ASC/brainXchange Webinar Series

Cultural Safety in Cognitive Testing and Dementia Case-Finding for Older First Nations Adults

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Overview of today's presentation

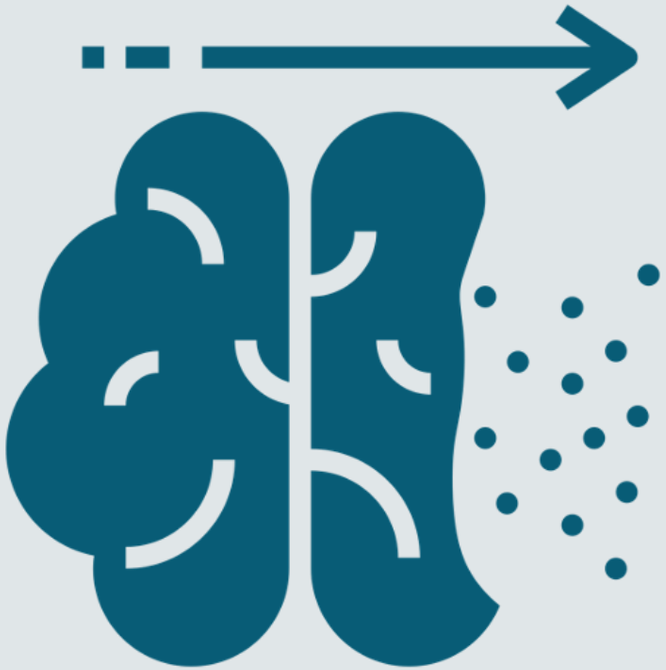
This webinar will highlight the importance of a First Nations-specific approach to cognitive assessment; describe the development of the Canadian Indigenous Cognitive Assessment; and demonstrate how appropriate use of the tool can contribute to improved dementia diagnosis and surveillance.

Cultural Understandings of Dementia in Indigenous Populations

- Diverse cultural perspectives exist, and they change over time
- Contrary to biomedical understanding, dementia is often considered to be a natural part of the circle of life by Indigenous people
- Dementia is sometimes described as “Returning back to the stage of infancy”
- Still, caregivers express lack of information about dementia risk factors, symptoms, progression, and treatments

Jacklin K, Walker J. Cultural understandings of dementia in Indigenous peoples: a qualitative evidence synthesis. Canadian Journal on Aging/La Revue canadienne du vieillissement. 2020 Jun;39(2):220-34.

Limited existing research suggests that:



