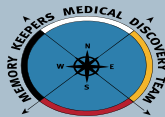



Mentation: Mind, Thinking, and Memory in AI/AN Communities.

Community-engaged research to explore mentation and cognitive health

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Age Friendly Healthcare in American Indian Elders
March 24, 2023



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Outline

- About me – who is Jordan
- Current context and risk factors
- ADRD research with dementia caregivers
- Memory Keepers Medical Discovery Team - resources
- Dementia caregiver research, intervention development
- Implications
- Questions and discussion

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Objectives

- Attendees will be able to list three ways Indigenous peoples understand thinking and mentation.
- Attendees will be able to list three ways non-Indigenous providers understand dementia in Indigenous communities.
- Attendees will be able to explain two principles of community-engaged research.
-

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About me



- Unangax/Aleut
- Commercial fishing background
- Raised among Elders in my family and community:
 - Great grandparents, late Paul & Anna Chukan
 - Grandparents, late Gordon & Anisha McCormick; Alden & Muriel Lewis
 - Elders in village of Naknek

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Naknek, Alaska



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Cannon Beach, Oregon



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ADRD Prevalence: American Indians (AI)

- By 2050, one new case of Alzheimer's Disease and related disorders (ADRD) is expected to develop every 33 seconds, resulting in nearly 1 million new cases per year; the estimated prevalence is expected to range from 11 million to 16 million.
- AN/AI population aged 65 years and older has nearly tripled since 1976, from 4.8% to 14.1%, and tribal health systems are ill-prepared to address the challenges associated with ADRD.
- There is an increasing urgency to articulate Alaska Native views of ADRD.

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AIAN ADRD Current Context

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- AI/AN population aged 65 years and older has nearly tripled since 1976, from 4.8% to 14.1%, and tribal health systems are ill-prepared to address the challenges associated with ADRD.
- There is an increasing urgency to articulate AI/AN views of ADRD.

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Risk factors for ADRD in AIAN Communities

- Limited physical activity
- Low socioeconomic status
- Hypertension
- Type 2 diabetes
- Obesity
- Smoking
- High cholesterol

Carty, C. L., Noonan, C., Muller, C., Saner, D., Reiman, E. M., Buchwald, D., ... & Nelson, L. A. (2020). Risk factors for Alzheimer's disease and related dementia diagnoses in American Indians. *Ethnicity & Disease*, 30(4), 671.

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Study Focus

- To date, no research has focused specifically on Alaska Natives and ADRD.
- Understanding the cultural construction of ADRD can:
 - Provide insight for health care providers to integrate cultural beliefs into treatment
 - Improve the processes of care for families
 - Enable Alaska Natives to better comprehend and adhere to early, critical stages of treatment.

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Findings – Caregiver Onset

- Subtle cognitive changes were noticed, but uncertain of specific date when changes occurred.
 - *"Probably five years ago. Four or five years ago."*
- Caregivers used noticeable changes to guess the year they believed ADRD symptoms started.
 - *"I just started to notice over month's time that things were changed with her. She couldn't remember where she put things. And just her logic in discussions was not right. It was changing."*

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Findings – Caregiver Problems

- Lack of knowledge, ADRD process, and what to expect led to challenges.
 - *"What troubles me most is that I am trying to make sense of a disease that has no explanation and it's something that you cannot make sense of."*
- Personality changes in family member were unexpected and led to family staying away.
 - *"They just stay away. And that's the first thing they do, when a family gets dementia. The other family, they find out about it and they just stay away – why stick around when she doesn't remember them."*

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Findings – Caregiver Problems

- Role shifting was problematic for younger caregivers
 - *“And it was an odd conversation because I’m used to always being the daughter and taking direction from him. The roles flipped, which is real odd for me, telling him what to do.”*
- Lack of accessible education and training resources was problematic for caregivers and educating family members
 - *“I tried to explain it to my family when he was first diagnosed with dementia. They’re really good at denying stuff. It’s like this is not going away. This is not going to get better. This is what we are facing and I am going to need your help, but nobody.”*

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Findings – Caregiver Blessing

- There were unexpected blessings for caregivers.
 - *“I wouldn’t have traded it for anything. I was like, I am at peace with what I was able to – the time I spent, and my 32-year old, she was pretty young, she was in junior high. She said that was probably the best time in her life that she got to spend with her grandma. She said, ‘Thank god we had grandma.’”*

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Findings – Caregiver Causes

- Lifestyle choices were primary cause, including alcohol, being sedentary, unresolved trauma, and poor diet
 - *“Maybe drinking, drugs, alcohol. Elders tell me they drank when they were young and maybe that had something to do with it, but I don’t know.”*
 - *“I would think if they weren’t physically active. They’re just sitting there and not talking or visiting too would affect dementia.”*
 - *“I think trauma and just constantly being on edge all of the time.”*
- Some caregivers had no answer or idea on the cause:
 - *“I don’t think there is a clear yes or no answer, but part of old age.”*

