

Dementia Care for Indigenous Peoples

South East Knowledge Exchange
Network Webinar Series

January 19, 2022

12:00 - 1:00 PM

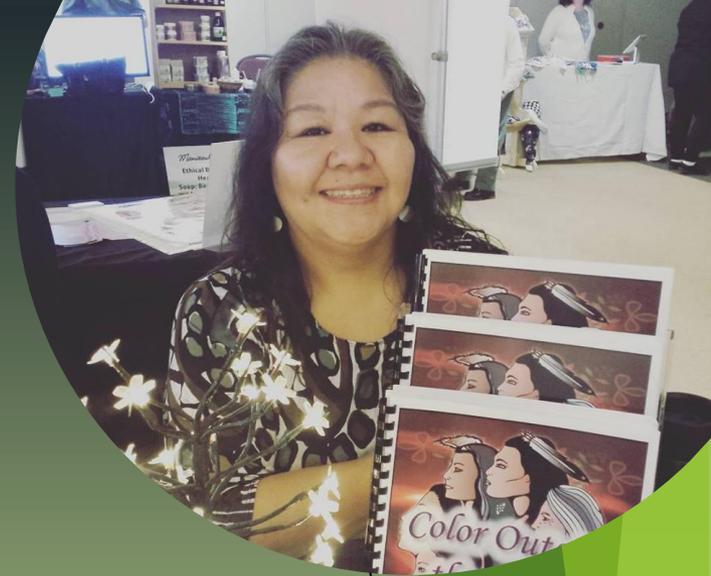
Sharlene Webkamigad, RN, MA, Ph.D.
Candidate in the School of Kinesiology
and Health Sciences, Laurentian
University

“Our thoughts alone can change how Indigenous health is perceived”

Sharlene Webkamigad miinwaa Waabe gegekwe n'dizhniikaaz, Nimkii bineshii n'doodem. Wiikwemkoong N'doonjibaa. My name is Sharlene Webkamigad, also, White hawk woman. I belong to the Anishinaabek Nation.

I am most at ease during rainfall or by the water, sacred gifts from mother earth. My children, E'Niigaanzit and E'jignat Nimkii Naapkawaagan, are also strengthened by the water.

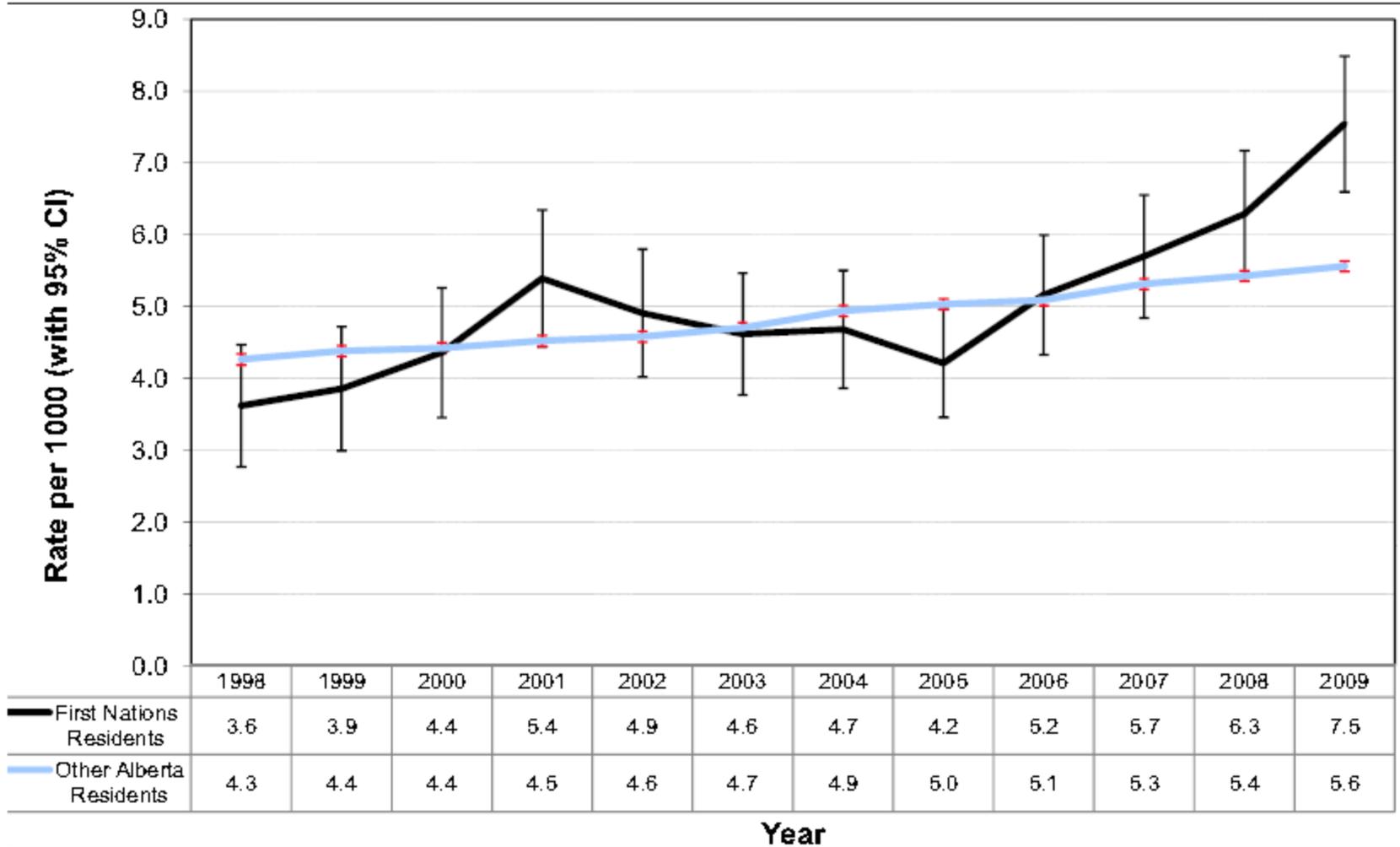
The colors I wear in the circle as a jingle dress dancer are vibrant and reflect my nature.



