

A Discussion of The Northern Cultural Assessment of Memory (N-CAM):

A Protocol Designed to Detect Cognitive Change in Indigenous Peoples

Margaret Crossley, PhD, R.D. Psych
Professor Emerita, University of Saskatchewan

Debra Morgan, PhD, RN
Professor and Chair, Rural Health Delivery
Director, Rural and Remote Memory Clinic
University of Saskatchewan

Rural Dementia Action Research (RaDAR)

October 29, 2015



- **Our aim is to share a dementia screening protocol that we designed at the RRMC at the UofS, in partnership with front-line workers in remote Indigenous communities. We intended the N-CAM to be gentle, contextually rich and culturally respectful, and sensitive to age-related cognitive change.**



Components of the N-CAM

- “High-risk” check-list for front-line workers
- Family member interview designed to identify functional and behavioural change
- Cognitive screen designed to identify changes in memory and other higher brain functions that tend to accompany the earliest stages of dementia



Goals for this workshop...

- 1) Describe the participatory research methods used during the development of the N-CAM**
- 2) Provide an overview of the intended uses for the N-CAM and preliminary information about its utility and limitations as a clinical and research tool based on our work at the Rural and Remote Memory Clinic in Saskatoon**



Goals for this workshop...

- 3) Briefly summarize the administration, scoring and interpretation guidelines for the N-CAM .**

NOTE: Training and supplementary materials can be made available for those who may be interested in using and modifying the N-CAM for their communities.



Goals for this presentation....

- 5) To encourage your feedback during the Q and A on the perceived strengths and limitations of the N-CAM for culturally fair assessment of Indigenous seniors

- 6) To demonstrate the importance of interprofessional collaboration and community based consultation when developing applied research strategies and clinical interventions for rural, remote, and Indigenous seniors



But first...

- We need to acknowledge our funding sources and collaborators, and to provide some context and background for the development of the N-CAM



Funding Partners

- Canadian Institute of Health Research
 - Aging, Hlth Serv and Policy Res, Rural and Northern Health Initiatives
- Alzheimer Society of Saskatchewan
- Saskatchewan Health Research Foundation
- Northern Scientific Training Program (2005 – 2007)
- Indigenous Peoples' Health Research Centre (2002; 2011)
- Sask Health (Rural and Remote Memory Clinic)
- University of Saskatchewan



Collaborators

Team Members at the University of Sask

Megan O'Connell, RRMC, Dept of Psychology, UofS

Lesley McBain, First Nations University of Canada

Allison Cammer, Freda Elash, and Duane Minish

Graduate and Undergraduate Students:

Shawnda Lanting, PhD (CIHR PHARE, NSTP)

Delaine Engelbregston (2002 IPHRC Summer Award)

Hannah St.Denis-Katz (2011 IPHRC Summer Award)

**N. Haugrud, P. Corney, L. Lejbak, A. Agar, K. Calverley, M. Sharp,
K.Sigurdson, D. Andersen, L. Sewall, S. Gelb**



Community Partners:

Home Care Staff in the Keewatin Yatthé Regional Health Authority (2003- 2013)

Saskatoon Community Clinic:

Grandmother's Group (2002- 2011)

Westside Clinic Volunteers (2011-2012)

Telehealth Saskatchewan (2003 – 2013)

Northern Medical Services (2005 – 2013)



