources as expected. Perceived benefits minus barriers were also not correlated with traditional help-seeking intentions scores, although this was anticipated.

Hierarchical regression analyses were conducted to evaluate the role of model variables in predicting help-seeking intentions. For informal help-seeking intentions, it was anticipated that health system barriers would be the greatest predictor of informal help-seeking intentions. As such, the distal variables hypothesized to predict informal help-seeking included rural residential status, and higher AI/AN cultural identity as these variables have been associated with greater health system barriers in previous research (Adakai et al., 2018; Alzheimer's Association & CDC, 2019; Bradford et al., 2010; Department of Health & Human Services, 2016; U.S. Census Bureau, 2012). Given this, hypotheses for the regression analysis predicting informal help-seeking were as follows. At step one, it was hypothesized informal help-seeking scores would be predicted by older age, female gender, rural residential status, and higher AI/AN cultural identity. At step two, higher factual knowledge of AD, higher cultural beliefs of AD, and higher endorsement of health system barriers were hypothesized to predict informal help-seeking intentions after controlling for background variables entered at stage one. Finally, at step three, higher perceived threat of AD and higher perceived benefits of seeking help were hypothesized

to predict informal help-seeking intentions after controlling for all previous variables. Results did not support these hypotheses. The amount of variance explained by predictor variables in help-seeking intentions scores was not significant at any of the three steps. Cultural identity was the only individual predictor found to contribute uniquely to variance in informal help-seeking, although in the opposite direction hypothesized.

For biomedical help-seeking intentions, it was anticipated that higher AD factual knowledge scores would be the greatest predictor of biomedical help-seeking as suggested in previous research. Fewer health care barriers and lower cultural belief scores were also thought to be significant predictors. For the regression analyses it was hypothesized that at step one, biomedical help-seeking scores would be predicted by older age, female gender, urban residential status, and lower AI/AN cultural identity. At step two, higher factual knowledge of AD, lower cultural beliefs of AD, and lower endorsement of health system barriers were hypothesized to predict biomedical help-seeking intentions after controlling for background variables entered at stage one. Finally, at step three, higher perceived threat of AD and higher perceived benefits of seeking help was hypothesized to predict biomedical help-seeking after controlling for all previous variables.

Results from the analysis of biomedical help-seeking intentions were somewhat consistent with hypotheses. The entire model including all predictor variables was significant. AD factual knowledge also contributed uniquely to the variance in biomedical help-seeking scores at both step two and in the final model. Health system barriers also contributed uniquely to variance in biomedical help-seeking scores, although in the opposite direct hypothesized.

Traditional help-seeking intentions were anticipated to be predicted primarily by higher AI/AN cultural identity scores. For the regression analysis predicting traditional help-seeking



scores it was hypothesized that at step one, traditional help-seeking would be predicted by older age, female gender, rural residential status, and higher AI/AN cultural identity. At step two, lower factual knowledge of AD, higher cultural beliefs of AD, and higher endorsement of health system barriers were hypothesized to predict traditional help-seeking intentions after controlling for background variables entered at step one. Finally, at step three, higher perceived threat of AD and lower perceived benefits of seeking help were hypothesized to predict traditional help-seeking after controlling for all previous variables. Results did not support these hypotheses. The amount of variance explained by predictor variables in traditional help-seeking intentions scores was not significant at any of the three steps. Furthermore, none of the individual predictor variables contributed uniquely to variance in traditional help-seeking scores at any step.

Overall, results from this study appear to indicate that the proposed model of age, gender, residential status, cultural identity, AD factual knowledge, cultural beliefs, perceived threat, and perceived benefits minus barriers in predicting help-seeking for AD-related symptoms, was significant in predicting help-seeking intentions from biomedical sources in this sample. Furthermore, consistent with previous research, AD factual knowledge was found to be a significant predictor of intentions to seek-help from biomedical sources. The proposed model, however, was not found to significantly predict help-seeking intentions from informal or traditional sources of care. This may suggest that the variables involved in predicting help-seeking intentions may vary across different sources of help.