Learning Objectives

- ▶ You will identify why it is important for care providers to provide culturally safe care
- ▶ You will Learn how Indigenous worldviews of dementia differ from non-Indigenous worldviews
- ▶ You will learn about culturally safe approaches and identify where to locate these and more resources

Figure 2. Age-adjusted treated prevalence of Alzheimer's disease and dementia, Alberta, 1998 to 2009



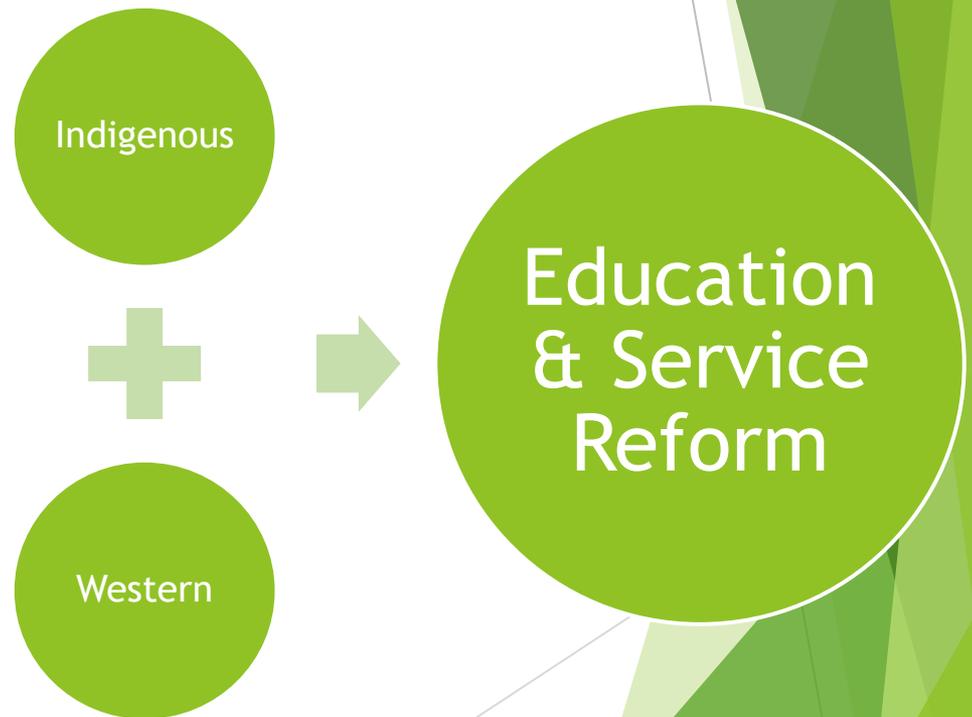
Data sources and notes: Alberta Health Physician Claims Data and Alberta Health Care Insurance Plan Population Registry, Most Responsible Diagnosis of 290 or 331.0.