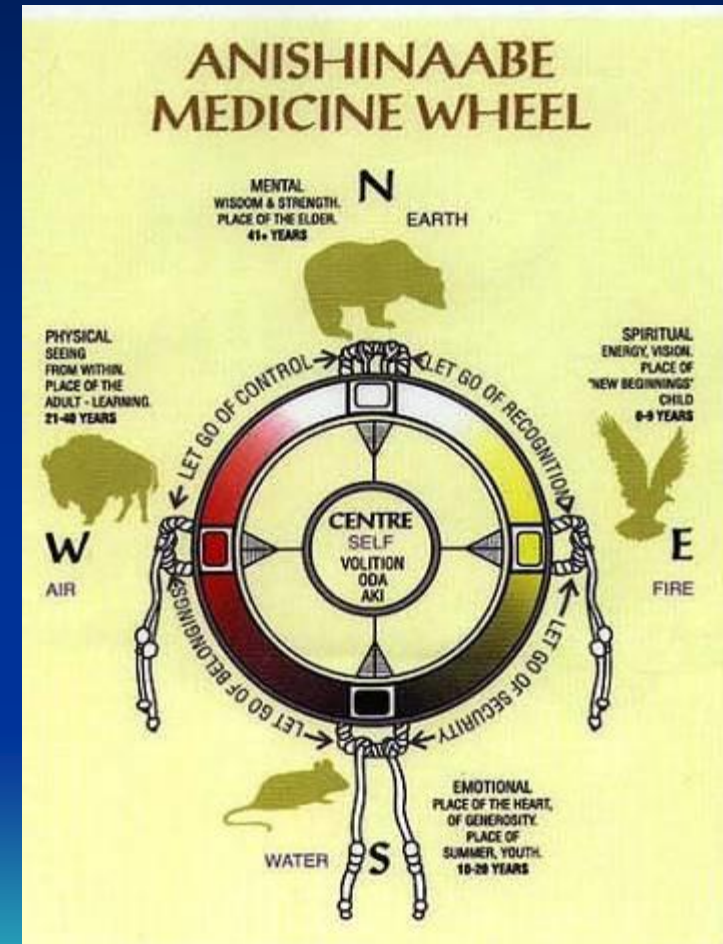
Univ of Sask's Rural and Remote Memory Clinic

- 1) a one-day, streamlined, interdisciplinary clinic for assessment, diagnosis, and management of early stage and atypical dementias among rural and remote residents of Saskatchewan
- 2) Evaluation of telehealth as a means of providing follow-up care to individuals with dementia and their caregivers



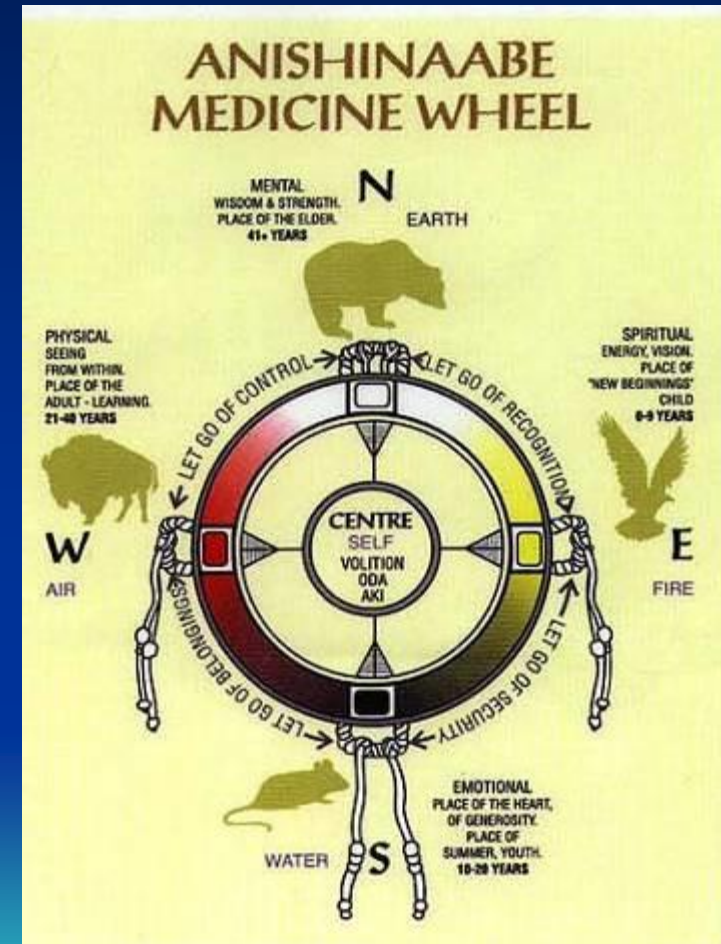
Importance of Investigating Dementia in Aboriginal Seniors

- Aboriginal peoples (First Nations, Inuit, Métis) make up approximately 4% of Canadian population
- Over 15% of the population in Saskatchewan self-identified as Aboriginal based on 2011 NHS
- Aboriginal seniors (55 and older) are one of the most rapidly growing demographic groups in Canada