### **Limitations and Considerations**

This study has several limitations including limited generalizability to AI/ANs outside of the study sample. While participants on average endorsed overall positive views of their AI/AN cultural identity, they reported relatively little engagement in behavioral expressions of AI/AN

culture (e.g., participating in cultural activities or practices, socializing with other AI/AN friends/family, speaking or thinking in AI/AN language). This may be associated with residential status in that only 16 (13.6%) of participants endorsed residing in a tribal community or reservation with the majority (52.2%) endorsing residing in an urban area. Furthermore, although only participants who provided a tribal affiliation were included in this study, the extent of their attachment to their tribal affiliation or community is unknown. Taken together, results from this study may be more reflective of AI/ANs who reside in more urban areas with minimal to occasional engagement with AI/AN tribal communities or cultural practices. This may also have influenced the correlation between AI/AN cultural identity and cultural beliefs, as well as predictions of traditional help-seeking intentions.

The majority of his sample (60%) fell between 45 and 49 years of age. Only five participants (4.2%) identified as older than 65, which is the age at which the majority of late onset AD is diagnosed. Since this study was primarily interested in assessing help-seeking intentions for early or mild symptoms associated with AD, individuals at risk for subjective cognitive decline (i.e., those 45 years and older) were also included in the study. However, the lack of association between age and perceived threat or help-seeking intentions may be related to the relatively younger age of this sample.

There are several limitations pertaining to the measurement of AI/AN cultural beliefs of AD-related memory loss. While previous studies implementing qualitative methods for analyzing AI/AN cultural beliefs about AD and related dementia, samples differed geographically and tribally across studies. Although only general themes noted across studies were included in this study's design, it is possible they may not pertain to beliefs of AI/ANs from this sample. In addition, while the items were chosen from studies with AI/AN groups, it is

possible these beliefs may be present in other cultural groups. For example, the attribution of AD symptoms to normal aging has been noted in other research evaluating beliefs about AD outside of AI/AN populations (Bradford et al., 2010; Botsford et al., 2011; Mukadam et al., 2010; Withers et al., 2019). This may in part explain the limited association between cultural beliefs and AI/AN cultural identity in this study.

### **Clinical Implications and Future Directions**

To the best of the author's knowledge this study was one of the first to examine the influence of AI/AN cultural beliefs, knowledge of dementia, perceived threat and benefits of seeking help for AD, and health care barriers on decisions to seek care for early symptoms of AD among AI/ANs within the framework of the Health Belief Model. With expected increase in life expectancy of AI/ANs and anticipated increase in AD and related dementia among AI/AN older adults, it is important to understand the factors contributing to recognition of AD and help-seeking intentions among this population. This study has contributed to previous literature by providing preliminary information on factors that may influence help-seeking intentions of early symptoms of AD among AI/ANs.

Future research evaluating cultural beliefs among AI/ANs that may contribute to delays in help-seeking is warranted. This study gathered items to evaluate cultural beliefs of AD among AI/ANs based on themes from primarily qualitative research. However, results indicated AI/AN cultural identity was not significantly correlated with these cultural beliefs in this sample. Further development and identification of specific cultural beliefs about AD-related memory loss utilizing quantitative methods may be helpful in further evaluation of the influence of these beliefs on help-seeking intentions. Evaluation of AI/AN cultural beliefs of AD would benefit

from assessment of differences in beliefs across various geographic regions as well as differences between rural and urban residing individuals.

It may also be beneficial to evaluate factors suggested to influence help-seeking intentions among specific AI/AN communities. AI/ANs are a heterogeneous group and their cultural values, beliefs, and practices may vary substantially across communities. Additionally, availability of health care, including programs and interventions for AD and related dementias, may vary as well. Evaluation at the community level would allow for study results to be more applicable to guiding intervention efforts and programming for AI/AN communities with similar cultural backgrounds and health care access.