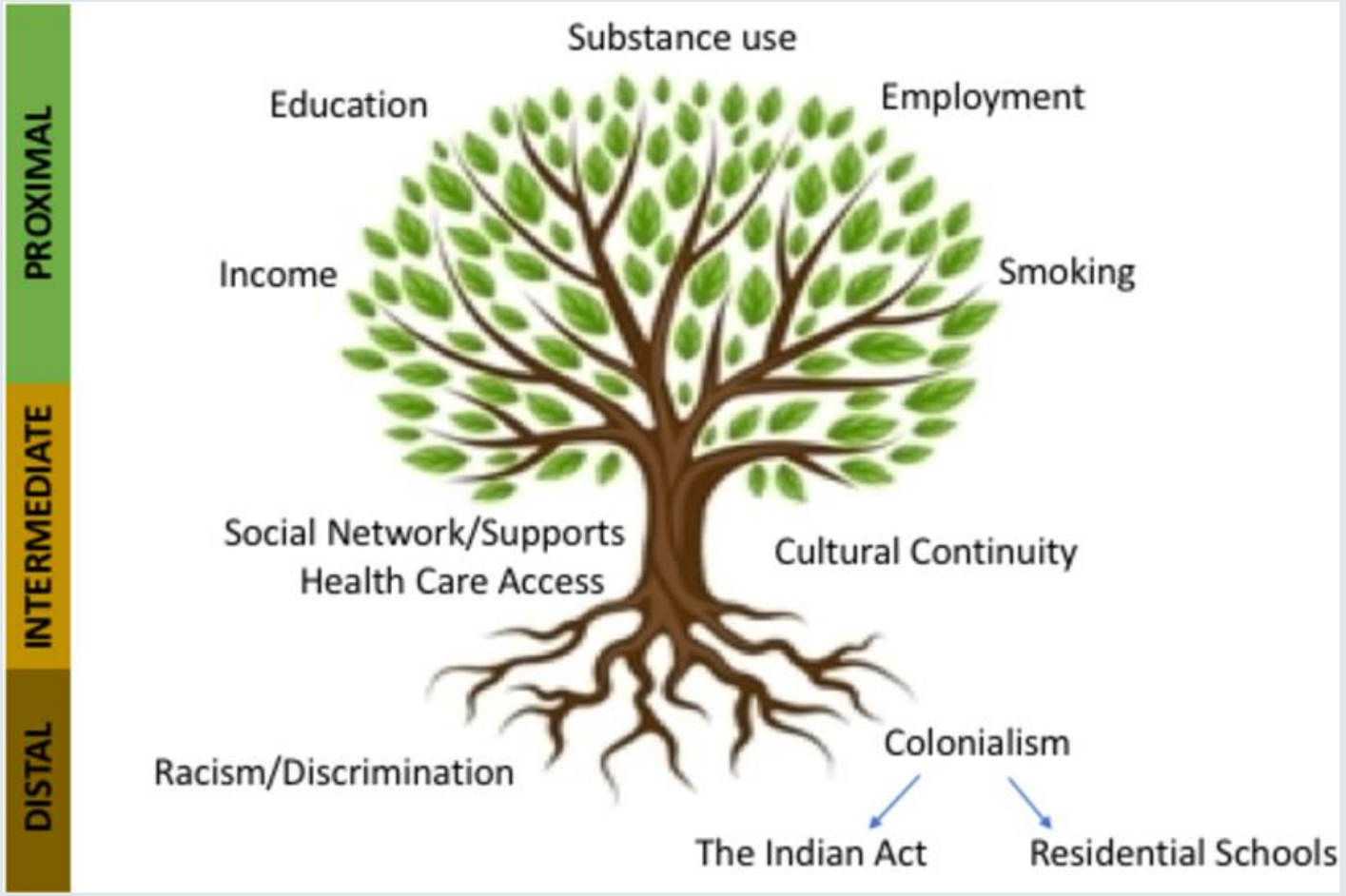
- The risk of developing dementia is higher in First Nations populations versus non-Indigenous populations in Canada

- First Nations populations in Canada experience dementia at earlier ages compared to non-Indigenous populations

Walker J, Jacklin K. Current and Projected Dementia Prevalence. Indigenous peoples and dementia: New understandings of memory loss and memory care. 2019 Jun 1:24
Jacklin KM, Walker JD, Shawande M. The emergence of dementia as a health concern among First Nations populations in Alberta, Canada. Canadian Journal of Public Health. 2013 Jan;104(1):e39-44.

Risk Factors for Dementia in First Nations Populations

- Cardiovascular disease, low educational level, head injury, hypertension, poor mobility, childhood trauma, smoking, low body mass index, alcohol use
- Inadequate focus on intermediate, and distal determinants of health



Walker D, Spiro G, Loewen K, Jacklin K. Alzheimer's disease and related dementia in Indigenous populations: a systematic review of risk factors. Journal of Alzheimer's Disease. 2020 Jan 1;78(4):1439-51;
McConkey, S. R. (2018). The Indigenous determinants of health as predictors for diabetes and unmet health needs among urban Indigenous People: A respondent-driven sampling study in Toronto, Ontario.