Importance of Investigating Dementia in Aboriginal Seniors

- Although there is still little research on dementia among Indigenous seniors, recent studies by Jacklin, Walker, & Shawande (2013) suggest rates of dementia may be 34% higher among First nations compared to non-Aboriginal populations, rates may be rising quickly, and onset is thought to be an average of 10 years earlier
- Pop health research (Wilson et al, 2010, 2011) reveals large health disparities and many risk factors for Aboriginal seniors



Barriers to Accessing Dementia Care for Indigenous and other Culturally Diverse Seniors:

- Language and cultural differences
- Dementia may not be viewed as an illness
- Feelings of shame, stigma, and negative experiences with the health care system
- Assessment protocols have been developed with majority culture adults

(Mukadam, Cooper, Livingston, 2011)



Rural, remote, Northern, and Aboriginal communities have relatively few formal health care services and supports, and residents must...



...travel long distances to services, face transportation difficulties, and bear high costs.



Potential Risks and Negative Consequences for Ethnically Diverse Seniors

- Ethnically diverse older adults with cognitive impairment are less likely to receive needed assessments and intervention services and are diagnosed much later in the disease spectrum.
- Knowledge gap re normal aging and epidemiology of cognitive impairment in ethnically and culturally diverse seniors

(Cooper et al., 2009)



Potential Risks of Using Unmodified Assessment Procedures with Culturally Diverse Seniors

- **False Positives:** cognitive impairment and dementia is over-diagnosed due to biased tests, when lower performance results from educational and health disparities, or differences in test-taking strategies or test-taking comfort level

(Manly et al., 2006, 2008)

- The challenge for the RRMC team was to develop a fair assessment of cognitive functioning for culturally and geographically diverse seniors from rural and Saskatchewan, and especially for Aboriginal seniors



Addressing the Challenges



Test Development:

- Monthly focus groups with Aboriginal Grandmothers Group
- The quality of our work with the Aboriginal Grandmothers Group was enhanced through mutual story-telling, shared food, some remuneration, & mutual respect



Addressing the Challenges



Test Development:

- Multiple trips to remote Northern communities of Saskatchewan fostered collaborative partnerships
- Bi-annual workshops and telehealth conferences over 4 years to review and revise test protocols



Keewatin Yatthé Homecare Staff and IPHRC Students



Key Findings from Focus Groups, Travel to Remote Communities and Collaborative Partnerships



- The assessment process can be comfortable, informal, and engaging
- By considering cultural context and incorporating humour, colour, and natural images into the assessment protocol, the therapeutic experience can be enhanced both for the patient and the caregivers.

Key Findings (cont'd)



- Careful attention to relationship building is key
- Assessments need to be administered in the language of the patient and are enhanced by family caregiver participation
- Screening instruments that assume or require formal education will be problematic for many remote seniors

Evaluation of Existing Cognitive Screens

- We did use and evaluate in a case study analyses existing screening protocols designed for Indigenous and other culturally diverse seniors . The CSI'D (Hall et al.) and the CASI (Teng et al) had acceptable sensitivity to major forms of dementia when combined with other cognitive measures and in the context of an interdisciplinary assessment
- But limitations were evident, especially for seniors who had no formal education

Development of the Northern Cultural Assessment of Memory (N-CAM)

