

Nakoda Oyáde Ománi Agiktuža: Adapting the Canadian Indigenous Cognitive Assessment in a Nakoda First Nation Community

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Article

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Abstract

Increasing rates of dementia in First Nations populations require culturally grounded approaches to dementia diagnosis and care. To respond to the need for a culturally appropriate cognitive assessment tool, a national team of health services researchers and community partners, guided by a Nakoda Advisory Group, aimed to adapt the Canadian Indigenous Cognitive Assessment tool for a Nakoda First Nation in Carry the Kettle First Nation, Saskatchewan, Canada. The adaptation of the CICA for a Nakoda First Nation community resulted in a slightly modified version of the CICA signalling that the CICA requires minimal adaptation to be used in different First Nations contexts.

Résumé

Les taux croissants de démence constatés dans les populations des Premières Nations exigent des approches de diagnostic et de soins fondées sur la culture. Pour répondre au besoin d'un outil d'évaluation cognitive culturellement pertinent, une équipe nationale de chercheurs en services de santé et de partenaires communautaires, guidée par un groupe consultatif de membres de la Première Nation nakota, a cherché à adapter l'outil Canadian Indigenous Cognitive Assessment (CICA) à la Première Nation nakota Carry the Kettle, établie en Saskatchewan, au Canada. L'adaptation du CICA à une communauté de la Première Nation nakota a abouti à une version légèrement modifiée de cet outil, ce qui indique qu'une adaptation minimale est requise pour son utilisation dans différentes communautés de Premières Nations.

Introduction and background

Rising rates of dementia in Canada represent a growing concern for an increasingly ageing population, with a projected 1 million Canadians living with dementia by the year 2030 (Alzheimer's Society, 2022; Public Health Agency of Canada, 2017). Although there is a dearth of data concerning dementia in First Nations populations living in Canada, the limited research available suggests that rates of dementia for First Nations populations living in Canada are higher than for the general population, and First Nations people experience dementia at a younger age than non-First Nations people, on average (Jacklin & Walker, 2020; Jacklin et al., 2013; Warren et al., 2015). These increased rates may be attributed to the ageing of First Nations populations (Statistics Canada, 2022) but may also be impacted by higher rates of related comorbidities (FNIGC & Walker, 2020), such as diabetes, a known risk factor for dementia (Livingston et al., 2020), and social inequities that are underpinned by colonization and disruption (Jacklin et al., 2013; Halseth, 2018). Social and structural determinants of Indigenous health, such as historical and ongoing impacts of colonization, income, education, and food security (Greenwood et al., 2015; Reading, 2018; Smylie and Firestone, 2016) necessitate a distinct approach to dementia assessment and care that is culturally safe and culturally grounded. Unfortunately, commonly used cognitive assessment tools present limitations for use with Indigenous people including cultural and educational biases, which may result in over and underdiagnoses of dementia (Jacklin et al., 2020).

To respond to the need for early and accurate detection and diagnosis of dementia for First Nations populations living in Canada, a national team of community partners and researchers developed the Canadian Indigenous Cognitive Assessment (CICA) Tool with Anishinaabe communities on Manitoulin Island, Ontario, Canada (Jacklin et al., 2020). The CICA, available in Anishinaabemwin and English at www.i-caare.ca, is a culturally relevant cognitive assessment tool, consisting of 11 chapters, each representing a domain of cognition that is assessed by the

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tool. The CICA was adapted from the Kimberley Indigenous Cognitive Assessment (KICA), a cognitive assessment tool developed and validated with Indigenous communities in the Kimberley region of Western Australia (LoGiudice et al., 2006). The process to adapt the CICA from the KICA involved adaptation of the KICA to ensure its cultural relevancy with Anishinaabe communities on Manitoulin Island; translation of the adapted tool into Anishinaabemwin; back-translation to English; and piloting the resulting tool (Jacklin et al., 2020). Following the work to adapt the tool, the CICA was tested for inter-rater reliability and construct validity (Walker et al., 2021).

A dementia community research advisory committee (CRAC) in File Hills Qu'Appelle Tribal Council (FHQTC), Saskatchewan, Canada, identified a need to assess and adapt the CICA for their communities. Saskatchewan's rural setting and geographically dispersed population pose a challenge to accessing specialized health-care services (Morgan et al., 2015), including geriatric and dementia care; consequently, access to culturally grounded dementia care for First Nations populations in Saskatchewan is limited, despite Indigenous people making up nearly 11% of the total population (Statistics Canada, 2017). The CRAC undertook this work as part of a national research study with researchers that included an Indigenous epidemiologist, a clinical neuropsychologist, a geriatrician, a medical anthropologist, and an Indigenous family physician who were collectively working to adapt and validate the CICA for diverse Indigenous populations across Canada. This paper outlines the work to adapt the CICA for the Nakoda people in one of the communities served by FHQTC, Carry the Kettle Nakoda Nation, Saskatchewan.