Challenges with dementia surveillance in First Nations populations

- Lack of culturally safe, culturally adapted cognitive assessment tools

- Geographic and cultural barriers that prevent Indigenous peoples from accessing health services; therefore, the data may not represent actual dementia prevalence

- Difficulties in identifying Indigenous peoples within administrative health data

- Restrictive definitions of dementia in administrative data algorithms

Jacklin K, Pace JE, Warry W. Informal dementia caregiving among Indigenous communities in Ontario, Canada. Care Management Journals. 2015 Jun 1;16(2):106-20.
Warren LA, Shi Q, Young K, Borenstein A, Martiniuk A. Prevalence and incidence of dementia among indigenous populations: a systematic review. International psychogeriatrics. 2015 Dec;27(12):1959-70.

Neuropsychological assessment with Indigenous Peoples

- Cultural appropriateness can refer to congruence between whether skills used to perform well on a test are valued in any given culture, which can lead to underestimates of performance (Avila et al., 2020)
  - e.g., speeded task performance versus slow and careful performance

- Linguistic diversity (i.e., diversity relative to how the test was developed and normed) can result in underestimates of neuropsychological test performance (Franzen et al., 2020)

- Few years of education can result in underestimates of neuropsychological test performance (Franzen et al., 2020)

Neuropsychological assessment with Indigenous Peoples

- Normative data can equate biases in measurement (if done properly; O'Connell et al., 2021)

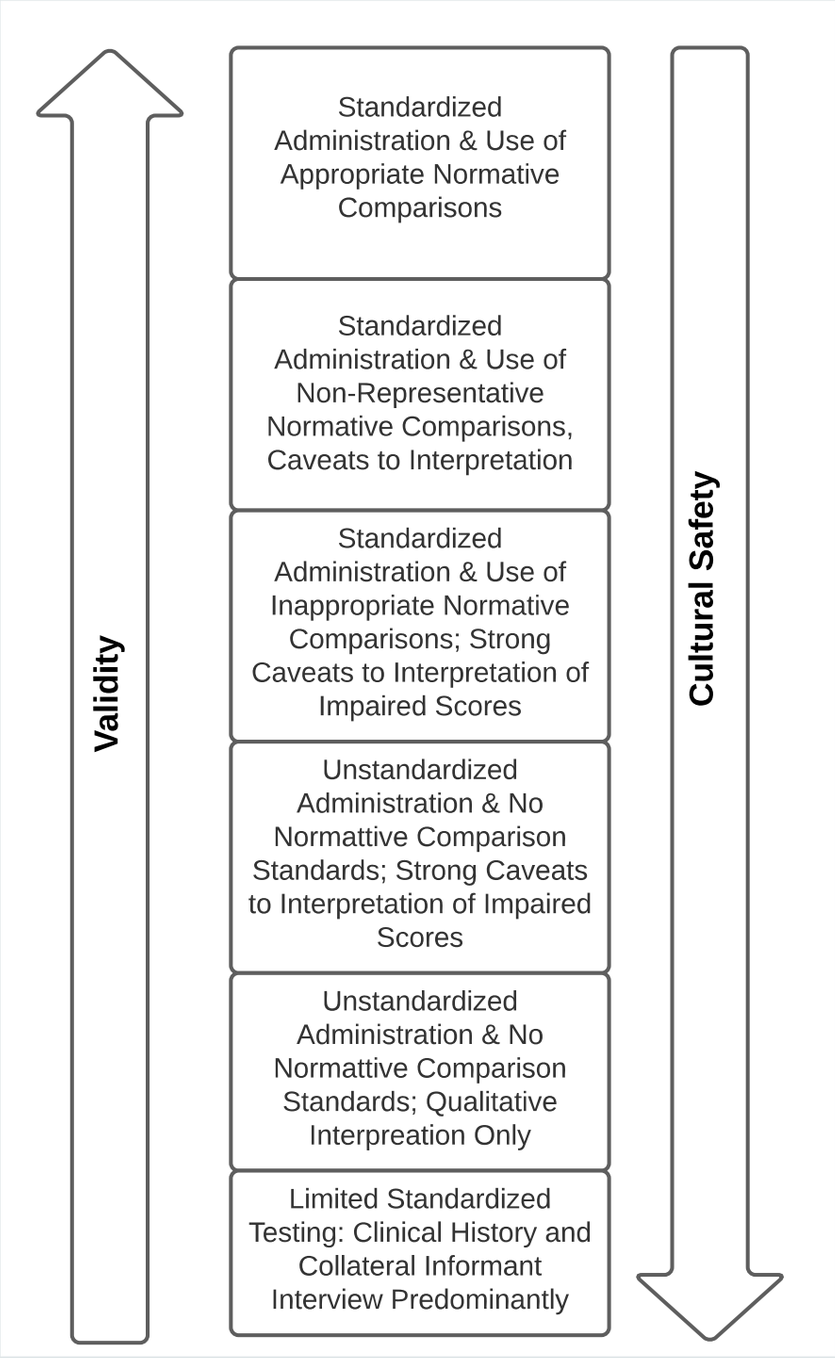
- No known neuropsychological normative comparison standards exist for the Indigenous Peoples of Canada (O'Connell et al., 2022)

