Cultural Diversity in Neuropsychological Assessment
Developing Understanding through Global Case Studies
Farzin Irani, Desiree Byrd

Neuropsychological Assessment with Indigenous Peoples in Saskatchewan

Publication details
https://www.routledgehandbooks.com/doi/10.4324/9781003051862-17
Megan E. O'Connell, Ivan Panyavin, Lisa Bourke-Bearskin, Jennifer Walker, Carrie Bourassa
Published online on: 28 Feb 2022

How to cite:- Megan E. O'Connell, Ivan Panyavin, Lisa Bourke-Bearskin, Jennifer Walker, Carrie Bourassa. 28 Feb 2022, Neuropsychological Assessment with Indigenous Peoples in Saskatchewan from: Cultural Diversity in Neuropsychological Assessment, Developing Understanding through Global Case Studies Routledge
Accessed on: 18 Oct 2023
https://www.routledgehandbooks.com/doi/10.4324/9781003051862-17

PLEASE SCROLL DOWN FOR DOCUMENT

Full terms and conditions of use: https://www.routledgehandbooks.com/legal-notices/terms

This Document PDF may be used for research, teaching and private study purposes. Any substantial or systematic reproductions, re-distribution, re-selling, loan or sub-licensing, systematic supply or distribution in any form to anyone is expressly forbidden.

The publisher does not give any warranty express or implied or make any representation that the contents will be complete or accurate or up to date. The publisher shall not be liable for an loss, actions, claims, proceedings, demand or costs or damages whatsoever or howsoever caused arising directly or indirectly in connection with or arising out of the use of this material.
Section I: Background Information

Sociocultural Context and Perspective

The lead author and clinician practicing in the area of clinical neuropsychology (MEO) is a first-generation White settler on her father’s side and second-generation settler on her mother’s side. Despite working with humility to learn to be an Indigenous ally in Treaty 6 Territory and the Homeland of the Métis, as a clinician, MEO must be aware that she comes from a position of power and privilege and is, therefore, more at risk of perpetuating colonial practices. This introduction is an example of reflection and positioning of oneself, which begins the process of self-awareness and is one of the core steps involved in providing culturally safe clinical care. Cultural safety is a process, beginning with self-awareness, then involves seeking cultural sensitivity and cultural competency, and culminates in an environment of culturally safe clinical care. In this definition, cultural safety for Indigenous Peoples goes beyond cultural competency to being culturally secure and trauma informed regarding the continued violence and harm burdened by Indigenous Peoples. Clinical psychologists and clinical neuropsychologists are trained to constantly engage in reflective practices, but they might be more likely to focus this reflection on personal biases or countertransference reactions.

Colonial Context for Indigenous Peoples

When working with Indigenous Peoples, it is important to understand the history of colonialism and this history’s past, present, and future impacts on Indigenous Peoples. For those who are unaware, Canada, as an independent nation and as a dominion of Britain, has engaged in longstanding policies and practices to disenfranchise the independence, land ownership, and self-determination of the First Nations, Inuit, and Métis Peoples who have been inhabiting the geographic areas of North America for tens of thousands of years, which has implications for the health of Indigenous Peoples. In Canada, a concerted government effort in forced assimilation and cultural genocide included forced relocation onto reserve lands and forced attendance at residential schools, settings where abuses of children, including those involving interpersonal violence, were common. The country is attempting to heal by following the recommendations of the Truth and Reconciliation Commission and its limitations, but the impacts of intergenerational trauma, past and present racism persist. The perspectives of Indigenous Peoples for psychological health must be understood from this holistic perspective—the current client conceptualization in the context of the past, the present, and the colonial context. Understanding this history will foster awareness of the power of language, terminology, and Rights. As a clinical

DOI: 10.4324/9781003051862-17
neuropsychologist, you cannot determine if you provided culturally safe care; only your clients can determine this. Knowing this requires humility, an open mind, and willingness to elicit feedback. Stated another way, the power for determining culturally safe care does not lie with the clinical neuropsychologist; rather the clinical neuropsychologist must strive to provide an environment that fosters cultural safety in clinical practice.