All-embracing education focuses on similarities between different belief systems

How can health promotion materials concerning dementia be developed to meet the needs of Indigenous peoples living in an urban community of Northeastern Ontario?

How do culturally safe supports and services look for older Indigenous adults and their caregivers?

How can you implement this into practice?

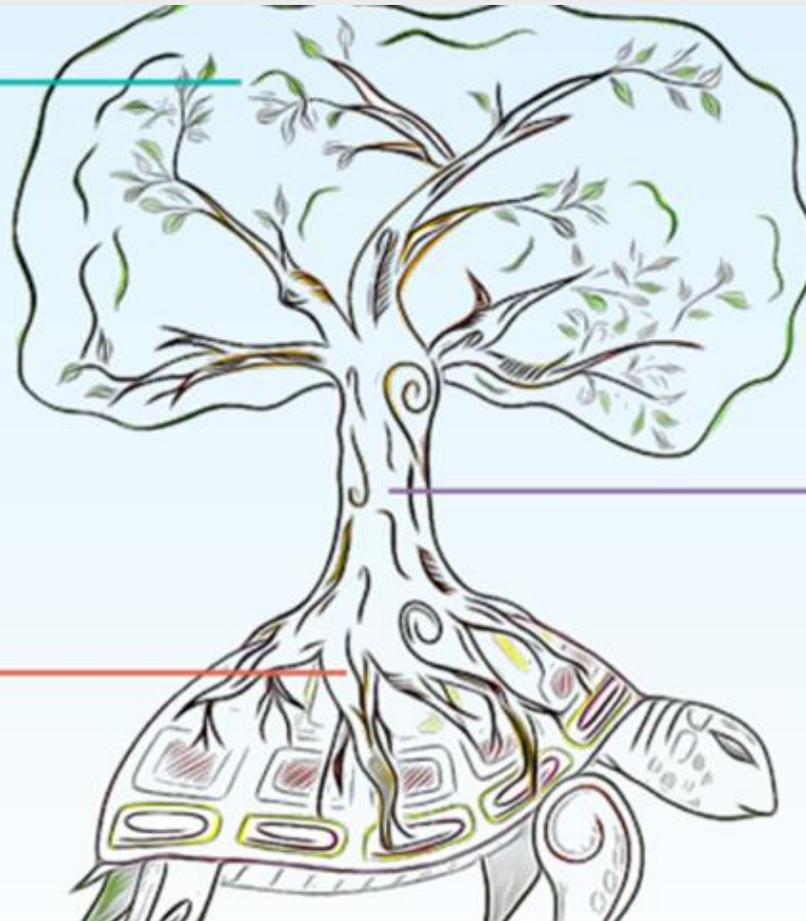


**Proximal Determinants
(Crown)**

Early childhood development
Income and social status
Education and literacy
Social support networks
Employment
Working conditions
Occupational health
Physical environment
Culture and gender

Distal Determinants (Roots)

Historical
Political
Ideological
Economic
Social foundations



**Intermediate Determinants
(Trunk)**

Health promotion
Health care
Education and justice
Social supports
Labour markets
Government
Private enterprise

Source: Reading C. Structural determinants of Aboriginal peoples' health. In: Greenwood M, de Leeuw S, Lindsay NM, Reading C (editors). Determinants of Indigenous Peoples' Health. Toronto, ON: Canadian Scholars' Press, 2015. p. 3-15. Illustration by Robyn Rowe. Retrieved from <https://www.ices.on.ca/Publications/Atlases-and-Reports/2019/First-Nations-and-Diabetes-in-Ontario>

Cultural Safety and Health Literacy

- ▶ Health care providers can address cultural safety and health literacy by considering the:
 - ▶ languages
 - ▶ cultural and social influences
 - ▶ education levels
 - ▶ reading skills
 - ▶ language-comprehension skills
 - ▶ listening skills
 - ▶ background knowledge and concepts of health-related topics
 - ▶ numeracy skills
 - ▶ emotional and physical factors, and
 - ▶ the individual's level of comfort in the health setting (Korhonen 2006)