- No known evidence on measurement invariance of neuropsychological tests for Indigenous Peoples has been reported (O'Connell et al., 2022), and data on differential item functioning or measurement invariance is needed for clinical use (Pedraza & Mungas, 2008; Avila et al., 2020)

Neuropsychological assessment with Indigenous Peoples

- Standardized testing can be inappropriately used, including with Indigenous Peoples

- Inappropriate testing can be harmful (O'Connell et al., 2022)

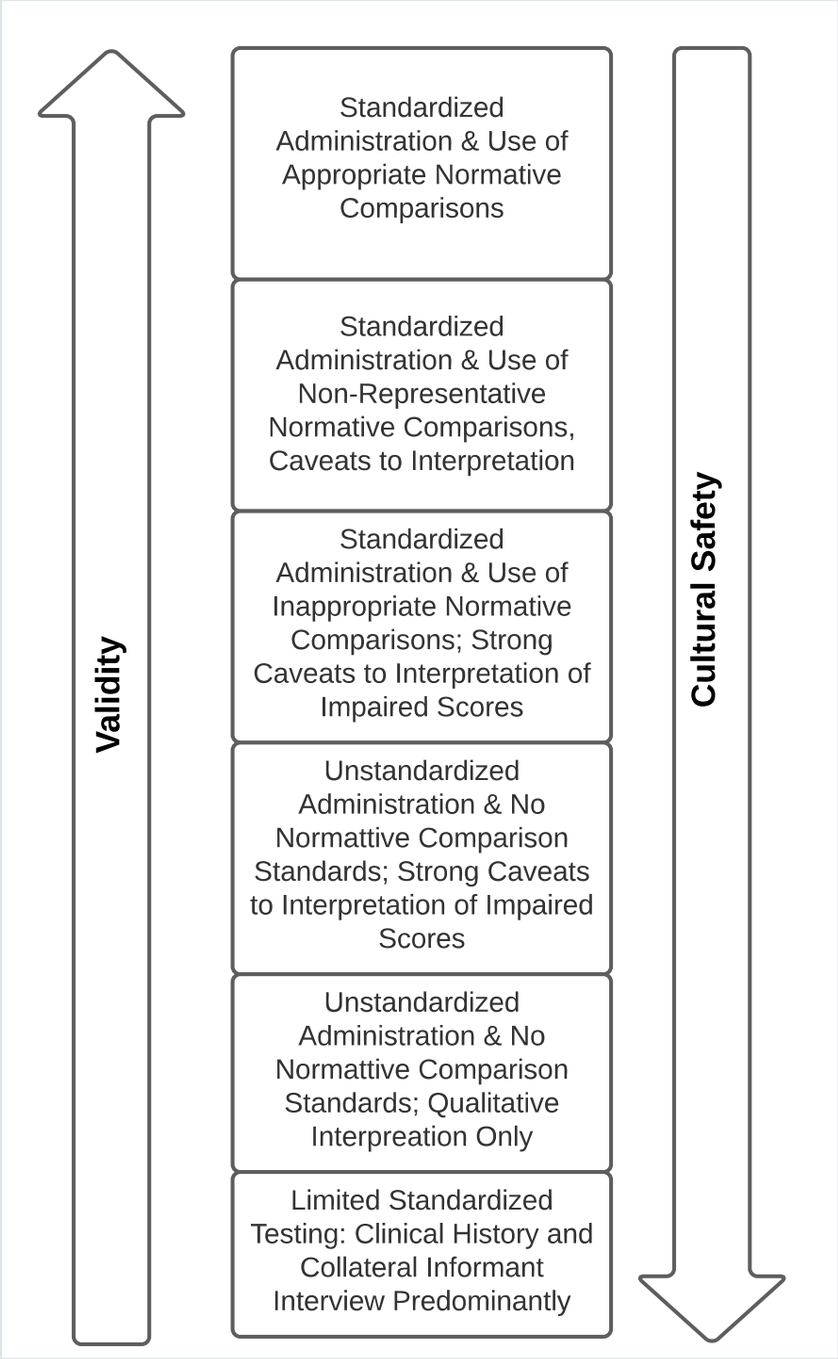


O'Connell, M. E., et al. including Walker, J. (2022). Neuropsychological assessment with Indigenous Peoples in Saskatchewan: A lesson in cultural humility. In Irani, F. (Ed.) A handbook of cultural diversity in neuropsychological assessment: developing understanding through global case studies. Routledge.

Neuropsychological assessment with Indigenous Peoples

- Under some circumstances it is best to choose not to administer such tests and use interview data predominantly (O'Connell et al., 2022)
  - If reasons for a low score are likely to extend beyond cognitive impairment
  - Consider the potential harm associated with inappropriate assessment

- Alternatively, assessment procedures are administered but interpreted qualitatively or with great caution (Thompson et al., 2005).


Validity
Standardized Administration & Use of Appropriate Normative Comparisons
Standardized Administration & Use of Non-Representative Normative Comparisons, Caveats to Interpretation
Standardized Administration & Use of Inappropriate Normative Comparisons; Strong Caveats to Interpretation of Impaired Scores
Unstandardized Administration & No Normattive Comparison Standards; Strong Caveats to Interpretation of Impaired Scores