**Geography and People**

The province of Saskatchewan (one of ten provinces and three territories that make up the North American country of Canada) is home to 1,178,681 individuals. Saskatchewan is a geographically vast area, occupying 651,900 km² (251,700 mi²). Consequently, nearly 60% of the population resides in small to medium population centers and rural municipalities. Historically, individuals residing outside the major population centers have experienced a lack of access to specialist medical care. Of the population of Saskatchewan, 13.5% self-identify as Indigenous, which includes First Nations, Métis, and Inuit Peoples, with each comprising much variability in culture and language. For example, there are 74 First Nations in Saskatchewan: 10 Salteaux Nations, 7 Dene Nations, 8 Nakota/Lakota/Dakota Sioux Nations, and 49 Cree Nations. Each First Nation has its own governance structures, and the First Nations governance structures interact with the provincial and federal colonial government systems. Préfontaine described the origins of the word Métis as “mixed,” Métis Peoples are a unique cultural and linguistic group whose ancestry includes members from various First Nations (commonly thought of as Cree or Salteaux but includes many Nations) and European settlers (from countries in Western Europe, notably France and Scotland, but also some from Eastern European regions).

**Language**

All Indigenous languages in Canada are at risk of extinction yet are considered to be protective factors for health. There are over 60 Indigenous languages spoken in Canada. For example, the Cree, who are the most widespread of Canada’s First Nations Peoples, speak five main dialects of the Cree language. The Saskatchewan Indigenous Cultural Centre supports language projects in Plains Cree, Woodland Cree, Swampy Cree, Nakota, Dakota, Dene, Lakota, and Saulteaux. Michif, which is the traditional language of the Métis, is also spoken in Saskatchewan. The threat of language loss is a growing concern, given the historical context of residential schooling and consequent lack of exposure of children to their ancestral language. However, community efforts to revive Indigenous languages are underway, with the establishment of immersion programs for students across the province and the growing demand for language education at times outpacing available teacher supply. The local health region has Cree interpreters available, but this is only one of the many languages spoken, and the clinic setting MEO and IP work within is not within the health region and so does not have access to these resources. The revitalization of the Language Act Bill C-91 reaffirms Indigenous rights as a fundamental issue that will help to ensure the survival of traditional knowledge systems, including language, and hopefully interpretation services will be more accessible in the future.

**Culture**

The cultural, spiritual, and educational backgrounds of the Indigenous Peoples of Saskatchewan are as diverse as the languages spoken. Culture is a lived experience; the way people communicate and interact with one another and builds on the premise that culture is shared norms, values,
and customs that influence the way health and wellness is established. Each First Nation has its own identity and community-based history of interaction with settler populations. According to Stonechild, some commonalities in traditional views include a belief that humans are one part of the interdependent circle of life, which also includes plant, animal, and (seemingly) inanimate features of nature. Each part of this circle of life includes a spiritual dimension, and wellbeing is achieved by relating to all facets of the circle of life; the aim of some ceremonies is to gain a better relationship with the spiritual dimension. Colonization has led to some integration of Indigenous spiritual beliefs with Christian beliefs. For example, Métis Peoples are varied in their religious and spiritual views, and some practice a mix of Christian and Indigenous spiritualism, others are Roman Catholic, and others practice various denominations of Protestantism.

**Education**

Indigenous Peoples of Saskatchewan have either directly experienced or have experiences via intergenerational transmission of the traumas experienced from the attempted cultural genocide with residential schools. The last residential school closed in 1996 in Saskatchewan. Educational policies ranged from isolation and assimilation in the residential school system to the present day which has more partnership-based approaches with First Nations, Métis, and government bodies. Due to the trauma associated with residential schools, asking about educational attainment, a common question for intake interviews in neuropsychology, can be a challenging area to discuss. Data are available from Statistics Canada detailing that over half of Indigenous Peoples have post-secondary qualifications, with higher levels of education for younger than for older cohorts. Nevertheless, the Indigenous Peoples of Saskatchewan experience an education gap relative to non-Indigenous Saskatchewanians, which has implications for workforce participation and lifetime earnings. The education gap is higher for Indigenous Peoples residing in rural settings than for those residing in urban settings. The education gap is being addressed with numerous Indigenous-specific educational programs. For example, the University of Saskatchewan has numerous initiatives to attract and retain Indigenous students, including small classes for Indigenous students with instructors who are culturally safe and engagement in cultural practices. Although as a group most Indigenous Peoples in Canada have achieved a high school diploma, estimates from 2016 were that 52% of Inuit Peoples, 32% of First Nations Peoples living off reserves, and 25% of Métis Peoples had less than a high school diploma.