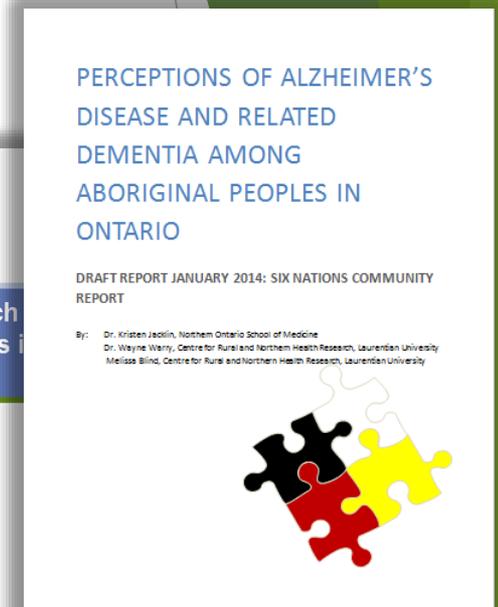
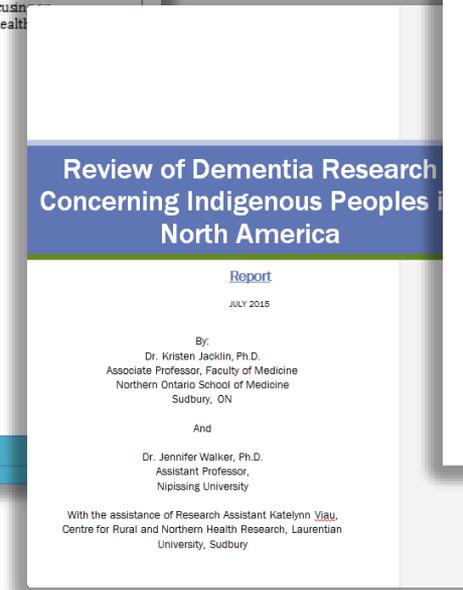
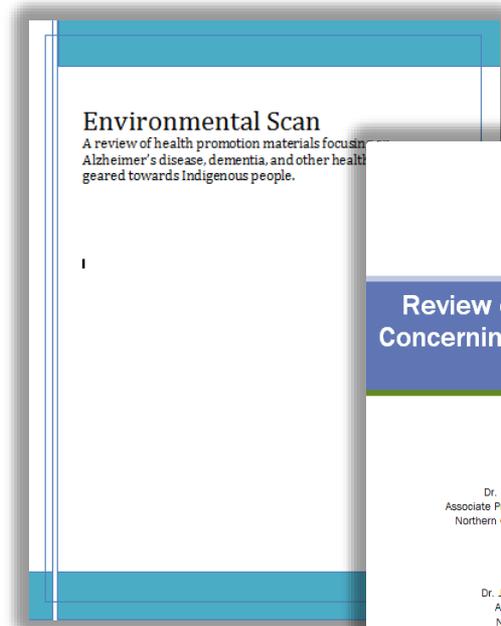
How is dementia defined and perceived in Indigenous and Western cultures?

Language choice is very important in defining and describing dementia and other concepts

- ▶ There are differences in the meanings of memory loss/dementia
- ▶ Some concepts are perceived differently, for example, 'loved one'

Literature Review

- ▶ Dementia information materials were developed using research findings from an Ontario-based research study concerning perspectives on dementia in six Indigenous communities and a systematic literature review and environmental scan on dementia in Indigenous populations.



Findings: Literature Review

Symptoms may not be problematic

NATURAL AGING rarely discussed

BACK TO THE BABY STAGE
natural/normal

going through the full circle of life

dementia is under-diagnosed

your dementia
diagnosed late

not well understood

circle of life

Findings: Review of Community Reports (Ontario)

What is Dementia?

- ▶ Going back to childhood/second childhood; going full circle; being closer to the Creator.
- ▶ Individuals entering the later stages of life may be more connected to the spirit world and see or hear things that other people may not.
- ▶ It was also widely accepted that elderly people may exhibit certain child-like behaviours and will need more personalized care as they age
- ▶ Later stage dementia was more often problematized, especially by the family caregivers.