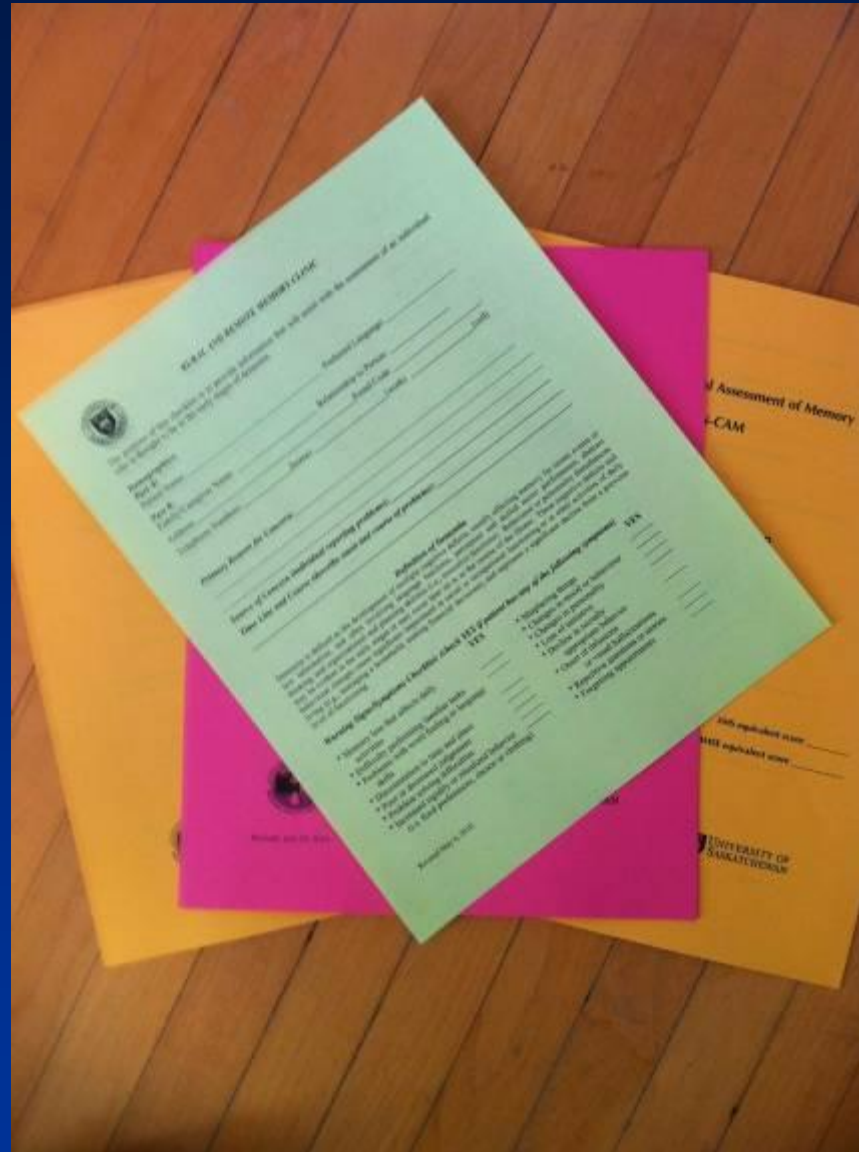
Caregiver Interview and Patient
Cognitive Assessment



Components of the N-CAM

1. High-risk check-list provides a definition of dementia
2. The family member interview contains standardized measures of function, behavioral assessment scales, and integrative story-telling that is an essential component of the cognitive assessment.
3. The cognitive screen contains measures of: attention; general orientation; prospective, episodic, and semantic memory; language; executive functions; and skilled movement (praxis).