**Communication**

Our practice is informed by the research findings and personal experience and advice/suggestions of colleagues, patients, and family members from Indigenous backgrounds. Recommendations frequently found in the literature highlight the importance of establishing initial rapport—starting with personal introductions, which are suggested to be less formal—and interpersonal comfort in the context of clinical setting, which ought to reduce possible discomfort and mistrust. First-hand experience of working with individuals from the Indigenous communities—particularly from those who are also involved in health care provision (e.g., nurses, medical doctors, social workers, etc.)—has provided the following tips for communication to establish a better therapeutic alliance and facilitate relational practice. Initial contact should be focused on establishing trust between the clinician and the patient. Relational practice involves genuineness and open communication. Our informal interview with an Indigenous caregiver who is also a healthcare provider suggested that male clinicians are advised to consider removing their necktie, rolling up the shirt sleeves in order to appear less “clinical” and “buttoned-up” and more open and receptive.
Nonverbal communication and body language are similarly important, with a consequent suggestion of being on a client’s level—“sit and listen”—potentially foregoing scribbling and note-taking in order to focus on rapport-building and being present in the moment. An important insight regarding verbal communication was provided by an Indigenous nurse from an Indigenous Northern community: “if they agree to everything you say and ask by saying yeah, aha, yep—they are probably not really listening to you.” The clinician should be cautious not to interpret the lack of direct eye contact as a sign of avoidance or disrespect; in fact, gaze avoidance is likely an indication of the opposite. An offer of “tea and snack” (a cup of tea, crackers, a slice of toast) to the patient and their family is a warm gesture that may serve as a solid first step in establishing a good working relationship. If the patient or their family, as a sign of respect or appreciation, offer a gift, the clinician is advised to accept it, as doing otherwise can be considered an insult. Health care practitioners oftentimes inform the family that they may not personally keep the gift (such as a beaver pelt)—instead asking the family’s permission to display their token of appreciation in the common area of the Health Clinic for everyone to enjoy.

Disparities in Health Conditions
The arrival of colonial settlers and the displacement of Indigenous Peoples from their traditional ancestral bases has resulted in ongoing cultural, spiritual, emotional, and physical violence, with consequent negative health outcomes, disparities, and inequities. These are evident across a number of metrics of particular relevance for neuropsychologists. Indigenous Peoples have higher rates of health problems than settler populations. These include, but are not limited to, infectious disease burdens, diabetes, hypertension, cardiovascular, and chronic renal disease, as well as diseases caused by environmental contamination, cigarette smoking, and substance use. Few data exist related to Saskatchewan, but fewer First Nations Peoples have a primary healthcare provider than for settler populations in Saskatchewan. First Nations in-patients tended to be younger than settler in-patients in Saskatchewan.

Dementia in Indigenous Peoples
Partially due to health disparities the rates of dementia are higher, and in recent years have increased at a faster rate among Indigenous Peoples in Alberta, Canada. Moreover, dementia tended to be diagnosed at a younger age in Indigenous Peoples, and the most common etiology was vascular, and males were more likely to have dementia, which is in contrast to the etiology and sex and gender profile of dementia in settler populations. Not only does the epidemiological profile of dementia look different in Indigenous Peoples relative to settler populations, but Indigenous Peoples also have different views of dementia than those from the dominant culture. A 2020 review of the research on Indigenous Peoples and dementia found that dementia was more often seen as a part of life versus as a biomedical disease, which appears to reflect a lack of stigma about dementia. This view is also reflected in views of some symptoms in a positive way (e.g., hallucinations could be viewed as demonstrating a strong connection with the spiritual dimension) and views of dementia as a disease that is Western.

Neuropsychological Approach
Standardized testing, such as is the cornerstone of clinical neuropsychological practice, can work against providing culturally safe practices and perpetuate colonialism for the following three reasons: (I) the role of tester and testee perpetuates colonialist power dynamics and can be contrary
to relational practices, (2) use of standardized testing that is not appropriate, either in the normative comparison standards or has not been explored for measurement invariance can lead to misidentification of cognitive status, and (3) use of standardized tests that are not culturally appropriate can lead to inadequate engagement with the testing process and underestimate cognitive ability. Development of culturally appropriate assessment procedures is a long and involved process for collaborative design and establishing evidence for psychometric properties, a process that has not been completed for many neuropsychological tests across cultures and has not been completed for Indigenous Peoples. There have, however, been gains made in the development of cognitive screening tools for Indigenous Peoples.

