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

LTSS Research: Cognitive Assessments

Literature Review

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Glossary

Activities of daily living	Activities of daily living are basic activities a person must perform during a normal day to remain independent. These daily activities can include getting in and out of bed, dressing, bathing, eating, walking, and using the bathroom.[1]
Alzheimer's disease	Alzheimer's disease is the most common type of dementia. It is a progressive disease that effects the brain and "causes problems with memory, thinking, and behavior." [2]
Cognitive assessment	Cognitive assessments are brief assessments conducted by health care providers, most likely primary care providers, to detect possible cognitive impairments and determine whether a full dementia evaluation is necessary.[3]
Dementia	Dementia is a broad term used to describe a wide variety of symptoms related to decline in mental ability. Dementia is not a specific disease.[4]
Long-term services and supports (LTSS)	LTSS are a set of health, personal care, and social services delivered over an extended period to persons unable to perform their activities of daily living independently. LTSS may be provided in a variety of settings or in the person's home.[5]

[1] Centers for Medicare & Medicaid Services (CMS). (ND). *Glossary.* Retrieved from https://www.cms.gov/apps/glossary/
[2] Alzheimer's Association. (2017). *What is Alzheimer's?* Retrieved from https://www.alz.org/alzheimers_disease_what_is_alzheimers.asp
[3] Alzheimer's Association. (n.d.). *Health Care Professionals and Alzheimer's: Cognitive Assessment.* Retrieved from https://www.alz.org/health-care-professionals/cognitive-tests-patient-assessment.asp
[4] Alzheimer's Association. (2017). *What is Dementia?* Retrieved from https://www.alz.org/what-is-dementia.asp
[5] CMS. (2016). *LTSS Overview.* Retrieved from https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/ltss-overview.html

Introduction

Given the rapid increase of the population over 65 years of age in the American Indian and Alaska Native (AI/AN) population, Alzheimer's disease and related dementias (ADRD) are a serious concern in Indian Country. The proportion of AI/ANs living with dementia is not known due to a lack of research (Griffin-Pierce et al., 2008; Garrett, Baldridge, Benson, Crowder, & Aldrich, 2015). Under reporting and inaccurate diagnosis of dementia among AI/ANS may occur due to cultural views that normalize symptoms of dementia, lack of access to health care, and a lack of culturally appropriate cognitive assessment tools. The availability of valid cognitive assessments can support timely detection and diagnosis of dementia; however, there are currently no cognitive assessment tools in use that have been tailored and validated for AI/AN populations. One tool, the Southwestern Indigenous Cognitive Assessment, is currently in development and undergoing pilot testing for use among older American Indian adults in Arizona (Ewbank, n.d.).

Individuals with dementia require a high provision of long-term services and supports (LTSS). LTSS are a set of health care, personal care, and social services delivered over an extended period to persons who are unable to perform their activities of daily living independently (Centers for Medicare & Medicaid Services, 2016). Improved assessment of cognitive impairment among AI/ANs would allow for more accurate provision of LTSS in Indian Country.

This report examines the available literature on cognitive assessments, cognitive assessment tools, and their use in Indian Country. Information for the report was drawn from peer-reviewed journal articles, government and nonprofit organization reports, and interviews with three subject matter experts on aging in Indian Country. The report reviews the following topics:

- background information on cognitive assessments,
- the need for improved cognitive assessments in Indian Country,
- challenges with using cognitive assessment tools in Indian Country, and
- cognitive assessment tools that may hold promise for use in Indian Country, and
- recommendations for tailoring and developing culturally appropriate cognitive assessment tools for use in Indian Country.

Background Information on Cognitive Assessments

Brief cognitive assessments are an important step in identifying dementia. Ideally, cognitive assessments take about 5 minutes to complete. Health professionals conduct these assessments to detect for possible cognitive impairments and determine whether a full dementia diagnostic evaluation is necessary (Alzheimer's Association, n.d.). Cognitive assessments are recommended for:

- individuals who have expressed concerns about declining memory capabilities;
- individuals with family members or caregivers who have expressed concerns about their memory, thinking, or behavior;
- older patients who are having difficulties managing chronic conditions like diabetes; and
- Medicare beneficiaries (Alzheimer's Association, n.d.).

Assessment of cognition has been a required part of the Medicare Annual Wellness Visit, since the annual visit was initiated under the Affordable Care Act in 2011 (National Institutes on Aging, 2014; Alzheimer's Association, n.d.). Despite changes in health care law, the annual visit and cognitive assessment remain in place. They are also commonly conducted when an individual enters a nursing facility (Gleason, 2017).