Unstandardized Administration & No Normattive Comparison Standards; Qualitative Interpreation Only
Limited Standardized Testing: Clinical History and Collateral Informant Interview Predominantly
Cultural Safety

Cultural ‘adaptations’

- Many attempts have been made to create culturally appropriate cognitive screening tools

- These were developed from a colonial perspective – led by researchers or clinicians to map onto Eurocentric screening tools currently in place

- Our team embraces Indigenous research and community-based participatory research methods – we chose a tool **developed with** and not merely for Indigenous peoples

Australia and community-based co-design of cognitive screening

- Researchers in Australia began in 2006 to create a dementia screen grounded in the cultural beliefs of Aboriginal communities in Australia (LoGiudice et al., 2006)
- The Kimberley Indigenous Cognitive Assessment (KICA) used community-based participatory research, consultation with linguists and clinical experts, as well as translation and back-translation from English to Walmajarri, to craft a tool that was embedded in cultural knowledge and language
- The KICA has revealed a high prevalence of dementia diagnoses in more than one Aboriginal community (Smith et al., 2009; Smith et al., 2008)

Development of the Canadian Indigenous Cognitive Assessment (CICA) Tool with Anishinaabe communities in Manitoulin Island, Ontario

1. Community Consultation and Engagement

Recruitment of expert language speakers & knowledge holders to guide the development of the CICA

- Recruitment of a Community Advisory Council (CAC) to guide the work
  - Advised the research team and ensured community voice and participation.

