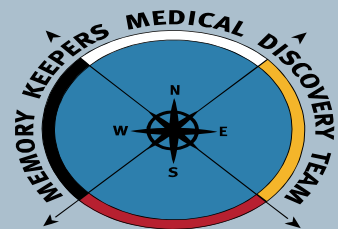


Alzheimer's Disease and Related Dementias in Indigenous Populations

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National Collaborating Centre for Indigenous Health
Webinar
September 21, 2021



Acknowledgements

- Dr. Kristen Jacklin, Executive Director
- Dr. Melissa Blind, Senior Research Associate
- Indigenous caregivers, family members, Elders

Memory Keepers Medical Discovery Team



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



Memory Keepers Collaborative Workspace



Outline

- Current context and risk factors
- Memory Keepers Medical Discovery Team - resources
- Dementia caregiver research, intervention development
 - Savvy Caregiver for Indian Country – cultural adaptations
 - Future caregiver research

Risk factors for ADRD in AIAN Communities

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

AIAN ADRD Current Context

- 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.
- 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.

Indigenous Understandings of Dementia

- More research is needed to explore cultural understandings of 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 and support for families
 - Enable Indigenous people to better comprehend and adhere to early, critical stages of treatment.

Cultural Safety and Resources

- Cultural safety:
 - An approach that considers how social and historical contexts, as well as structural and interpersonal power imbalances, shape health and health care experiences.
- Cultural safety model for ADRD care requires:
 - Understanding Indigenous perspectives of ADRD
 - Understanding family and community care preferences

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Indigenous Cognition & Aging Awareness Research Exchange

Home About Projects Resources CICA Indigenous Dementia Research Network Contact

Introducing the Canadian Indigenous Cognitive Assessment (CICA)

The CICA Validation team, Expert Anishinaabemwin Language Group, and Manitoulin Island Advisory Council Members are pleased to announce the launch of the CICA materials and training videos

[Learn More](#)

Indigenous Dementia Fact Sheets

WHAT IS DEMENTIA? Indigenous Perspectives and Cultural Understandings

SIGNS AND SYMPTOMS OF DEMENTIA: An Indigenous Guide

WHAT TO EXPECT AFTER A DIAGNOSIS OF DEMENTIA: An Indigenous Persons' Guide

PREVENTING DEMENTIA IN INDIGENOUS PEOPLES BY AGING WELL Advice from older Indigenous peoples

The Path of Dementia

DIAGNOSIS: Getting an accurate diagnosis as early as possible can rule out causes of memory loss not due to dementia and can help you access care that you need. Having a family member or friend with you for diagnosis is helpful.

CONNECT WITH A DOCTOR OR NURSE YOU TRUST: It will be important for you to be under the care of a doctor or nurse regularly. If you live on-reserve you should be referred to the Home and Community Care Program, off-reserve you should be referred to provincial Home Care services. If you speak an Indigenous language it is extra important to let your doctor or nurse know and to have someone with you who can translate.

TREATMENT: It is important to stay well by being active, getting enough sleep, and eating well. All of these can slow the dementia. Your doctor might also suggest medications to use. There is no cure for dementia, but there are medications that have been shown to slow the progression in some people. If you try these medications, it is important to be in regular contact with your doctor about side effects. Some people also use plant-based medicines, ceremony, or spiritual practices to help with the symptoms.

TRANSITIONS: Now you, your caregivers and loved ones will be focused on your comfort and preparing for your transition out of this life. As you come full circle, it is important that your loved ones understand and are able to carry out your final wishes to help make your transition as gentle as possible.

EARLY STAGES: You are noticing some memory problems but are still very healthy. It is important to stay physically and socially active. You can still be independent. Many people use humour to talk about changes they are experiencing.

PLAN FOR THE FUTURE: This is the time to talk to family, trusted friends or health care providers about how you can be supported. What changes need to be made to your house to help you stay independent? Where do you want to live when you can no longer live on your own? Is there someone you trust as your caregiver? Someone you trust to make financial and medical decisions for you?

MIDDLE STAGES: By now you may notice that the changes to your memory and the difficulties with everyday tasks are making life more challenging. Many people say that there can be days with moments of frustration and anger and other days that are peaceful and joyful. You may need help remembering household routines and names. You may find yourself repeating stories or getting lost in time. Whether you are living on or off-reserve you should now have home care services in place. It is important to have someone with you at appointments to help remember what is said.