Due to lack of evidence for validity of cognitive screening tests when used with different cultural groups, a team of researchers, community partners, expert language speakers, Elders, and clinicians collaborated to develop the Canadian Indigenous Cognitive Assessment tool. The CICA was adapted from the Kimberley Indigenous Cognitive Assessment, a culturally grounded cognitive assessment tool developed with Aboriginal communities in Northern Australia. The adaptation process involved not only language translation and language interpretation but also cultural translation, with an iterative process of feedback about how the adaptation for language or cultural reasons could impact how cognition was measured. Evidence for validity of the CICA is in the process of being published but has been presented at an international conference.

The clinical setting MEO and IP tend to work within is an interprofessional memory clinic. The one-stop diagnostic Rural and Remote Memory Clinic (RRMC) model was devised to reduce travel burden for rural and remote residents of the province; consequently, the model includes a single full-day assessment with diagnosis provided by the end of day, and the authors MEO and IP practice clinically in this setting. The RRMC is an interprofessional clinic with a neuropsychology team, a neurologist, a nurse, a physical therapist, and a registered dietitian when available. To achieve the aim of providing a diagnosis to families by the end of the day, numerous changes were required to the typical practices of these health care professionals. Foremost, the clinic nurse sends each family requisitions for blood work to rule out potential medical causes of the cognitive impairment and an electrocardiogram to assess for potential contraindications for anticholinesterase medications. Families complete consent procedures, a medical history, and medication review with the clinic nurse. This information is provided to the interprofessional team, who subsequently joins the family for a joint interview (neurology, neuropsychology, and physical therapy). The interprofessional joint interview has the advantage of being time efficient but also allows families to share their stories only once and allows all team members to hear the clinical history.

After the joint interview, the patient completes a neurological exam while the family stays with the rest of the team. A typically presenting patient to the clinic attends a neuropsychological assessment, which is a brief battery of approximately two hours that assesses the domains of premorbid cognitive status (Advanced Clinical Systems (ACS) word reading), suboptimal effort (for those under age 65 ACS Word Choice; for all California Verbal Learning Test-II (CVLT-II) forced choice; ACS/Weschler Adult Intelligence Scale-IV (WAIS-IV) Reliable Digit Span; ACS/Weschler Memory Scale-IV (WMS-IV) Logical Memory Recognition), language (Short Form Boston Naming Test (BNT); Token Test, visuospatial processing (WMS-IV Block Design); Brief Visuospatial Memory Test-Revised (BVMT-R) if needed Repeatable Battery of Neuropsychological Status Line Orientation, attention/speed of mental processing (WAIS-IV Digit Span and Coding); Delis Kaplan Executive Function System (DKEFS); Trails Visual Scanning, Letter & Number Sequencing, Motor Sequencing; DKEFS Interference Colour & Word Naming), semantic memory (Short Form BNT; CVLT-II Semantic Clustering; and if needed Point & Repeat test; DKEFS Category Fluency), episodic memory (BVMT-R; CVLT-II short form; WMS-IV Logical Memory), executive function (DKEFS Letter Fluency, Category Fluency,
Switching; DKEFS Interference Inhibition & Inhibition/ Switching; DKEFS Trails Number/ Letter Switching), and social cognition (Social Norms Questionnaire56). There are no normative data for Indigenous Peoples for the tests in this battery, and no data on measurement equivalence for these tests when given to Indigenous Peoples. The CICA is included in the RRMC battery, but due to its preliminary evidence for validity (at the time of this chapter writing, evidence for validity has not been published), it is included as an optional research task and is not used clinically. In the Clinical Engagement with Indigenous Clients section of the chapter, we discuss how or if we use the above-mentioned tests with Indigenous peoples presenting to the memory clinic.