Symptoms

- ▶ Forgetfulness, including not being able to recognize people, places, or objects; repeating stories; misplacing objects;
- ▶ Impaired judgement, including not understanding instructions; not understanding cause and effect; sense of time is off;
- ▶ Changes in mood and personality, including emotional outbursts; easily upset or frustrated; withdrawn from family, friends, or favourite activities; increased fear, paranoia or distrust of others; compulsive behaviour;
- ▶ Changes in hygiene, including forgetting to brush hair, teeth; not interested in washing or getting cleaned up;
- ▶ Getting lost, this may include wandering or pacing;
- ▶ Seeing or hearing things that nobody else can, including connections with people who have passed; hallucinations.

Culturally safe care in supports and services

How do culturally safe supports and services look for older Indigenous adults and their caregivers?

What resources are available to families before long term care?

Improving Cross-Cultural Communication

Journal of Cross-Cultural Gerontology (2020) 35:69–83
<https://doi.org/10.1007/s10823-019-09388-2>

ORIGINAL ARTICLE

An Approach to Improve Dementia Health Literacy in Indigenous Communities

Sharlene Webkamigad¹ • Wayne Warry² • Melissa Blind² • Kristen Jacklin² 

Published online: 18 December 2019

© The Author(s) 2019



Fact Sheet #1: What is Dementia



Fact Sheet #2: Signs and Symptoms



Differences

► Here is the Alzheimer's Society definition of dementia:

What is Dementia? First Nations Perspectives and Cultural Understandings

Health Care Providers Understandings of Dementia

"Dementia is an umbrella term for a variety of brain disorders. Symptoms include loss of memory, judgement and reasoning, and changes in mood and behaviour. Brain function is affected enough to interfere with a person's ability to function at work, in relationships or in everyday activities." *The Alzheimer's Society of Canada*

Differences

► Views of dementia based on First Nations people of Ontario:

First Nations Understandings of Age-Related Dementia

There is some evidence that suggests age-related dementias have only recently become more common in Indigenous populations. As people live longer they are more likely to experience dementia.

Just as First Nations communities in Canada are different, First Nations peoples, communities and cultures hold different understandings of dementia, memory loss, forgetfulness and confusion related to aging. These understandings may be very different from those held by doctors, nurses and support workers.

Some descriptions of dementia that are common are that:

- “It’s normal”
- “It’s natural”
- “It’s part of the circle of life” or “coming full circle”

Dementia may also be described as a “second childhood” and a time when one is “closer to the Creator.” A person’s spiritual beliefs often influence how dementia is viewed.

Historical changes in diet, changes to the land or environment, disconnection from culture, as well as trauma, intergenerational trauma, stress, and unresolved grief are significant factors that cause people and communities to sometimes be out of balance and may partially explain a rise in the number of elderly with dementia.

Uniqueness

- ▶ The word dementia is not familiar to the Native language of some First Nations

Talking about Dementia

Dementia may or may not be an accepted term for all people. It may be more appropriate to speak of forgetfulness or thoughts being mixed up. There is no word that has been identified to mean dementia in Aboriginal languages in Canada. Instead, First Nations languages have words that describe the symptoms or state of mind. For example, words and phrases such as:

- “forgetful”
- “confused”
- “thoughts mixed up”
- “something wrong with my head”
- “mind changes”
- “going back to childhood”

The words people use to describe the symptoms often indicate the severity or stage of the illness which can be helpful for health care workers, physicians and specialists in their assessments and care planning.

Health care worker interactions with First Nations people concerning dementia should include an early conversation with the patient and family to explore their understandings of the symptoms being experienced and the acceptability of words such as dementia or Alzheimer’s disease.

Views held by the family and individual can be respected by adjusting your language use and approach to care.

Similarities

- ▶ Signs and symptoms are very similar between Indigenous and non-Indigenous peoples however, First Nations peoples may experience them 10 years earlier than non-First Nations peoples.