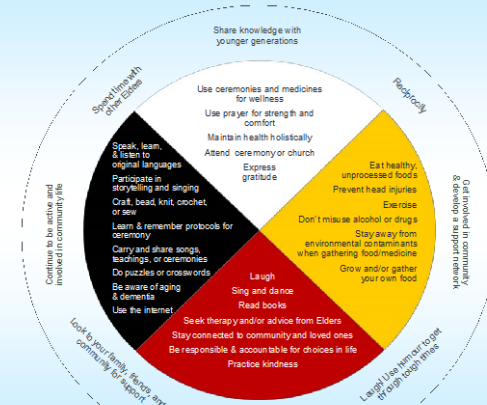
LATE STAGES: Some people describe this as going back to childhood or coming full circle. You will need much more help with meals, getting dressed, and getting washed. You will also need to be cared for more closely. Many people experience visions and see and hear things that others around you cannot. Depending on your spiritual beliefs, you may feel closer to the spirit world. You will need more support in everyday routines. You may wish to spend more time with loved ones. You will still have many stories to share and wisdom to pass on. It is important to continue to communicate however you can. Your caregivers and health care providers will help you prepare for your transition to the next stage.

GETTING EXTRA SUPPORT: At this time, you might want to get extra support for everyday routines and needs. Explore community services such as Friendship Centres, Aboriginal Health Centres, Elder's Centres, and Home Care Programs.

TAKING EXTRA CARE: At this time, some people start to forget more important tasks, like turning off the stove, or putting on matters when it is cold outside. Sometimes you may leave the house and forget to tell someone where you are going. You and your caregivers should talk about making sure that you, your loved ones, and your home are safe and that you have a system in place to keep track of you when you go out. This might include making changes to your home.

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PREVENTING DEMENTIA IN INDIGENOUS PEOPLES BY AGING WELL Advice from older Indigenous peoples

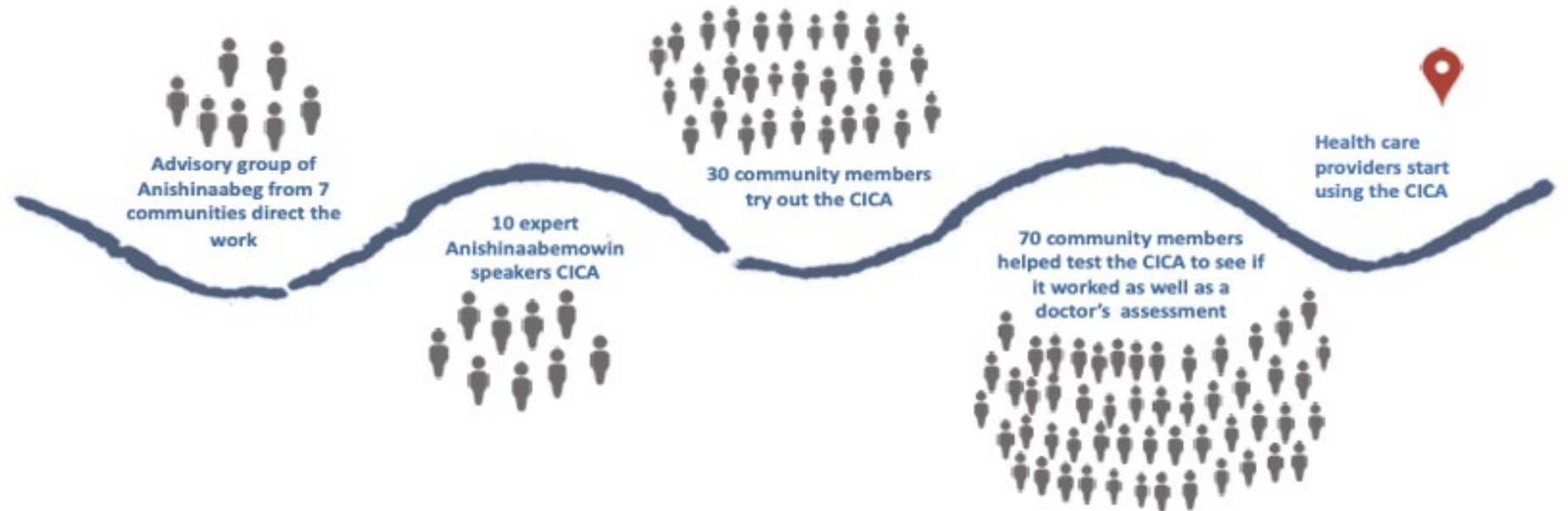


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Canadian Indigenous Cognitive Assessment (CICA) Adaptation to Validation(2015-2019)