Further assessment in the clinic includes interview with the family while the client is performing the neuropsychological battery and administration of standardized scales of function, behavior, and mood. Finally, the RRMC team meets and discusses the profession-specific findings (the neurologist interprets the medical workup), and the neurologist and neuropsychologist come to a consensus diagnosis. The team contributes to an interprofessional letter with recommendations. The neurologist and neuropsychologist meet with the family and communicate the diagnosis, recommendations, and plan for management and follow-up. This process occurs for two families on clinic day: The intake and feedback interviews are staggered, and while one family is performing the neuropsychology assessment the other family is receiving the physical therapy assessment. Follow-up occurs as needed and is provided by the neurologist using Telehealth. One year post initial assessment all families return to the RRMC for a half-day assessment by neuropsychology and physical therapy; further assessment and feedback of the in-person assessments is provided by Telehealth with the neurologist. Subsequent in-person assessments are provided only for a sub-set of patients: (1) whose diagnosis remains ambiguous, (2) patients who are diagnosed with mild cognitive impairment, (3) patients for whom their presentation of dementia is atypical.

Clinical Engagement with Indigenous Clients

Working with Indigenous Peoples as patients in the RRMC requires careful consideration because the structures and procedures of the RRMC are not, in themselves, culturally safe. Foremost, the RRMC model uses standardized scales that could be culturally and psychometrically inappropriate. Neuropsychological tests are compared with published comparison standards that are age and sex stratified, and for some tests also stratified by education. No known neuropsychological normative comparison standards exist for the Indigenous Peoples of Canada, and no known evidence on measurement invariance of neuropsychological tests for Indigenous Peoples has been reported, and data on differential item functioning or measurement invariance is needed for clinical use.57,58 It is a clinical decision that takes great care—should we administer standardized tests at all? Villarreal59 described the tensions between culturally appropriate assessment with Indigenous Peoples and need for standardization—and we described many of the practices involved in standardized assessment, particularly neuropsychological assessment as colonizing practices. Cultural appropriateness is one factor, but we also see people with few years of education, which can result in underestimates of neuropsychological test performance.60 Would administration do more harm than good? If an Indigenous Person with zero years of formal education performs poorly, can we trust that poor performance on this standardized test to reflect cognitive functioning, at least to some degree? If unsure, it is best to choose not to administer such tests and use interview data predominantly. Alternatively, assessment procedures are administered but interpreted qualitatively.61 Westerman and Wettinger62 describe issues to consider when determining if psychological assessment with Indigenous Peoples is valid, including not only the content of what is assessed but also the methods used to assess. If test procedures are modified, it threatens the validity of
the neuropsychological tests. An additional consideration is lack of appropriate normative comparison standards: Even if assessment processes are consistent with standardized procedures, interpretation of tests is nonstandardized due to inappropriate normative comparison standards. Postal and colleagues created a framework used for deciding when deviation from standardized administration of neuropsychological tests is warranted based on a consideration of numerous factors, including incremental validity for the pandemic, which we have adapted for consideration of appropriate neuropsychological assessment with Indigenous older adults. If test administration is nonstandardized (either by virtue of administration procedures or normative comparisons) we consider whether the testing would add incremental validity, and if not, we choose to weigh our diagnostic process on the clinical history from interview with patient and collateral informants. This clinical decision is based on an understanding of the colonial nature of standardized assessment and the importance of increasing cultural safety in the context of diagnostic assessments when working with Indigenous Peoples.

Relational practices to help facilitate the process of a culturally safe clinical assessment involve an open discussion with the person who is participating in the assessment and with the family. The RRMC is set up to mimic a home-like environment. Each family gets a private room with some amenities for the day. The couches are commonly used for naps, they have a locking cupboard to keep possessions, and a computer and internet access are provided. Families are provided coffee or tea and shown the kitchenette where they can help themselves to additional drinks and asked to “make themselves at home.” Although we do this for all families, MEO makes an attempt to personally offer coffee or tea with Indigenous families, even if the clinic nurse has already provided the first cup.