- Recruitment of an Expert Anishinaabe Language Group (EALG)
  - Helped adapt the KICA into Anishinaabemwin

Jacklin K, Pitawanakwat K, Blind M, O'Connell ME, Walker J, Lemieux AM, Warry W. Developing the Canadian Indigenous Cognitive Assessment for Use With Indigenous Older Anishinaabe Adults in Ontario, Canada. Innovation in Aging. 2020;4(4):igaa038.

2. Adaptation and Translation

Expert language speakers & knowledge holders translate the CICA

- Adapted questions were analyzed for clarity and face validity, sentence structure was simplified, and the rationale for each question was fully explained.

- Final draft was then reviewed with the EALG to ensure the translation to Anishinaabemwin, and back translation to English was accurate
  - The CAC also reviewed the questions and approved it for piloting.

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3. Piloting the CICA

Expert language speakers & knowledge holders translate the CICA

Community members provided feedback on the pilot adaptation:

- Some felt that the questions brought up past traumas including impacts of colonialism, residential schools, banning of cultural practices, intergenerational trauma
  - E.g. The KICA asks to run a comb through their hair. Community members emphasized the sacredness of hair.
- Highlighted the need to account for cultural beliefs, values, and practices
- Back translation from Anishinaaabemwin to English was not always clear

Guidance from community members was essential to reflect linguistic and cultural nuances needed for a culturally safe adaptation.

Jacklin K, Pitawanakwat K, Blind M, O'Connell ME, Walker J, Lemieux AM, Warry W. Developing the Canadian Indigenous Cognitive Assessment for Use With Indigenous Older Anishinaabe Adults in Ontario, Canada. Innovation in Aging. 2020;4(4):igaa038.

4. Reliability of the CICA

Establish inter-rater reliability (individuals assessed twice in one day; once in morning by assessor A, once in afternoon by assessor B)

To establish inter-rater reliability, CICA assessments were conducted twice in one day: once in the morning by assessor “A”, and then once in the afternoon by assessor “B”.

- 15 participants
  - 7 women, 8 men
  - 6 younger (45 – 65)
  - 9 older (66-96)
  - 9 living with memory issues
- Assessments conducted in morning and afternoon by two separate assessors

Reliability assessments conducted by: Louise Jones, Karen Pitawanakwat, Melissa Blind

Walker JD, O'Connell ME, Pitawanakwat K, Blind M, Warry W, Lemieux A, Patterson C, Allaby C, Valvasori M, Zhao Y, Jacklin K. Canadian Indigenous Cognitive Assessment (CICA): Inter-rater reliability and criterion validity in Anishinaabe communities on Manitoulin Island, Canada. Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring. 2021;13(1):e12213. DOI:10.1002/dad2.12213

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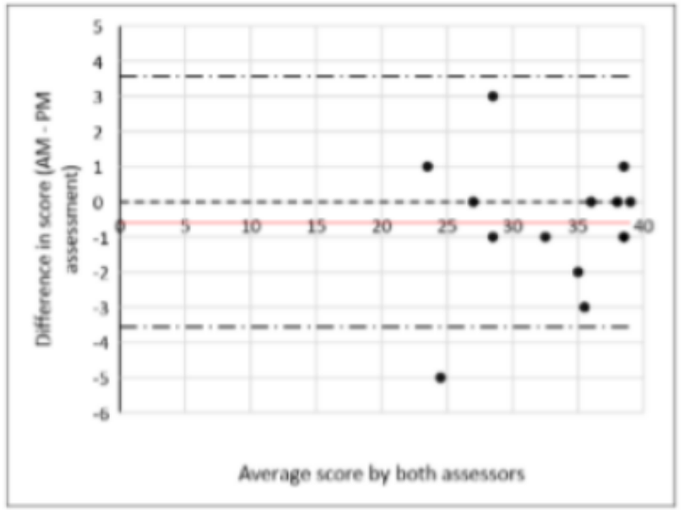