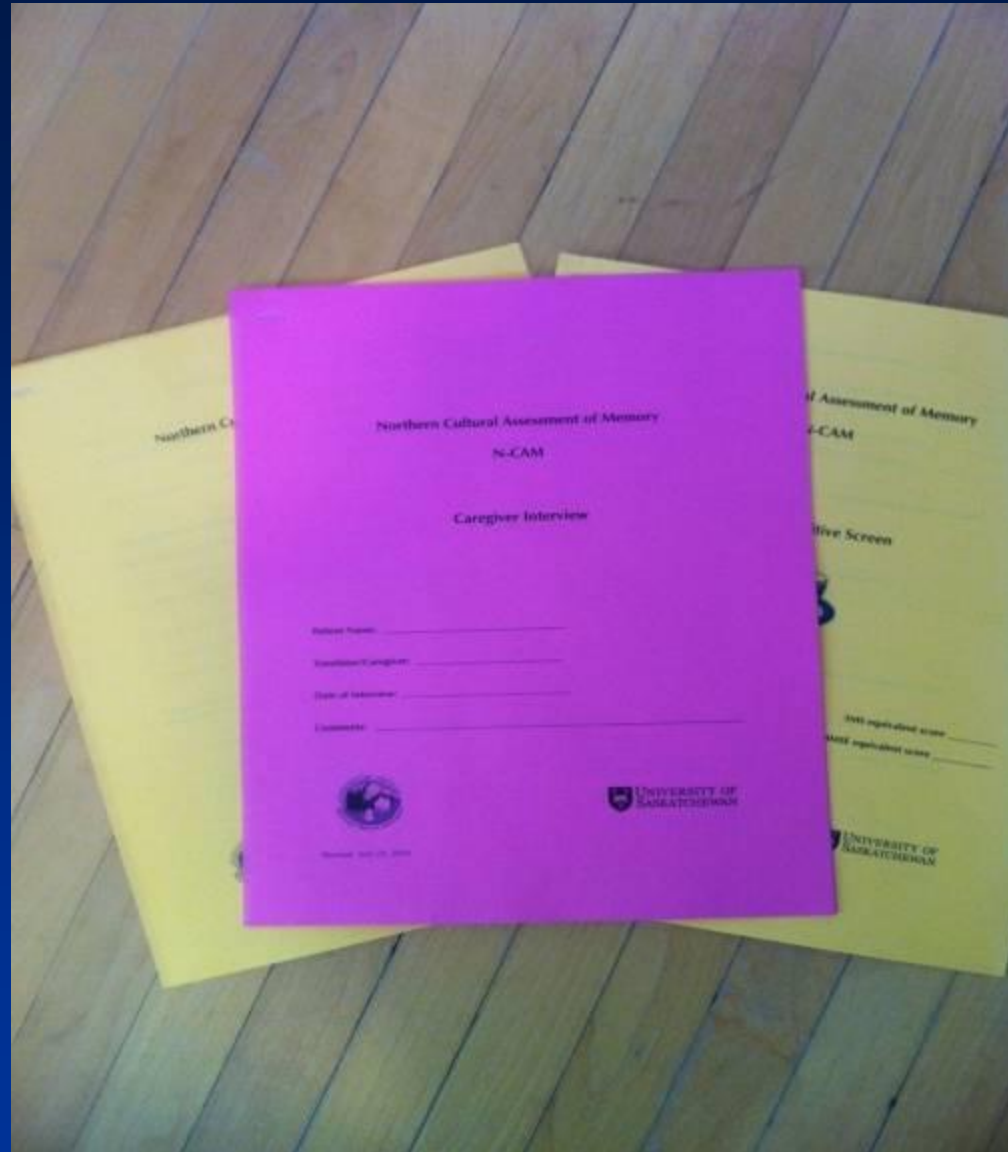


NET: Strategies to Improve the Care of Persons with Dementia in Rural and Remote Areas

High-Risk Checklist: The “green” form

- A one-page checklist to document the concerns of family members or front-line health workers about individuals who demonstrate MCI or early-stage dementia. An educational tool to guide assessment and referral to the RRMC.....
- Primary Reason for Concern
- Source of Concern ,Time Line, and Course
- Definition of Dementia
- Warning Signs/Symptoms Checklist
- Medical History
- Risk-factor Checklist





NET: Strategies to Improve
the Care of Persons with
Dementia in Rural and
Remote Areas

The Caregiver Interview: The “rose” form

- A five-page semi-structured interview to document the family caregiver’s assessment of the patient’s functional and cognitive status. An essential component of the N-CAM that is required to guide decision making , interventions, referral, and follow-up.....
- Past occupation, current interests, judgement and problem solving abilities
- Memory and language skills; Personality and Mood
- Functional Assessment Questionnaire (FAQ; Pfeffer et al., 1984)
- General health, alcohol and medication use
- Checklist to determine appropriateness for cognitive testing
- Description of two autobiographical events (imp. event during the past week; most recent evening meal)
- Provides an opportunity to assess the family system (e.g., caregiver)



NET: Strategies to Improve
the Care of Persons with
Dementia in Rural and
Remote Areas

The “goldenrod” Patient Cognitive Screen: The “Tea” and “Seed” forms

- A mental status examination that documents the patient’s verbal answers and actions in response to standardized questions intended to assess:

Memory

- For personal and general information (Semantic)
- For new learning (Episodic) & recent (Autobiographical) events
- Prospective memory – to carry out a cued future task
- Orientation to time and place

Language

- General comprehension and expressive skills, object naming, & speeded verbal fluency

Visuospatial ability, skilled motor performance, executive & problem solving skills (calculations, speeded & sequential tasks)



Characteristics of the N-CAM

- Can be administered in the language of the patient using translation by a caregiver
- Family member or other caregiver involvement in the assessment is assumed
- Cognitive test items do not require or assume literacy
- Test materials are colourful, familiar, and include easily assembled and “everyday” household items



NET: Strategies to Improve
the Care of Persons with
Dementia in Rural and
Remote Areas



NET: Strategies to Improve
the Care of Persons with
Dementia in Rural and
Remote Areas