As clinicians, MEO and IP make few assumptions and check in with the family and, if appropriate, the person being assessed for dementia. Although MEO might make decisions that the neuropsychological tests might be inappropriate, she checks her decisions with the families, and there are numerous other standardized scales we administer for mood, behavior, and function at the RRMC. Indigenous Peoples vary widely in formal education, occupational attainment, and immersion/exposure to the dominant culture in Canada. Sometimes it is appropriate to administer these standardized tests and use the existing normative comparison standards and provide caveats for the interpretation of such tests in the written report and triangulate neuropsychological testing data with interview data and other standardized scales measuring function. Sometimes we administer the aforementioned neuropsychological battery, and sometimes we administer none of the standardized tests. MEO asks herself—can she trust that a very low score would reflect impairment, or would she wonder if it was due to lack of cultural appropriateness of the tests or lack of exposure to formal education, or both—if she is not sure, she chooses NOT to administer the typical battery of tests and uses interview data predominantly. MEO believes if you cannot be relatively confident in what the test performance means, it is more ethical to avoid administration of this neuropsychological test. Participating in a neuropsychological assessment is rarely enjoyable, and if the resulting test scores are highly suspect, this process does not adequately honor your patients’ time and effort. This is a decision made on a case-by-case basis and whenever possible in consultation with the family.

Section II: Case Study — “A Lesson in Cultural Humility”

As an illustrative case, the following clinical assessment is provided, but this is a generated composite of presentations across patients. Henry Stony (not an RRMC patient’s name) is an 80-year-old man who has lived in Île-à-la-Crosse for his entire life. Île-à-la-Crosse is a 5-hour drive north of the clinic in Saskatoon one-way, and Henry arrived by medical taxi at the RRMC. He speaks
Cree at home, and the variant of Cree he speaks is a mix of Plains Cree (spoken in the south) and Michif (a mix of French and Cree), which is common to several northern SK communities. He understands aural English and speaks some, but does not read or write, with a report of no years of formal education. He reported that his parents hid him from the government agents who tried to take him away from his home and his community for forced attendance at residential schools. He worked for most of his life as a trapper and guide and only recently gave up guiding the summer before the current appointment. Henry never married and currently lives alone. Henry is physically healthy (past medical and mental health history is negative for any diseases/disorders), takes no Western medications, and drinks medicinal teas to help with his sleep. He reports no current sleep disturbance, and his only problems remain in the domain of memory—forgetting names of people he knows but recognizing their faces. Henry has no surviving siblings, and he attended the appointment with his 19-year-old nephew, John. John is not genetically related to Henry, nor is he a longstanding member of the Île-à-la-Crosse community. He grew up in Saskatoon and was transplanted to Île-à-la-Crosse as a teenager. He was a neighbor of Henry’s in Île-à-la-Crosse, and they adopted each other. Although John currently lives in Saskatoon to attend University, he keeps in touch with Henry remotely and feels he can act as a collateral informant. John’s first language is English, but he is fluent in Plains Cree, and not Michif.

During interview Henry presents with moderate to severe hearing loss, but it is challenging to figure out if impaired comprehension is due to hearing acuity or the fact that he speaks in Cree most often, and the interview is conducted in English. We discuss with the family whether we should try working through any language barrier together. The lack of formal interpretation services is a limitation of our clinic setting and the one-day assessment model. Our interviews are family interviews so the ethical pitfalls of using family for interviews is somewhat lessened by the group nature of this method of interviewing. If, however, we have to perform some testing through translation we engage in a lengthy discussion about the pitfalls of this approach. The ethical quandary of not providing services versus the ethical issues of using a family member must be considered. The clinic setting does not have access to a translation service, and the logistics of incorporating a translation service for a one-day clinic model where we would not know a translator might be helpful until after we have started the assessment is another consideration. In Henry’s case, asking him to travel the 5 hours back home only to travel back to the clinic at a time when a professional interpreter was available would not be an ethical choice. After discussing the pitfalls of using John for interpretation when needed, we decide to proceed.

John spontaneously begins to repeat what we ask Henry and then translate into Cree, and Henry appears animated and can answer questions in English with a low volume and Cree accent, but he elaborates very little. Henry displays more generative output in English when describing where he grew up and how he worked on the land. He denied any known developmental delays, and John reveals that Henry worked as a well-known and respected guide in the North. We ask Henry if he thinks he can do a physical exam with the doctor in English or would he prefer to have John come translate, and he jokes that he can as long as he won’t get poked. While Henry and the neurologist are working together, the neuropsychology team speaks alone with John, who reveals that members of the community have expressed worries about Henry because they have noticed he has a hard time remembering people, and he keeps joking about how they’ve changed, and that is why he can’t remember them. John recently discovered that Henry has been forgetting to pay bills, and he worked to set up automatic payments for Henry. Finally, John described a recent episode where Henry appeared to get lost in the bush. Although Henry denies he was lost and laughs off the incident, apparently the community was mobilized to search for him due to the minus 40-degree Celsius temperatures. This episode was a huge shock for the community given the large extent of Henry’s longstanding trapline, his leadership in guiding, and his well-respected
general knowledge of the land. John is concerned for his uncle's welfare since he is unsure about what is going on. John is in touch with his mother who is Henry’s neighbor, and she helps John keep tabs on Henry during the 4 months of the school term when John is unable to see Henry. They feel Henry's problems go well beyond his marked hearing loss.