Further exploration of differences in help-seeking intentions between varying sources is important. While research does suggest that the majority of people who experience mild symptoms of memory loss do not seek help from professional sources (Alzheimer's Association, 2020), this does not take into account informal sources of help, which have been found in other studies to be highly endorsed by individuals experiencing mild symptoms of memory loss (Begum et al., 2012). Further understanding of the factors involved in decisions to seek help from informal or traditional sources, in addition to biomedical sources, would be helpful. Additionally, while the focus of this study was on help-seeking intentions for mild symptoms of AD to facilitate further understanding of factors contributing to delays in care, it may be helpful to evaluate differences in help-seeking intentions across different levels of AD severity as well.

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## Appendix A

### Cultural Identity Questionnaire

**Instructions:** This questionnaire will collect information about your background and cultural identity. For each item please the answer that best describes you.

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neither Agree nor Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
1. I am proud of my Native American cultural heritage.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I feel connected to my Native American culture.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Native American culture is important to my everyday life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<b>Never</b>	<b>Rarely</b>	<b>Occasionally</b>	<b>Often</b>	<b>Very Often</b>
4. How often do you attend traditional activities (e.g., pow wows)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. How often do you attend traditional religious or spiritual ceremonies (e.g., sweat lodge)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. How often do you speak tribal language?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. How often do you think in tribal language?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. How often do you visit with Indian relatives or friends?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Have you ever lived on a reservation?				<b>Yes</b>	<b>No</b>
12. Where do you currently live? (Choose the answer that best describes where you reside most of the time)					
a. Reservation or tribal community					
b. Rural area, near a reservation or tribal community					
c. Rural area, away from a reservation or tribal community					
d. Urban city, near a reservation or tribal community					
e. Urban city, away from a reservation or tribal community					

## Appendix B

### Health Care System Barriers Questionnaires

**Instructions:** Below are some reasons people have difficulty getting the health care services they need. Please indicate how often these are a problem for you.

	Never	Sometimes	Often	Always
1. Not having transportation to get to appointments.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Having to care for my child(ren) or family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Not having health insurance or being unable to afford health services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Health services are not available at convenient times.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I don't have easy access to the health services I need.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. The health care system is confusing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I don't know where to go for the health services I need.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Instructions:** We are interested in knowing about your experiences with Western health care services (not including traditional or cultural healing services). Please indicate how much you agree or disagree with each statement.

	Extremely Disagree	Disagree	Neither Agree nor Disagree	Agree	Extremely Agree
1. I am afraid to visit Western health care services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Information provided by health care professionals cannot always be trusted.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I feel that I am treated poorly by health care professionals because of my cultural background.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Health care professionals don't respect my cultural beliefs or health practices.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I do not trust the health care system.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Appendix C

### Knowledge of Dementia Survey

Listed below are a number of symptoms that may or may not be experienced by people with Alzheimer's disease or other related dementias. Please indicate whether you think any of these symptoms is a symptom commonly experienced by people with Alzheimer's disease by selecting either *Agree*, *Disagree*, or *Not Sure*.

	Agree	Disagree	Unsure/Don't Know
Wandering	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting lost in familiar places	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asking or saying the same thing repeatedly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty learning new things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty completing familiar tasks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble remembering events from a long time ago. For example, difficulty remembering where they grew up.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Weight loss	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sudden increases in confusion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stuttering	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Problems with hearing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Frequent headaches	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble remembering recent events. For example, difficulty remembering what they had for breakfast or a conversation from earlier that day.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Below is a list of possible causes and risk factors for Alzheimer's disease or other related dementias. A risk factor refers to something that increases the risk of getting the disease. For each item, please indicate whether you *Agree*, *Disagree*, or are *Unsure* that it is a cause or risk factor for Alzheimer's disease.