NET: Strategies to Improve
the Care of Persons with
Dementia in Rural and
Remote Areas



NET: Strategies to Improve
the Care of Persons with
Dementia in Rural and
Remote Areas



NET: Strategies to Improve
the Care of Persons with
Dementia in Rural and
Remote Areas



NET: Strategies to Improve
the Care of Persons with
Dementia in Rural and
Remote Areas



NET: Strategies to Improve
the Care of Persons with
Dementia in Rural and
Remote Areas

Administration and Scoring of the N-CAM

- Detailed written administration and scoring guidelines are provided with the cognitive test protocol and a training video was completed with the assistance of the Media Access and Production Services (eMAP) at the UofS.
- The cognitive screen is scored on a scale from 1 to 100.
- Scoring grids are provided on each page for easy and accurate computation



Scoring the N-CAM

- Caregiver Interview: FAQ (scores range from 0-30)
- Patient Cognitive Screen: Accompanied by detailed scoring guidelines

1. Memory

Semantic Memory – 17/100

Episodic & Autobiographical – 25/100

Prospective memory – 4/100

Orientation to time and place – 19/100 Total: 65/100

2. Language

Object naming and verbal fluency – 20/100

3. Skilled motor performance, executive & problem solving skills -
15/100



Interpretation Guidelines and Considerations:

- The N-CAM provides useful clinical information about the strengths and limitations/challenges of referred patients and their family systems
- Although not a neuropsychological or diagnostic tool, the N-CAM can assist front line clinicians to make effective judgements about the need for medical follow-up and treatment, referral to specialty teams, or for additional supportive services or resources
- Together, the caregiver interview and cognitive screen can identify and document cognitive decline that is characteristic of mild cognitive impairment or dementia



N-CAM: Collection of Normative Data

- IPHRC Summer Research Award to Hannah St. Denis-Katz (May – August, 2011)
- Collaborative partnership with the Westside Community Clinic, Saskatoon
- Inner city health facility serving primarily Aboriginal families



Methods

Materials administered:

- 1) health and culture interview
- 2) standardized cross-cultural measures of memory and language (Grasshoppers & Geese Test (Lanting , Crossley et al., 2011),
- 3) the N-CAM cognitive protocol with a modified story-telling component

Assessments were completed in approximately one hour and fruit baskets were provided to show appreciation.



Findings

- Participants: $N = 81$, 41 males, 92% Aboriginal, age range from 19 to 81 yrs
- High levels of chronic health and social problems:
 - 70% with addiction problems
 - 48% with hepatitis C
 - 38% with a history of head injury
 - 68% with less than high school education.



Findings (cont'd)

- N-CAM scores ranged from 73 to 99 ($M = 93.4$)
- Total scores were not influenced by age ($r = -.165$) or by education ($r = .20$)
- Total scores were highly correlated with measures of memory ($r = .513$), confrontational naming ($r = .508$), and semantic associations ($r = .601$) from the Grasshoppers and Geese Test (support for construct validity)



Findings (cont'd)

- Individuals (N = 5) with scores falling below 80 performed in the impaired range on one or more of the standardized measures of memory indicating that the N-CAM has good sensitivity to cognitive impairment
- Over 95% of participants were rated as “fully cooperative” and 16% as “test anxious” indicating high test tolerance
- For this normative sample and appropriate for a screening protocol, virtually all tasks on the N-CAM, including episodic and prospective memory, orientation, and verbal fluency were performed near ceiling.



N-CAM with Indigenous Seniors at the Rural and Remote Memory Clinic

- Of those Aboriginal seniors diagnosed with AD or Vascular Dementia at the RRMC (N= 16):
 - FAQ: Average (Range) = 21.4 (9 – 29)
 - N-CAM: Average (Range) = 48.5 (6 – 77)

As expected, tasks of episodic and prospective memory, and orientation were highly sensitive to early-stage dementia



Findings from the RRMC clinic.....

- Of those Aboriginal seniors diagnosed with MCI or No Cog Impair:

FAQ: Average (Range) = Fully Indep (0-1)

N-CAM: Average (Range) = 94 (88-99)

For this small clinical sample (N=6) with very mild or no cognitive impairment, virtually all tasks on the N-CAM, including episodic and prospective memory, orientation, and verbal fluency were performed very well (i.e., “at or near ceiling”).