Our premorbid estimate of Henry is restricted to his developmental and occupational history, given the lack of formal education and inappropriateness of the word reading test in this context. We estimated Henry’s premorbid ability was in the average range. We also decide that we would ask him questions about his mood rather than try to give him our standardized scale that requires a high level of reading fluency. We decide that most, if not all, of the standardized scales would likely be inappropriate for Henry, but in order to provide medications under the government formulary we need scores for a commonly used cognitive screening test. We decide to work with Henry on this screening test and subsequently make decisions about the rest of the assessment. We discuss with Henry and John the problems with the tests we give—they are culture bound and make assumptions about things taught in school. We discuss how these tests do not ask about his areas of extensive knowledge and ask things that might seem silly to him or not seem relevant to him or his life. We state that there is one test that the neurologist might need and we could give it a try together and see how it goes. We ask Henry if he thinks we should try it alone or should we try it in Cree and have John help with translation. Henry and John think it is a good idea to do this together and we can start in English and try in Cree as well. We begin the test in English. Henry does not answer the first question, and we decide to try this in Cree. Henry agrees, stating that he can hear Cree better—we joke that maybe he can hear John’s deep voice better than the high voice of MEO. The three of us discuss the challenges with having John do the translation, and we discuss the lack of formal translation services available to us. They both agree we can give this a try.

MEO discusses with John how hard it will be to not elaborate on a question or an answer, and the purpose of these questions is to see how Henry can do on his own. We discuss how this process can feel odd because MEO will be making eye contact with Henry, but John will be speaking. MEO asks questions and John translates the question, Henry answers, and John translates. This occurs for much of the cognitive screening test, but on occasion Henry answers a question in English before John can translate. Once, John and Henry spoke back and forth in Cree, but the question was brief and the anticipated answer was also brief. I asked what was happening, noting the length of their discussion for such a brief question (recalling that it can be hard for family not to explain a question or elaborate on this). It turns out Henry responded with a word John was unfamiliar with due to difference in dialect and he was clarifying. We finish the cognitive screening task and discuss what Henry thought of it; he said it was ok but was a bit silly.

Henry had marked difficulty with this screening task, and given the collateral reports of decline in daily function we decide that further testing was not needed from a diagnostic viewpoint. That is, the incremental validity that could be provided by additional standardized testing was determined to be low, so we decided to limit our standardized testing with Henry to maximize the cultural safety of the clinical assessment. While Henry performs the physical therapy assessment, after a collaborative discussion about the appropriateness, John fills out some standardized scales about Henry’s functioning, and we get permission to speak with John’s mother over the phone given that she has been acting as more of the primary care provider now that John has moved to Saskatoon. She reports she is now providing Henry with meals because he was not cooking and had moldy food in the fridge, and she is needing to prompt him to bathe. She is scared that he will get lost again and not be able to find his way back home.

After Henry participates in a neuroimaging exam, the team meets to discuss the results from the comprehensive blood panel (requisition mailed before clinic day), the neuroimaging, the neurology
exam, and the neuropsychology assessment. The physical exam procedures are all within normal limits. Much of the diagnostic process is based on clinical interviews and collateral interviews, which is not ideal. Nevertheless, the team understands that standardized assessments under inappropriate conditions make it impossible to tell if poor performance is due to the inappropriate assessment procedures, the lack of standardization due to translation, or reflect poor cognitive performance. The neurologist and neuropsychologist decide there is enough information to suggest a clinical diagnosis of dementia. We speak with Henry and John to discuss this diagnosis and its implications and discuss how we will be communicating a management plan with Henry’s primary care provider. After the neurologist leaves, the neuropsychology team spends time debriefing with Henry and John about the diagnosis and the assessment process. Recommendations are provided for Henry, John, and Henry’s primary care provider, which includes linkages with local homecare resources. Our clinic is 5 hours away and must rely on the local resources for postdiagnostic care.