Methods

Ethics

Research ethics approval was granted by Laurentian University (REB file #6013811, July 2018) and McMaster University (Delegated Ethics Approval, May 26, 2023). The work emerged from a community priority set by the dementia CRAC at FHQTC, and the research activities were approved by the CRAC and Carry the Kettle First Nation.

Setting

FHQTC is a political and service organization delivering programs and services to the 11 First Nations in the Treaty Four Territory representing five distinct language groups: Nakoda, Saulteaux, Cree, Dakota, and Lakota. During initial discussions about pursuing work to adapt the CICA, a member of the CRAC advocated for the translation into Nakoda as it is an endangered language (The Canadian Press, 2021) with few language speakers left, and work dedicated to adapting the tool into Nakoda was seen as one mechanism to revitalize the language. Following group consensus to adapt the tool to Nakoda, a CICA information session was organized, and the Nakoda Advisory Group (NAG) was formed. The original group consisted of 6 Elders, 1 male, and 5 females from Carry the Kettle Nakoda Nation. During the study, two of the females passed away and their work on this project was honoured. The NAG was responsible for translating the CICA into the Nakoda language, adapting the CICA to the Nakoda cultural, historical, and community context, and guiding the overall direction of the work. Carry the Kettle Nakoda Nation, a Nakoda-speaking community in Southeastern Saskatchewan, is located

approximately 80 km east of Regina, Saskatchewan in Treaty 4 Territory. There are approximately 460 First Nations residents, of which approximately 16% report Nakoda as their first language (Statistics Canada, 2018).

Data collection and analysis took place from June 2018 until August 2022. The process involved the adaptation of the CICA into Nakoda, and back-translation into English, as well as the formation of the NAG to guide the adaptation process.

Community context and engagement

In alignment with Indigenous research methodologies (Smith, 1999; Wilson, 2020), the process to adapt the CICA with the NAG from Carry the Kettle was iterative, dynamic, and responded to community needs and priorities. The activities were supported by a community-based research coordinator who was hired directly through FHQTC. To begin the adaptation process, members of the project team held 6 three-hour in-person meetings with the NAG in July and August of 2018. Due to shifting community priorities, the group stopped meeting in Fall 2018 and reconvened in late 2021. In light of the COVID-19 pandemic, meetings in 2021–2022 were remote and held virtually, via Zoom. Community engagement was ongoing throughout the adaptation process, including regular meetings with the CRAC and the NAG, community presentations, and a summary presentation to the health directors of the FHQTC communities.

Adapting the CICA with the NAG

Each of the eight adaptation meetings opened and closed with a prayer. To begin the work, the initial monthly meetings focused on reviewing and discussing the 11 chapters of the CICA tool that represent domains of cognition. The NAG members imparted knowledge on the complexities of the Nakoda language and brought forward challenges with translating a cognitive assessment tool from English into Nakoda. Throughout the process of translating the tool from English to Nakoda, the NAG often struggled to agree on the most appropriate translation into Nakoda. The group spent a considerable amount of time reflecting and discussing whether certain English words could even be translated into Nakoda.

To respond to the challenges that the NAG was having in translating the language of the tool, the NAG suggested recruiting another well-known Nakoda language speaker and teacher, who was more fluent in the language and could assist with the direct translation. The individual brought forward some concerns regarding the process of translation, as well as nuances about the Nakoda language that shaped the direction of the work. He identified the regional variations in the Nakoda language, the relative newness of Nakoda being in a written form, and the scarcity of individuals who speak the language. These reflections raised questions about the practical need for a cognitive assessment administered in Nakoda and prompted a larger discussion with the NAG about the direction of the work and whether they wanted a fully Nakoda version as a final product of this collaborative work.

Iterative process with national CICA team

Throughout the consultation process with the NAG, the national CICA research team, which included the community and academic principal investigators from other CICA research sites and the community-based research coordinator, met bi-monthly and

shared progress updates and sought feedback from the perspectives of clinicians, cognitive scientists, measurement experts, Indigenous community partners, and research support staff who support community-driven CICA research across Canada. In this way, the national CICA research team prioritized sharing insight to ensure the standardization of the adapted tool. The collective national feedback on the suggested Nakoda adaptations was then taken back to the NAG for review and consideration.