CICA validation team April 2018



CICA tools

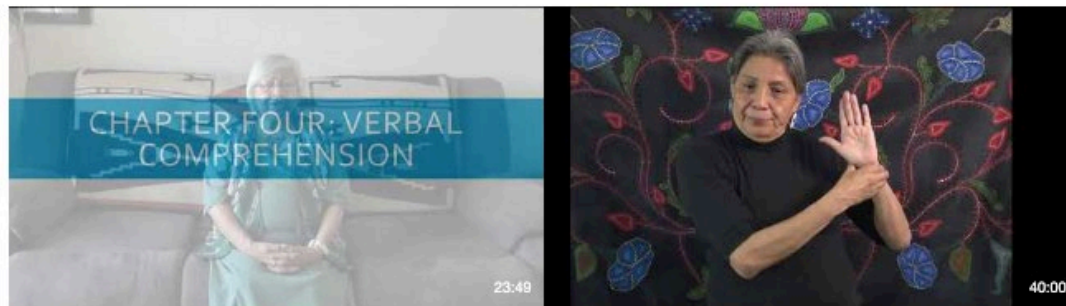
Available at www.i-caare.ca

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

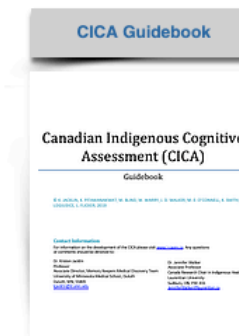
Canadian Indigenous Cognitive Assessment (CICA)

Welcome and thank you for your interest in the Canadian Indigenous Cognitive Assessment (CICA).

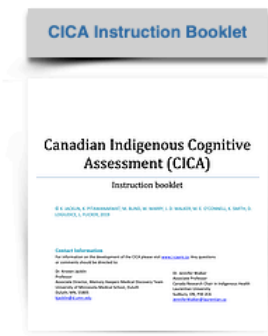
Below you will find the following five documents: The CICA Guidebook, The CICA Instruction Booklet, The CICA tool (English), The CICA tool (Anishinaabe with English translation) and The CICA drawings.

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.

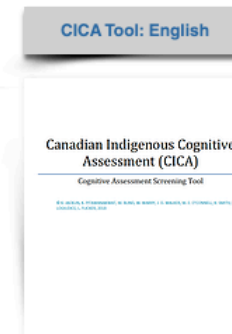
Canadian Indigenous Cognitive Assessment (CICA) Tool and Supplemental Materials



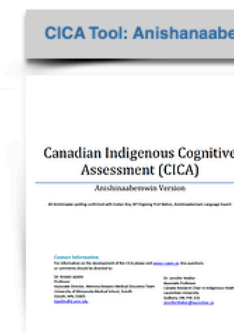
A culturally safe guide to using the CICA



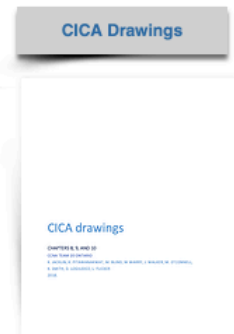
Instructions on using the CICA materials



The CICA tool: English



The CICA tool: Anishinaabe with English translation



The CICA drawings

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



**The Savvy Caregiver
in Indian Country**

TRAINER'S MANUAL

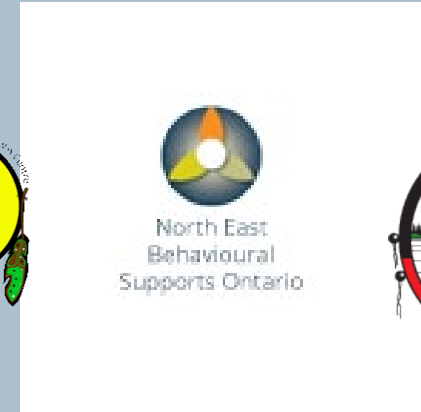
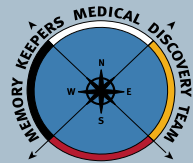
Caregiver Intervention Studies

- 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 and cultural supports
 - Provide sense of purpose and feelings of generativity/usefulness for past caregivers

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.

Thank you Comments / questions



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