We find it common to see patients presenting with overt cognitive impairments who could have been diagnosed in primary care. Ideally, we design a remote clinic where we can support the diagnostic procedures for primary care providers, saving the interprofessional assessment procedures of the RRMC for the most difficult to diagnose. The lack of neuroimaging facilities in the North makes a plan for a fully remote memory clinic challenging, and we continue with our current model because the assessment is completed in one day, which reduces travel time. We use relational practices and focus on interpersonal connection in an attempt to counter the highly medicalized nature of the RRMC, which could be seen as a setting that perpetuates colonial practices. Finally, we are aware of the limited contribution that standardized neuropsychological testing can have for people like Henry. The development of the CICA is one way to help primary care providers obtain information on cognition for Indigenous Peoples, but this is only a screening test. It is, however, a model for how to develop a culturally appropriate cognitive assessment tool that could be used for neuropsychological tests in the future (see https://www.i-caare.ca/cica-tool). Foremost, tests need to be co-designed rather than led by non-Indigenous clinicians. Tests need to be iteratively trialed with cultural and language experts. Finally, exploring evidence for the psychometric properties of these newly developed tests needs to be established.

Section III: Lessons Learned

- The historical context of colonialism and residential schools, as well as cultural and linguistic differences, necessitate the need for more competent cultural clinical practice, which can lead to culturally safe care for Indigenous Peoples.
- Neuropsychology clinicians from Indigenous backgrounds are needed.
- Clinicians from non-Indigenous backgrounds are urged to make every attempt to conceptualize their clients’ physical and psychological health needs from a holistic perspective, that is, in the context of the past, the present, as well as the colonial contexts.
- Culturally safe clinical assessment approaches can be developed by working with Indigenous Peoples such as been done with the CICA. While possible to do with neuropsychological tests, it is important that development of these tests prioritize co-design with the community rather than design led by non-Indigenous clinicians. Additional research on the psychometric properties would subsequently be needed before clinical use.
- Traditional neuropsychological assessment involves a balance between validity of test interpretation (either due to nonstandardized administration or nonstandardized application of normative comparison standards) with cultural safety. On a client-by-client basis, one needs to consider context (cultural context, language, education, colonial practices of the region
and its history, and the colonial experiences by your client) that could impact cultural safety. Although likely true for all cultural and linguistic groups, this clinical decision to maximize cultural safety is critical when working with Indigenous Peoples in Saskatchewan, given their intergenerational experiences, personal history, present, and future experiences with colonizing practices. As the client context increases in its distance from the dominant settler culture, the need for modifications to create a culturally safe assessment increase. These modifications decrease the validity of the test data (see Figure 8.1). We argue when balancing between validity and cultural safety clinicians should consider the incremental validity of the neuropsychological testing, that is, how critical is the testing information to the aim of the assessment. Can the aims of the assessment be achieved without them? Are deviations from standardization so large as to threaten all validity underlying test interpretation? If the answer to either of these

Figure 8.1  Validity of test interpretation and cultural safety
questions is yes, consider avoiding perpetuating a colonizing practice. In conclusion, we suggest standardized assessments are not necessarily culturally safe for some clients and should be used only when the incremental validity is high.

Maps (public domain): https://ian.macky.net/pat/map/ca/sk/sk_blu.gif
(https://ian.macky.net/pat/map/ca/sk/sk.html)64
(https://commons.wikimedia.org/wiki/File:Saskatchewan,_Canada.svg)65
(http://www.yellowmaps.com/map/saskatchewan-outline-map-589.htm)66

Acknowledgments

The writing of this chapter was supported and partially funded by funding from Team 15 on Rural Dementia Care (MEO & IP) in the Canadian Consortium on Neurodegeneration in Aging (CCNA) and Team 18 on Indigenous Dementia Care (MEO, JW, & LBB). CCNA is supported by a grant from the Canadian Institutes of Health Research (CIHR) with funding from several partners including CIHR Institute of Indigenous Peoples’ Health, the Saskatchewan Health Research Foundation, the Centre for Aging and Brain Health, and the Alzheimer Society of Canada.

References


64. Public Domain Maps of Saskatchewan; n.d.