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Findings – Caregiver Fears

- Loss of Elders and their knowledge was the primary fear discussed.
 - *“It’s a sad thing to see. You always want them to have their wits about them to the very end. That wisdom that they had way back when they were young and what they know.”*
 - *“Not being able to hear all they know deep within them. The wisdom and knowledge they picked up through the years with the grandmas and grandpas back in the early 1900s, 1800s, and not remembering.”*

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Findings – Caregiver Treatments

- Treatments focused on holistic approaches, treating the entire person, and not just ADRD symptoms or delaying disease progression.
 - *“I’d like to have her [Provider] review the rest of his health other than the Alzheimer’s to make sure that he’s up to date with the meds he’s taking and talk about other issues that have been bothering him [husband with ADRD].”*
- Traditional treatments were also used to treat more than physical health symptoms.
 - *“I had him going to a naturopath, for different supplements and things and different things that help, natural things to help him calm down.”*
 - *“We found that music soothed him so much.”*

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Findings – Provider Onset

- Difficult to determine approximate date of onset given patients came to clinic at later stages of ADRD.
 - *“Some people accept it as a natural part of aging and they’re not too worried about it until the person becomes such a care burden for the spouse, the family, that they bring the person to medical attention, and it’s pretty late in the disease.”*
- Patients and families did not understand ADRD and associated changes until it was too late.
 - *“I think a lot of them don’t really understand it a lot until pretty much it comes down to they have it [ADRD].”*

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Findings – Provider Problems

- Lack of resources across the State was the most discussed problem.
 - *“And sometimes they’re very isolated. There was this guy I always felt like there was nothing that I was able to assist with. We tried different things. We couldn’t hire respite workers to go in. I was pulling out my hair. It was almost like I dreaded calling him because I couldn’t – I didn’t feel I could help with him anything.”*
- Providers saw how lack of resources exacerbated family roles and relationships.
 - *“It’s a tough job to care for somebody with dementia. Families cannot do it. You can’t be a parent or grandparent and take care of something with dementia too.”*

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Findings – Provider Causes

- Causes of ADRD included dietary changes and being sedentary.
 - *“But I think with the change in the diet and high blood pressure, and those kinds of things, adds to dementia.”*
 - *“And we’re talking about the 60 year olds, they’re not as active as the elders used to be. I think that’s why we’re seeing higher numbers of dementia as well.”*
- Also discussed vascular and heart disease among patients
 - *“It seems like the cardiovascular risk factors are big correlates with dementing processes. So, it’s unsurprising that many of my patients with either AD, or vascular dementia, have comorbidities, high blood pressure, diabetes, and so on.”*

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Findings – Provider Course

- Despite scientific training, providers were much less knowledgeable in discussing and understanding cultural aspects of dementia.
 - *“Certainly providers know about it, but it’s hard to determine – a lot of things are cultural. If you don’t have exposure to those ideas and concepts - you don’t know if this is this individual having problems, or this is how ,as a whole people [Alaska Natives], think about certain things.”*

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Findings – Provider Treatments

- Included both western and traditional treatments, focused on physical activity and dietary changes.
 - *“Sticking to Native foods, as opposed to exposing themselves to some of the westernized, bad for you, foods. Berry picking and traditional mushroom picking and some of the grasses that are known to be good herbal remedies.”*
- Traditional healing was also prioritized.
 - *“If people are feeling like they’re not thinking right and they’re in the earlier stages of having unclear thinking, it can be really helpful for them to use traditional healing techniques. Helping them to remember what’s important in their life and to help them re-engage in their community, creating more structure, prioritizing, and creating that circle of healing in their own life.”*

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Findings - Summary

- Alaska Native caregivers' explanatory model of ADRD is similar to other racial and ethnic minority groups
 - Natural part of aging, seek support later in disease process, seeking more resources and supports for family and providers, blend of western and traditional healing
- Providers have concerns regarding lack of resources, cultural understandings, and engagement with racial and ethnic minorities earlier in disease process.
- The focus on blessings was not commonly found in literature and participants not stating specific answers may be culturally motivated in that Alaska Natives may not discuss disease by name to avoid bringing it upon their family.

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Implications

- State, local, and tribal health organizations need to develop rural outreach and support groups for caregivers
 - Reduce isolation, increase knowledge base of disease process
- Develop training and education on AN understanding of ADRD
 - Need for universal education/screening for memory loss at all appt
- Need for culturally responsive support groups, education, awareness

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Acknowledgements

- We would like to thank each Alaska Native caregiver who shared their time, stories, humor, tears, and recommendations to improve supports for other caregivers.
- We would like to thank the Alzheimer's Resource of Alaska, Aleutian Pribilof Islands Association, Bristol Bay Area Health Corporation, Fairbanks Denali Center, and Fairbanks Native Association for the support and guidance on this study.