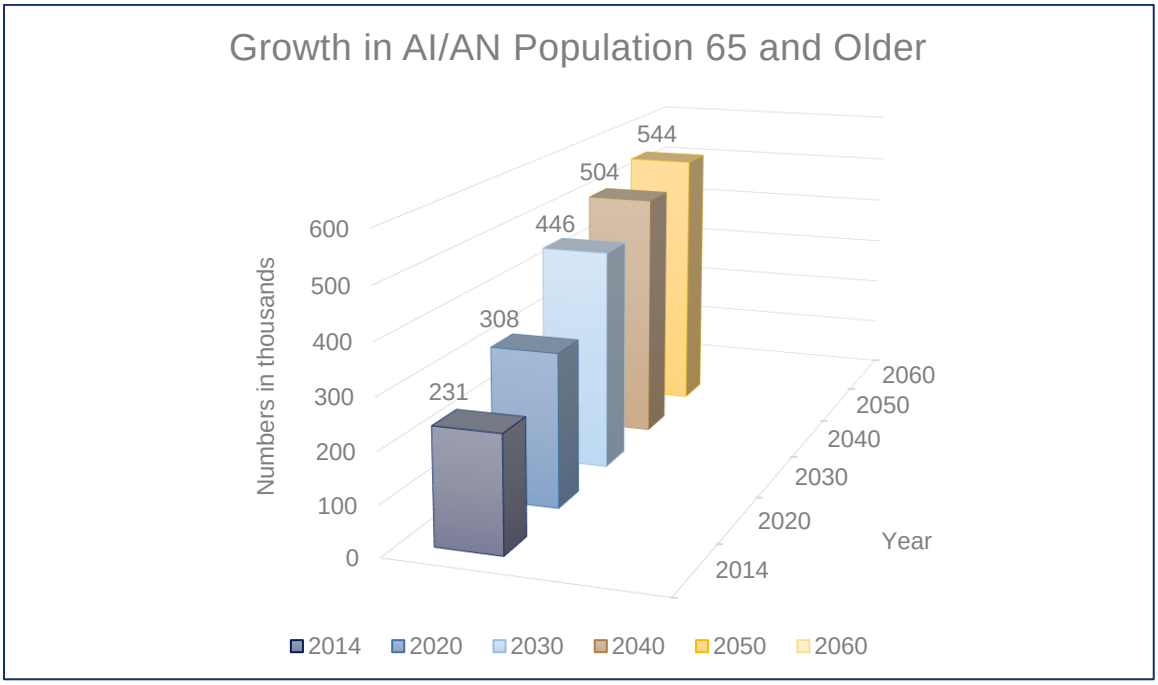
The main benefit of cognitive assessments is early detection of dementia. Early detection of dementia can help:

- address safety concerns related to memory problems;
- identify and designate a caregiver or other individual to assist the patient with medical, legal, and financial concerns;
- promote patients' autonomy, allowing them to express their preferences while they are still legally competent; and
- ensure the caregiver receives current information on the patient's status and referrals (National Institute on Aging, 2014).

Need for Cognitive Assessments in Indian Country

In terms of the aging population, the number of AI/AN people aged 65 and older is rapidly increasing. This population is projected to more than double from 231,482 in 2014 to 630,000 in 2060 (Administration for Community Living (ACL), 2017). (See Figure 1.) Although the prevalence of dementia among AI/ANs is largely unknown, recent data suggests that AI/ANs are among the groups at greatest risk for dementia and experience health and educational disparities that may put them at risk for the disease (Chen & Panegyres, 2016; Mayeda, Glymour, Quesenberry, & Whitmer, 2016; Jacklin, Walker, & Shawande, 2012; Radford, Mack, & Draper, 2015).

Figure 1. Projected AI/AN population ≥ 65 from 2014 to 2060 (ACL, 2017)



Studies suggest that people with less educational attainment are at a higher risk for developing dementia. In 2014, 72% of AI/AN students graduated from high school, which is considerably lower than the national graduation rate of 83% (McFarland et al., 2017). Research also suggests that individuals with health conditions, including diabetes, high blood pressure, and cholesterol, may be at higher risk for developing dementia. A 2017 Centers for Disease Control and Prevention (CDC) report identified AI/AN adults as having the highest prevalence of diagnosed diabetes out of all racial and ethnic groups in the United States.

While it is not known how widespread dementia is among AI/ANs, a 2016 study reports that, in a sample of patients enrolled in Kaiser Permanente of Northern California, the incidence of dementia among self-identified AI/ANs is second only to the incidence among African Americans (Mayeda et al., 2016). *(See Table 1.)* Another multi-city U.S. study found that AI/ANs demonstrated the highest prevalence of early onset dementia (onset before age 65) among the five U.S. Census racial groups (Chen & Panegyres, 2016). These studies offer preliminary support for the idea that social and health disparities experienced by AI/ANs correspond to an increased risk for ADRD.