Preliminary Conclusions.....

- The N-CAM family interview and cognitive screen is a relatively brief and well-tolerated protocol that demonstrates, with both Aboriginal community-based adults and clinical referrals to the RPMC, sensitivity to differences in higher brain functions and impairment, but not to culture, age, or education.



There are challenges and limitations...

- The N-CAM is designed for use by frontline staff and is not intended to be a protected psychological instrument. But this necessitates a commitment to training workshops, consultation, and ongoing support (e.g., training tapes, carefully prepared guidelines for administration and scoring).
- Despite the many iterations and modifications over the years, the instrument is imperfect and will not work equally well in all situations or with all Aboriginal seniors or diverse cultural groups



There are challenges and limitations ...

- The N-CAM will not appeal to busy practitioners who do not have time to conduct a home visit or to spend at least 1.5 hr with the patient and caregiver.
- Psychometric properties are not yet well established and equivalency to existing screening instruments should not be assumed.
- Similarly, health policies that prescribe dementia screening scores to guide decision making or reimbursement are problematic in light of evident difficulties interpreting results for Indigenous seniors.

What have we learned so far about modifying dementia screening protocols for Aboriginal seniors?

- Assessment procedures and tools can be modified to be culturally appropriate and sensitive to cognitive decline if developed in partnership with the stakeholders that the instruments are designed to serve (in keeping with CIHR's Aboriginal Research Guidelines)
- Dementia screening measures need not require literacy and can be designed to be administered in remote settings in the language of the Indigenous senior

What we've learned so far (cont'd).....

- As with majority culture seniors, assessment for early stage dementia is enhanced by active participation of engaged caregivers – in particular, the N-CAM is designed to be completed in the home and includes a functional assessment based on a caregiver interview
- The N-CAM is a relatively brief screening protocol that includes a functional home-based assessment and a cognitive component. The N-CAM, when administered by informed front line workers and with the assistance of engaged caregivers, can identify early stage dementia in community-dwelling Indigenous seniors.



What we've learned so far

- Modified cognitive screens such as the N-CAM have been generally well received by patients at the Rural and Remote Memory Clinic, although challenges remain for patients who do not speak English or are not accompanied by a skilled translator, or who suffer from hearing or visual impairments or other challenges that limit their engagement in the assessment process.
- Early clinical findings at the RRMC indicate that the N-CAM is both acceptable to Indigenous patients and their family members and adequately sensitive to cognitive decline; however, the N-CAM appears to be particularly well-suited to use in the community by frontline formal caregivers.

What we've learned so far

- Community-based and normative data collection using the N-CAM with inner city residents attending the West Side Community Clinic in Saskatoon suggest that the N-CAM may have utility for clinical and population-based research with Indigenous peoples.
- The cognitive components of the N-CAM have been adapted for use in basic research with older Inuit hunters participating in studies on visual perception and navigational skills (V. Bohbot, McGill University).
- The N-CAM is best viewed as a flexible protocol that can be modified to address the unique needs, that are presumed to evolve over time, of a particular Indigenous group or community.

Future directions and next steps....

- Consider the utility of the N-CAM as a protocol to facilitate judgments of capacity in Indigenous seniors who may be experiencing cognitive decline
 - Capacity (sometimes termed competency) determinations are important in mobilizing supportive services related to safe medication management, transportation, financial security, and home-based care and supervision, and are essential when considering decisions related to medical and research consent.
- A Special Issue (Volume 40) of Clinical Gerontologist will focus on Capacity Assessment of Older Adults: Current Research and Clinical Dilemmas and will consider submissions that address issues of diversity.



Future directions and next steps....

Canadian Consortium on Neurodegeneration
in Aging (CCNA)

Team 20: Issues in Dementia Care in
Rural and Indigenous Populations



Concluding comments....

The Cree phrase, *wîchêhtowin* means “we live together in harmony; we help each other; we are inclusive.”



Rural Dementia Care Website

The RaDAR Team at the University of Sask website:

<http://www.cchsa-ccssma.usask.ca/ruraldementiacare> :

- 1) contact information for all researchers and descriptions of current research projects, including the Rural and Remote Memory Clinic
- 2) Information, photos, and resources
- 3) Listings of resources and team publications, including links to articles
- 4) Link to our RRMC videos:
<http://youtu.be/yHcZjRH32Gw>