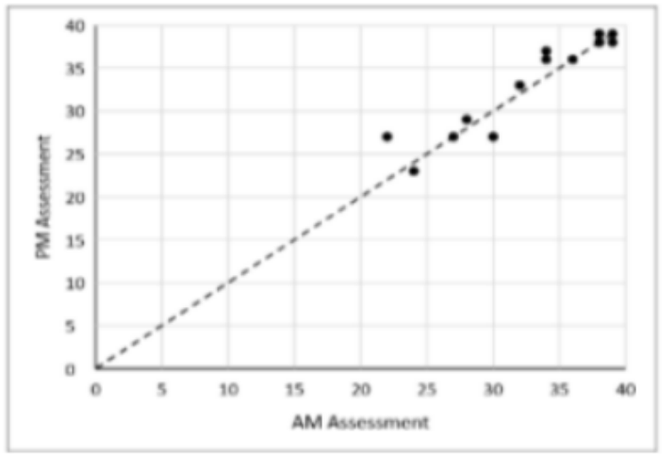

The CICA-ON shows strong inter-rater reliability.

- Intra Class Correlation (ICC) between total scores of two assessors was 0.94 (0.85,0.98).

Walker JD, O'Connell ME, Pitawanakwat K, Blind M, Warry W, Lemieux A, Patterson C, Allaby C, Valvasori M, Zhao Y, Jacklin K. Canadian Indigenous Cognitive Assessment (CICA): Inter-rater reliability and criterion validity in Anishinaabe communities on Manitoulin Island, Canada. Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring. 2021;13(1):e12213. DOI:10.1002/dad2.12213

5. Validating the CICA

Establish criterion validity (Comparison of CICA & Geriatrician assessments)

To establish criterion validity for the CICA, we compared a CICA assessment to the assessment by a Geriatrician.

The Geriatric assessment included:

- A clinical assessment
- A caregiver corroborative review
- Administration of MoCA, MMSE, RUDAS
- Vitals and medication review

A diagnosis was not given, but participants consented to preliminary results being shared with their primary care provider.

CICA validation team April 2018

Walker JD, O'Connell ME, Pitawanakwat K, Blind M, Warry W, Lemieux A, Patterson C, Allaby C, Valvasori M, Zhao Y, Jacklin K. Canadian Indigenous Cognitive Assessment (CICA): Inter-rater reliability and criterion validity in Anishinaabe communities on Manitoulin Island, Canada. Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring. 2021;13(1):e12213. DOI:10.1002/dad2.12213

5. Validating the CICA

Establish criterion validity (Comparison of CICA & Geriatrician assessments)

95 people were approached

- 4 declined to participate

91 people

- 19 people were removed by research staff due to high recruitment. Research staff lost contact with 2 people

70 people were assessed with CICA

- 15 people did not complete a clinical assessment

55 completed both a CICA & clinical assessment

[1 was unable to respond to Chapters 7-10 due to vision loss. (Their score was prorated by NewScore = RawScore (Chapters 1-6, 11)/22*39)]

Walker JD, O'Connell ME, Pitawanakwat K, Blind M, Warry W, Lemieux A, Patterson C, Allaby C, Valvasori M, Zhao Y, Jacklin K. Canadian Indigenous Cognitive Assessment (CICA): Inter-rater reliability and criterion validity in Anishinaabe communities on Manitoulin Island, Canada. Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring. 2021;13(1):e12213. DOI:10.1002/dad2.12213