Results

Each chapter of the CICA assesses a domain of cognition and some of the chapters generated more discussion than others. The results for the detailed discussion by chapter are presented below, with a focus on the chapters that assessed orientation, verbal comprehension, verbal fluency, and frontal/executive function.

Chapters/Domains that required substantial discussion

Orientation

The chapter on orientation required a lot of dedicated discussion from the NAG on how to appropriately measure and describe time. In Chapter 1 of the CICA, the first question asks the individual being assessed, “*What time of day is it right now?*”. The NAG noted that there is no way to ask someone, “What day is it?” in Nakoda as they do not use the seven days of the week used in Western culture. The NAG proposed to change, “*What time of day is it right now?*” to “*What time is it?*” as it was simpler to back-translate into Nakoda; however, the national CICA team had concerns that this proposed change made the question too vague and might be more challenging than the CICA to answer. There was also discussion around the question, “*What time are we in right now; is it spring, summer, fall or winter?*”. This question was slightly shortened to, “*What season are we in right now?*” which would make it easier to translate into Nakoda. The national CICA team was concerned with the simplification of this question and flagged that if the seasons were not explicitly provided as options to answer the question, then the Nakoda version would be more challenging than the CICA. The last question in the Orientation chapter asks, “*Do you know where you are right now? What is this place?*”. The NAG felt that asking, “*What is this place?*” might be confusing for the individual being assessed as it was not clear if they were referring to the room, the building, or the community they were in. The NAG proposed to change the question to “*Do you know where you are right now? What is this village called?*” as using the term “village” was seen as more appropriate and relevant for the group. When this proposed change was brought to the national CICA team there were concerns that the revised question asks for a much more specific response than what the CICA asks for, therefore making it more challenging and would be a substantial change to the cognitive assessment. When this feedback was provided to the NAG, they agreed to retain the original wording but were disappointed that their revised wording could not be used.

Verbal comprehension

In Chapter 4 of the CICA, the individual being assessed is asked to, “*Pick up this piece of paper, fold it once, and give it back to me*”. There was substantial conversation around the relevancy and appropriateness of the paper being used in this chapter. The NAG had reservations about the use of a piece of paper in this chapter due to its connotations with Residential Schools and

suggested that the piece of paper be replaced by a tea towel, to be more accessible and familiar for Nakoda Elders. The NAG proposed to change this question to, “*Pick up this tea towel, fold it once and give it back to me*”. The national CICA team understood the need to change this element of the verbal comprehension question to ensure the cultural safety of the tool but pointed out that it is important that the tea towel not have a fold or crease in it when presented to the individual being assessed as this could be a cue to the individual being assessed, thus making the task easier to perform.

Verbal fluency

Chapter 5 was another question that required longer discussions with the NAG. The CICA asks, “*Next I (we) will ask you to name as many animals as you can in one minute, wild animals or domesticated animals. Start (or please start now)*”. Like discussions around the Orientation chapter, the group debated over how best to specify a time limit in the Nakoda language. Ultimately, the NAG proposed to reframe the question to, “*Next name all the animals in one minute*”. When the national CICA team reviewed this proposed change, there was a discussion about whether the inclusion of the prompt in the CICA to ask the individual being assessed to think about wild and domestic animals helps provide a cue and the removal of this type of prompt would make this adaptation more challenging. As a result of this feedback to the NAG, they agreed that the original wording would be acceptable.

Frontal/Executive function

In Chapter 8, the individual being assessed is asked to, “*Copy these letters that you see here (show or point) on this piece of paper (show or point)*”. The individual is then asked to copy a series of Xs and Os onto a piece of paper. When reviewing this chapter, several members of the NAG suggested that “letter” be changed to “symbol”; some members believed that there was a Nakoda word for “letter”, while others disagreed. After considerable discussion, the NAG proposed to change the question to “*These letters I showed you, write them the way that they are*”. When this proposed change was brought forward to the national CICA team there was concern that the proposed change made the question more challenging to understand as the assessor would be pointing to the letters, rather than “showing” the letters. As a result of this feedback to the NAG, they agreed that the original wording would be acceptable.

Chapters/Domains that required some discussion: Free recall, cued recall, and praxis

The final three chapters did not generate much discussion during NAG meetings, and ultimately no changes were recommended. Chapter 9 assesses an individual’s ability to recall freely, asking the individual being assessed, “*Do you remember those drawings I showed you? In any order, tell me what was drawn.*” If the individual can recall each of the five drawings previously shown, then they could skip Chapter 10, which assessed cued recall. If individuals could not recall each drawing in Chapter 9, they were prompted with the example drawing and then asked again to recall each drawing. Chapter 11 tells the individual being assessed, “*I have already loosened this small bottle. Pour however much you want into the small cup. Show me how to use this spoon.*” NAG members discussed shortening the questions asked in Chapters 9 and 11, as the Nakoda translation was shorter but decided not to pursue any changes following advice from the national CICA team.