The literature also suggests that ADRD are under and misdiagnosed among AI/ANs due to factors including remote locations, lack of access to health care, and cultural perceptions of dementia (Griffin-Pierce et al., 2008; Garrett et al., 2015). The authors of a 2015 research paper describe dementia as a hidden malady among the AI/AN population (Garrett et al., 2015). Given the potential higher risk for dementia among AI/ANs, combined with underreporting, the need for increased cognitive assessments in Indian Country is paramount.

Table 1. Cumulative 25-Year Risk of Dementia at Age 65

Race/Ethnicity	Cumulative Risk of Dementia at Age 65
African American	38%
American Indian & Alaska Native	35%
Latino	32%
White	30%
Asian American	28%
Pacific Islander	25%

Challenges with Cognitive Assessments in Indian Country

The following section describes how various socioeconomic and cultural factors may impact the effectiveness of cognitive assessments among AI/ANs. Existing cognitive assessment tools are not tailored for use in Indian Country. Normative data is typically based on a large, representative sample of a population. Assessment tools have limited or no normative data for AI/AN populations, and do not account for varying educational attainment, language barriers, communication styles, or cultural differences (Jervis et al., 2010, Gleason, 2017).

Education and Access to Health Care

Use of cognitive assessment tools that do not account for cultural and educational variances may yield inaccurate results. For example, a 2010 research study assessing the performance of AI/AN elders (age 60 and older) on two cognitive assessment tools found that individuals with more years of education and higher access to needed health care performed better on the tests (Jervis et al., 2010). Poor test results could reflect lower education and overall health, rather than the presence of ADRD.

Language Style

Differences in language style also affect the accuracy of cognitive assessments. AI/ANs tend to be more story-based in language, so their ability to recall information during a cognitive assessment may be related to whether the information is conveyed in a story format (Griffin-Pierce et al., 2008). To be effective, cognitive assessments need to be relatable for patients (Winchester, 2017).

Cultural Perceptions of Dementia

Varying cultural perceptions of dementia in AI/AN cultures may also determine whether symptoms are identified as health problems that warrant health care intervention. Many AI/AN communities may not interpret the symptoms of ADRD as a disease or an illness, but rather as a normal consequence of aging (Cipriani & Borin, 2015). Spiritual beliefs may impact the view of dementia among AI/AN communities. For example, some AI/AN communities understand the confusion and hallucinations associated with dementia as part of an elder's transition to the afterlife (Henderson & Henderson, 2002).

Historically Negative Experiences with Researchers and Health Care Providers

Historically negative experiences between tribes and researchers and health care providers may also impede data collection efforts and the detection of dementia (Griffin-Pierce et al., 2008). AI/ANs have historically experienced unethical research, and held mistrust of health care providers due to discrimination in health care settings (NPR, 2017; Warne, 2006; Petereit & Burhansstipanov, 2008). Elder AI/ANs who do not frequently interact with health care providers may be uncomfortable and unwilling to participate in cognitive assessments (Griffin-Pierce et al., 2008). A health care provider's ability to establish trust with the patient may help them conduct a more accurate cognitive assessment.

Promising Cognitive Assessments for Use in Indian Country

The following section describes several cognitive assessment tools. No one tool is recommended for the initial identification of cognitive impairment (Alzheimer's Association, n.d.). The following tools are highlighted due to their potential adaptation for use in Indian Country.

Saint Louis University Mental Status Test

Currently, none of the available cognitive assessment tools were developed specifically for use in AI/AN communities. However, existing tools may be adapted to better assess

AI/AN. For example, Dr. Blythe Winchester, Chief Clinical Consultant in geriatrics and palliative care at Indian Health Service, modified the Saint Louis University Mental Status (SLUMS) test for her use with patients in Indian Country. The tool was created by researchers at the Saint Louis University School of Medicine's Division of Geriatric Medicine in affiliation with U.S. Department of Veteran Affairs (VA) for use among Veterans. It has since been adapted for use in the general population (Feliciano et al., 2013; Saint Louis University, n.d.). The SLUMS include a story component, during which a health care provider reads a brief story to the patient and asks them questions about the story to test recall abilities. Dr. Winchester tailored the story for relevance to use with her patients from tribal communities (Winchester, 2017). Given the preference for story-based communication among AI/ANs, this approach may hold promise for further use.