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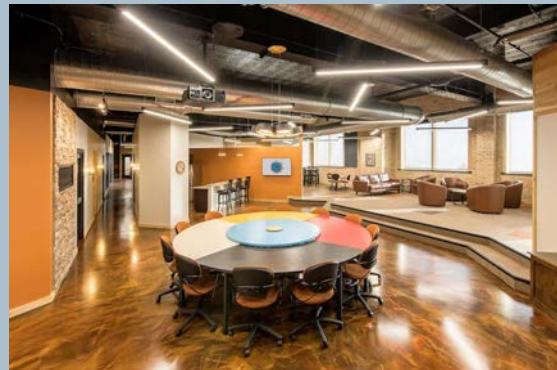
- WWAMI AIAN CTRC pilot study award (PI: Lewis, JP). Sub-award #: G248-17-W6223 (NIH NIGMS)
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Memory Keepers Medical Discovery Team



Entrance to Memory Keepers
624 E 1st Street, Duluth, MN



Memory Keepers Collaborative Workspace

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Website Hosted by I-CAARE: www.I-CAARE.ca



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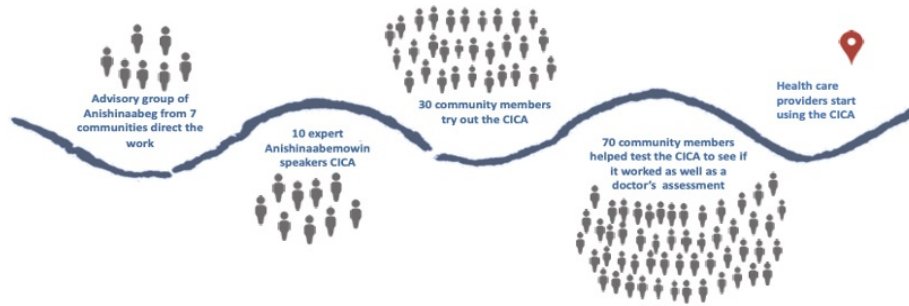
Indigenous Dementia Fact Sheets

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CICA validation team April 2018


Canadian Indigenous Cognitive Assessment (CICA) Adaptation to Validation(2015-2019)




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CICA tools Available at www.i-caare.ca


Canadian Indigenous Cognitive Assessment (CICA) Videos




The Canadian Indigenous Cognitive Assessment: English



The Canadian Indigenous Cognitive Assessment: Ojibwe



The Canadian Indigenous Cognitive Assessment: Translation




The Canadian Indigenous Cognitive Assessment: Sign Language

Canadian Indigenous Cognitive Assessment (CICA)


Welcome and thank you for your interest in the Canadian Indigenous Cognitive Assessment (CICA). Below you will find the following five documents: The CICA Guidebook, The CICA Instruction Booklet, The CICA tool (English), The CICA tool (Anishinaabe with English translation) and The CICA drawings.

The documents are followed by a series of four training videos: The CICA: English only; The CICA: Ojibwe only; The CICA: English to Anishinaabemwin using a translator; and The CICA: American Sign Language.


Canadian Indigenous Cognitive Assessment (CICA) Tool and Supplemental Materials




A culturally safe guide to using the CICA




Instructions on using the CICA materials



The CICA tool: English



The CICA tool: Anishinaabe with English translation

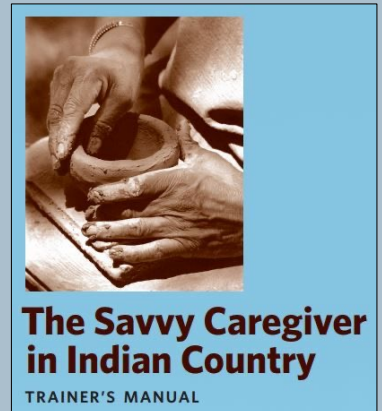


The CICA drawings

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AIAN Caregiver Intervention Studies

- Savvy Caregiver for Indian Country – White Earth Nation
 - Cultural advisory board
 - Modifications to incorporation cultural values & needs of WEN
 - Enhance feelings of mastery to improve quality of life for caregiver and family with dementia



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Caregiver Intervention Studies

- Dementia Caregiver Peer Mentoring Intervention (Dementia Advocates for New Caregiver Education - AIAN Dance)
 - Culturally adapt Senior Companion Program
 - Peer mentoring intervention with past and current caregivers
 - Weaving together AI caregiver experiences with Western ADRD training infrastructure
 - Provide support on cultural beliefs about ADRD and caregiving, develop effective coping strategies, enhance social ad cultural supports
 - Provide sense of purpose and feelings of generativity/usefulness for past caregivers

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Key Takeaways

- While research on this topic is slowly increasing, there are still significant gaps in our knowledge of how to best prevent, treat and care for dementia in *diverse* Indigenous populations.
- Cultural understandings of dementia need to be respected and considered in our approaches to care. Not doing so continues a process of colonization.
- Cultural safety is a framework that can be applied to our individual care efforts and at the organizational level to ensure we are providing appropriate and effective care to Indigenous clients.
- Important to partner with caregivers to culturally enhance training programs to improve caregiver mastery and experiences.

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**Thank you
Comments / questions**

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