Chapters/Domain that required little or no discussion: Recognition & naming, registration, recall, and visual naming

The chapters focusing on recognition and naming, registration, recall, and visual naming required very little discussion by the NAG to ensure its cultural relevancy for the Nakoda people. After consulting with the NAG, it was decided that these questions would not require adaptation.

In the end, direct Nakoda translations were made for two questions in the CICA. The question “What time are we in right now; is it spring, summer, fall or winter?” can be translated to “Nagáha táde’yye dágu he; Wédu, mnogédu, ptáyédu, or waniyedu?”, and the questions “Do you know where you are right now? What is this place?” are translated to “Dóki ya’ú né snokyáya he? dóken éjiyabi?”. These Nakoda translations may be used if the individual being assessed with the CICA is a fluent language speaker.

Reflections on the process to adapt the CICA with the NAG

While the initial intent was to have a fully translated Nakoda version of the tool, the challenges with Nakoda translation, lack of fluent Nakoda language speakers, the iterative feedback from the national CICA research team, and the recognized need for a culturally safe cognitive assessment for use with Nakoda individuals prompted a rethinking of the priority placed on having a fully translated Nakoda version of the tool. The NAG members shared that they believed that the CICA is ultimately based on Western, biomedical understandings of measuring and detecting mild cognitive impairment and dementia. The NAG emphasized that understanding and detecting dementia in a Nakoda context requires an approach grounded in Nakoda knowledge. The final meetings of the NAG prioritized knowledge sharing from the Nakoda Elders on appropriate changes to the English version of the CICA tool to reflect the distinct cultural and linguistic nuances of the Nakoda people in Carry the Kettle Nakoda Nation. They determined that an English version would be sufficient with as much Nakoda translation as possible.

However, this tension between the desire for this project to contribute to the regeneration of the Nakoda language, a language that has few speakers, and the desire to make available a validated cognitive assessment tool for Nakoda people was challenging. Notably, the national CICA research team was motivated to see as few changes to the previously validated version as possible to ensure the standardization of the adapted tool (Khan et al., 2022); unfortunately, what the NAG perceived as minor changes to the English wording to better reflect their Nakoda language were perceived by the national research team as unnecessarily introducing more complexity and variability to an already validated tool. During a NAG meeting to discuss the feedback provided by the national CICA team about the proposed changes in the Nakoda adaptation of the tool, members of the NAG became increasingly frustrated because they felt that their efforts to adapt the tool were being undermined and were not being reflected in the final version of the tool. For the research team, this brought important learning on communication, respect, and the need to establish clear processes for decision-making when there are disagreements, such as culturally appropriate meditation by an Elder.

Discussion

The overall objective of the research project was to adapt the CICA for appropriate use with older Nakoda adults in Carry the Kettle

Nakoda Nation, Saskatchewan, Canada. The results of this work highlight several key findings around consideration of linguistic and cultural differences when adapting a cognitive assessment tool with First Nations people, and the importance of prioritizing Indigenous ways of approaching and understanding cognition and dementia. Under the guidance of the NAG, the CICA was adapted into Nakoda and back-translated into English, following the same process as the work on Manitoulin Island to adapt the CICA from the KICA. The research has resulted in a slightly modified version of the CICA that is culturally relevant for the Nakoda people living in Carry the Kettle Nakoda Nation, Saskatchewan. In the end, only one change was made to the content of the CICA to ensure cultural relevancy for the Nakoda people in Carry the Kettle Nakoda Nation. The proposed change to Chapter 4, which tests verbal comprehension and asks a person to fold a tea towel in place of a piece of paper, was brought forward to the national CICA team for discussion wherein there was a group consensus that this change would not substantially impact the verbal comprehension test enough to require retesting the tool. Based on the findings highlighted above, it is likely that the CICA requires minimal adaptation to be used in different First Nations contexts and it provides a trauma-informed option for people to use an unfolded towel in this chapter rather than a piece of paper.