The Kimberley Indigenous Cognitive Assessment

In Australia, researchers designed a cognitive assessment tailored to Australian indigenous communities. The Kimberley Indigenous Cognitive Assessment (KICA) was designed to assess the cognitive functions of indigenous Australians aged 45 and older who live in rural areas (Dyer et al., 2017; Western Australian Centre for Healthy Ageing, n.d.). Heath care providers can use several different components of the KICA. The tool includes a short version of the screening tool, which can be completed in 10 minutes or fewer and a modified version for urban indigenous populations (Western Australian Centre for Healthy Ageing, n.d.). Research conducted on the KICA found it to be effective among indigenous Australians (Dyer et al., 2017). The tool is currently being adapted for use among indigenous populations in Canada, and it may be possible to adapt the KICA for use in the United States (I-CAARE, n.d.).

Rowland Universal Dementia Assessment Scale

The Rowland Universal Dementia Assessment Scale (RUDAS) was developed in Australia in 2004 for use in culturally and linguistically diverse communities (Dementia Australia, n.d.). The RUDAS is a six-item questionnaire that can be administered in approximately 10 minutes or fewer (Naqvi, Haider, Tomlinson, & Alibhai, 2015). Although the performance of the RUDAS has not been evaluated among AI/ANs, several studies have assessed its use among culturally diverse elderly populations (Naqvi et al., 2015; Rowland, Basic, Storey, & Conforti, 2006; Radford, et al., 2015b). A literature review and study that focused on use of the RUDAS in multicultural populations found it is less affected by language and education than other cognitive tools (Naqvi et al., 2015). The tool may hold promise for use among AI/ANs.

Montreal Cognitive Assessment

The Montreal Cognitive Assessment (MoCA) is a commonly used assessment tool in clinical geriatric settings. It is a 30-question test that takes approximately 10 minutes to complete (Donovan et al., 2012). The MoCA was created in 2005 to detect mild cognitive impairment that can indicate a risk for developing dementia (Donovan et al., 2012). Previous assessment tools did not indicate subtle cognitive problems. Therefore, the MoCA is considered useful for this purpose (Donovan et al., 2012). The MoCA is the most accurate for patients with 12 or more years of education (Donovan et al., 2012).

The MoCA's widespread use and availability (it is available for free download online), may make it a viable tool among AI/ANs with 12 or more years of education.

Mini-Cog

The mini-cog is a two-part cognitive assessment that takes approximately 3 minutes to administer and complete and was designed for use in clinical and community settings (The University of Texas Health Science Center at San Antonio, No Date). Although the mini-cog has not been evaluated among AI/ANs, it has been assessed with positive results in multiethnic and multi-lingual sample populations (Borson et al., 2005; Borson et al., 2000). These results, along with the brevity of the tool, may make it an attractive option for some health care providers working with AI/AN patients.

The Gerontological Society of America KAER Model

The Gerontological Society of America created a free online toolkit in 2015 to assist primary care providers with early detection of cognitive impairment. The toolkit focuses on a four-step process called the KAER model to detect cognitive problems. The four steps are: (1) kickstart the cognition conversation, (2) assess for cognitive impairment, (3) evaluate for dementia, and (4) refer for community resources. While the toolkit is not a cognitive assessment tool, it does include three recommended tools. These tools are, the mini-cog, the general practitioner assessment of cognition (GPCOG), and the memory impairment screen. Use of the toolkit among AI/ANs has not been evaluated; however, it may be a useful resource.

Key Findings

Based on the information gained from the literature and interviews with subject matter experts, this section presents key findings from the literature that may help improve the use of cognitive assessments in Indian Country and help more AI/ANs with dementia receive appropriate care.

- Requiring cultural competency training for health care providers who administer cognitive assessments to AI/ANs is an important step to improve the accuracy of cognitive assessments. Health care providers need to be aware of the disparities, historical trauma, and cultural differences that may impact cognitive assessment results.
- Encouraging health care providers who conduct cognitive assessments with AI/AN patients to establish a level of trust with their patients is essential for accurate results (Griffin-Pierce et al., 2008).
- Adapting existing cognitive assessment tools and creating tools that are relatable to AI/ANs using story-based communication is a promising practice worthy of further analysis (Winchester, 2017; Griffin-Pierce et al., 2008).

Conclusion

Despite health and educational disparities that put AI/ANs at higher risk for dementia, there is a lack of research assessing the impact of ADRD in Indian Country. Moreover, there has been little focus on developing appropriate cognitive assessment tools for this population. U.S. researchers might look to innovative approaches, including the KICA, that are implemented or being explored in Australia and Canada, for adaptation to AI/AN communities. Overall, more research is needed for tailoring and developing culturally appropriate cognitive assessment tools for use among AI/ANs.

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