	Agree	Disagree	Unsure/Don't Know
Alzheimer's disease is caused by abnormal changes in the brain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family history of Alzheimer's disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alzheimer's disease could be contagious	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alzheimer's disease is a normal part of aging	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alzheimer's disease is a form of mental illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alzheimer's disease is a part of the life cycle process	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
High blood pressure or heart problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alzheimer's disease is more likely with older age	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unhealth diet or poor nutrition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Excessive alcohol use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Smoking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stress or worry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Depressed mood or unresolved grief	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss of cultural traditions and practices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Imbalance in spiritual, emotional, mental or physical health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Poor immune system	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Not participating in cultural practices or ceremonies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gambling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pollution in the environment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking too many medications or medication side-effects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Below are some statements about treatment and care for Alzheimer's disease and other related dementias. Please indicate whether you *Agree*, *Disagree*, or are *Unsure* with each statement

	<b>Agree</b>	<b>Disagree</b>	<b>Unsure/Don't Know</b>
Staying active may help prevent Alzheimer's disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medicine may help slow down Alzheimer's disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is currently no cure for Alzheimer's disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alzheimer's disease can be diagnosed with a blood test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental exercises can prevent a person from getting Alzheimer's disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Appendix D

### Health Belief Model Variables Survey

Below are some statements about how people might think about Alzheimer's disease and other related dementias. Please choose how strongly you agree or disagree with each statement.

	<b>Strongly agree</b>	<b>Somewhat agree</b>	<b>Neither agree nor disagree</b>	<b>Somewhat disagree</b>	<b>Strongly disagree</b>
I will probably get Alzheimer's disease at some point in my life.	○	○	○	○	○
In the next few years, I will probably get Alzheimer's disease.	○	○	○	○	○
The thought of Alzheimer's disease scares me.	○	○	○	○	○
Alzheimer's disease is a serious condition.	○	○	○	○	○
If I were to get Alzheimer's disease, it would have major consequences for my life.	○	○	○	○	○
If I were to get Alzheimer's disease, it would severely burden my family.	○	○	○	○	○
Alzheimer's disease has serious financial consequences.	○	○	○	○	○
If I get Alzheimer's disease, it would strongly affect the way others see or treat me.	○	○	○	○	○
Getting Alzheimer's disease would cause me to lose my independence.	○	○	○	○	○
If I were to get Alzheimer's disease, my importance to my community would be lost.	○	○	○	○	○
There is very little that can be done to improve symptoms caused by Alzheimer's disease.	○	○	○	○	○
The negative effects of Alzheimer's disease can be prevented or avoided by treatment.	○	○	○	○	○
Getting help for Alzheimer's disease is not worth the cost and time.	○	○	○	○	○
Information and advice from experts may give information to reduce the chance of developing Alzheimer's disease.	○	○	○	○	○
Finding out if I had Alzheimer's disease in the early stages is important to me.	○	○	○	○	○
I think it is important to do things that benefit my health.	○	○	○	○	○

## Appendix E

### Dementia Care Seeking Questionnaire

**Instructions:** Please read the following paragraph then answer the questions that follow.

John is a 68-year-old male who has started to have some problems with memory. He has been forgetting recent events of importance to him. For example, John is interested in hockey but has been forgetting whether his favorite team won their last game, although he remembers watching the game itself. He forgets the names of people he has met recently. He is having difficulty handling his personal finances and planning leisure activities such as dinner parties or vacations. Simple decisions such as what to order in restaurants are more difficult to make. He enjoys hobbies such as puzzles or reading but has been having problems concentrating. When he is in social gatherings, he has more difficulty following the conversation. He is having trouble finding words to express his thoughts. He is having more difficulty driving and needs some help from friends or family to get to familiar locations like the grocery store. He needs to be reminded to shower or brush his teeth but can do these things on his own. He has started to post notes around his home to remind him of simple things like turning off the stove.

**If you were having problems like John how likely is it that you would seek help from the following people?** Please circle the number that best describes your intention to seek help from each help sources that is listed.

	Extremely Unlikely	Unlikely	Neither Unlikely nor Likely	Likely	Extremely Likely
Intimate partner (e.g., husband, wife, girlfriend, boyfriend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child or other family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctor/ Family physician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health provider (e.g., psychologist, social worker, counselor)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Traditional Healer or Medicine Person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community Elder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other religious or spiritual leader (e.g., pastor, priest, rabbi, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

What, if anything, do you think this person may be suffering from: \_\_\_\_\_