The CICA-Anishinaabe shows good sensitivity and specificity for dementia

Dementia vs MCI and Normal – Using 34 as a cut off point

	Sensitivity	Specificity	Area under the Curve (95% Confidence Interval)
Full Sample (N=55)	1	0.85	0.98
English Speakers (N=35)	1	0.87	0.97
Anishinaabemwin (N=20)	1	0.78	0.99
Female (N=25)	1	0.90	1.00
Male (N=30)	1	0.79	0.95

Walker JD, O'Connell ME, Pitawanakwat K, Blind M, Warry W, Lemieux A, Patterson C, Allaby C, Valvasori M, Zhao Y, Jacklin K. Canadian Indigenous Cognitive Assessment (CICA): Inter-rater reliability and criterion validity in Anishinaabe communities on Manitoulin Island, Canada. Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring. 2021;13(1):e12213. DOI:10.1002/dad2.12213

CANADIAN INDIGENOUS COGNITIVE ASSESSMENT (CICA – ON)

Date:_____

Assessor:_____

Participant:_____

I would like to ask you a few questions about your memory. Some will be easy or simple. Answer as best you can.

CHAPTER 1: ORIENTATION (__ / 3)

What time of day is it right now? (1)	
What time are we in right now; is it spring, summer, fall or winter? (1)	
Do you know where you are right now? What is this place? (1)	

CHAPTER 2: RECOGNITION AND NAMING (__ / 6)

Hold up each item in turn and ask:

What is the name of this: *Hold up* ***spoon*** (1)	
What is the name of this: *Hold up* ***cup*** (1)	
What is the name of these: *Hold up* ***matches*** (1)	

Hold up each item in turn and ask:

What is the purpose of this? *Hold up* ***Spoon*** (1)	
What is the purpose of this? *Hold up* ***Cup*** (1)	
What is the purpose of these? *Hold up* ***Matches*** (1)	

- The CICA-Anishinaabe consists of 12 Chapters
- Administering the CICA takes approximately 10 minutes

CICA in a Memory Clinic

Of 79 consecutive Rural and Remote Memory Clinic cases, 58 completed the CICA

Exclusion criteria:
- Consent for participation in optional research
- Completion of the 2 hour neuropsychological battery

- Diagnostic process by neurologist and neuropsychologist blind to CICA data

Participants (*N* = 58)

- Ages between 38-90 years; *M* = 65.3; *SD* = 12.3
- 52% male; of *n* = 34 with data for ancestry: 56% were of European origin; 15% were First Nations; 21% were Métis; 9% reported ‘other’

Results

- Classification accuracy was measured by the area under the receiver operating characteristic (ROC) curve (AUC) cut off that maximized sensitivity & specificity

- Strong accuracy for diagnoses of **dementia** (*n* = 21) **vs no dementia** (SCI and MCI; *n* = 37) **AUC = 0.78** (0.66 – 0.92) – cut off 35/40
- Accuracy was high for **cognitive impairment** (dementia and MCI; *n* = 35) **vs SCI** (*n* = 23) **AUC = 0.84** (0.74 – 0.94) – cut off 36/40
- As is typical, accuracy was lower for **MCI** (*n* = 14) **vs dementia** (*n* = 14) **AUC = 0.67** (0.49 – 0.85) – cut off 34/40

Why use the Canadian Indigenous Cognitive Assessment (CICA)?

- The CICA is a culturally relevant tool that takes language, culture and trauma into account

- May lead to earlier, more accurate diagnosis and improved health outcomes.

- Identify supports for the person and the family and caregivers, the community

Ongoing Work & Next Steps

- Confirmed the adaptation, and additional minor refinements, with community advisory research council in File Hills Qu'Appelle Tribal Council

- Developing the CICA-u with an urban Indigenous population in Calgary.

- Renewed funding from the Public Health Agency of Canada
    - Development of an online CICA Training Program
    - Implementation of CICA into EMRs with the Anishinabek Nation

    - Developing guidelines to support future adaptations and implementation of CICA Tools

Thank you

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