Like the work to develop the KICA in the Kimberley region of Australia, and the CICA with Anishinaabe communities on Manitoulin Island, a great amount of time and detail was required during the translation process of the CICA into Nakoda. The Nakoda language is a complex language with many different dialects across North America; therefore, throughout the process of adapting the CICA into Nakoda and then back-translate into English, there were many conversations amongst the NAG about the most accurate translation of both language and concepts and sometimes the group did not resolve these differing views. One key example of the challenges of linguistic and cultural differences was during discussions around the Orientation chapter. The NAG members shared that concepts of time and orientation are not expressed in the same ways that they are understood in Western culture, a point that was similarly shared by advisory groups during the processes of developing the KICA and the CICA (Logiudice et al., 2006; Jacklin et al., 2020). This created difficulties in adapting the Orientation chapter into Nakoda, while simultaneously ensuring that the adapted chapter would measure orientation in the same way as previous versions of the CICA. In the end, the NAG did not use the English back-translation from Nakoda and kept the questions from the English version of the CICA developed on Manitoulin Island. This decision was partly connected to the low number of fluent Nakoda speakers who would actually require an assessment in the Nakoda language.

Similar to the process of adapting the CICA with Anishinaabe communities on Manitoulin Island, elements of the tool adapted for Nakoda people needed to be considered to ensure the cultural safety of the tool given their connection to experiences at Residential Schools (Jacklin et al., 2020). The process of adapting the Praxis chapter of the KICA with Anishinaabe communities required substantial discussion to ensure the cultural safety of the tool. The KICA asked the client to, “show me how to use this comb” which was rejected by the advisory group as hair is sacred in Anishinaabe culture. The revised praxis stimuli of a key were proposed instead, which was also rejected quickly given the connotations of Indigenous children being locked in rooms and closets in Residential Schools (Jacklin et al., 2020). Common to both adaptations was the guidance by local advisory committees and expert language speakers who ensured the adaptation was relevant

and appropriate for their communities. Collaboration and engagement with Indigenous leaders and community members are essential to ensuring that healthcare interventions align with the cultural context and needs of each distinct community (Chakanyuka et al., 2022).

The approach taken for the Nakoda adaptation mirrored the approach taken on Manitoulin which included monthly meetings with the community advisory group, and findings from those meetings were brought to the national CICA team. Given the miscommunications between the NAG and the national CICA team, further considerations for future adaptations may include having members of the advisory group attend bi-monthly national CICA team meetings to ensure that community priorities and perspectives are being honoured and reflected in the work and there is clear and respectful communication between all members involved in the work. Similarly, it may be pertinent that members of the national CICA team attend advisory group meetings throughout the adaptation process to encourage an ethical space of engagement (Ermine, 2007) that respects and reflects the diversity of the knowledge of the team.

Conclusions

This work produced a culturally informed version of the CICA for the Nakoda people in Carry the Kettle First Nation and highlights that minimal adaptation of the CICA is likely needed in a First Nations context. There is a need to reflect on the process for future adaptations of the CICA. Future work with First Nations partners should reflect a process of relationship-building and communication between community advisory groups and academic partners to help align priorities and perspectives. This process should be clearly defined at the outset of the work to ensure meaningful engagement and respectful relationships between all parties. Additionally, a key challenge to this work was the frustration experienced by the NAG in feeling as though their contributions to the translation process were undermined by the national CICA team. Future work to adapt the CICA into other First Nations' languages should consider whether an accurate translation would be possible and required for use for that First Nations group.

Limitations

One of the most substantial limitations of the project was the impact of the COVID-19 pandemic on the NAG's ability to meet in-person throughout the process of adapting the CICA tool into the Nakoda language. Considering the pandemic, the NAG meetings shifted their monthly meetings from in-person to an online platform. Conducting meetings online made it more challenging to review the content of the CICA tool to propose revisions and alter the dynamics of how the group interacted with one another. Throughout Zoom meetings, members of the group continually expressed the importance of gathering in-person. Future work to adapt the CICA should consider the feasibility of meeting in-person to prioritize the desired method of community partners to gather and connect as a group.

As previously noted, there are very few Nakoda language speakers living in Carry the Kettle First Nation. Unlike the CICA adaptation on Manitoulin Island where at the time the work was conducted, approximately 20% of the First Nations population reported Anishinaabemwin as their first language learned (Jacklin et al., 2020), very few members of Carry the Kettle Nakoda

Nation report that Nakoda is their first language learned. As a result, very few older First Nations adults living in Carry the Kettle Nakoda Nation would require a cognitive assessment to be conducted in Nakoda. Additionally, the process to adapt the tool to Nakoda may have happened more easily if there was dedicated space to talk about the nuances and intricacies of the Nakoda language as a group. Future adaptation studies should consider some of the linguistic challenges faced in this project to assess whether a translation is possible and, importantly, if it would truly benefit the community to have a cognitive assessment tool in their language.

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