SOME FACTS:

Rates of dementia in First Nations people are higher than they are in non-First Nations people in Canada. Research suggests that the number will continue to rise and by 2031 there may be a 4.6 times increase in the number of on-reserve First Nations people living with dementia.¹

Symptoms of dementia may begin in people as young as 45-50 or may begin much later depending on the type of dementia. Recent studies suggest that Alzheimer's disease and dementia may occur as much as **10 years** earlier in First Nations people compared to non-First Nations people in Canada.²

Signs and Symptoms

▶ 1. Forgetfulness and memory loss that affects day-to-day living

“she forgets right from one minute to the next uh, when she ate last, for example” Manitoulin Caregiver

1. Forgetfulness and memory loss that affects day-to-day living

- Misplacing things like your keys, purse or wallet
- Having a hard time remembering the names of people who you know, especially family members
- Forgetting to turn off the stove, leaving the fridge door open, forgetting to turn off the water
- Repeating yourself; telling the same story over many times in the same day
- Needing lots of reminders, missing appointments
- Walking into a room and forgetting why you went there
- Forgetting if you took your pills or forgetting to get cleaned up in the morning
- Forgetting things that happened through the day but remembering things from way back

2. Difficulty performing familiar tasks

How can health promotion materials concerning dementia be developed to meet the needs of Indigenous peoples living in an urban community of Northeastern Ontario?

Exploring the Appropriateness of Culturally Safe Dementia Information with Indigenous People in an Urban Northern Ontario Community

Sharlene Webkamigad,¹ Sheila Cote-Meek,² Birgit Pianosi,³ and Kristen Jacklin⁴

RÉSUMÉ

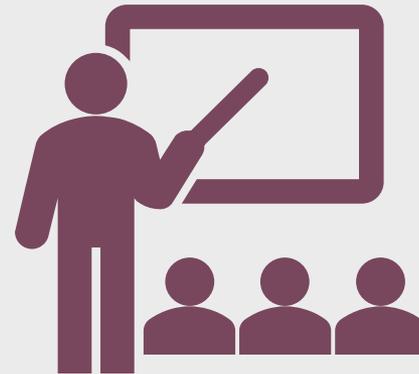
Ce projet en application de connaissances a exploré la pertinence d'une documentation en promotion de la santé élaborée pour une population autochtone nationale en vue de son utilisation dans une communauté autochtone urbaine

Publication:

Webkamigad, S., Cote-Meek, S., Pianosi, B., & Jacklin, K. (2019). Exploring the appropriateness of culturally safe dementia information with Indigenous people in an urban northern Ontario community. *Canadian Journal on Aging*, p. 1-12.

Who to involve

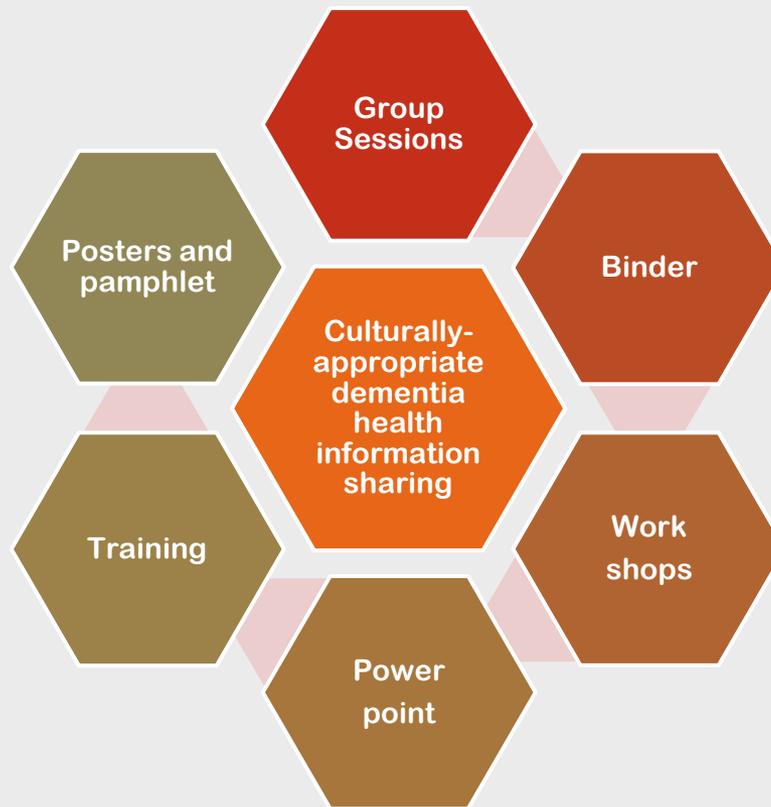
“We should have our own people. You know, like involved in anything, even education. ...we should get our own people to teach our own kids. That’s why we like to see you guys, you know come in there to do the health. Our own teachers teaching our own children.”



Where to share the information

“And a lot of our First Nations, they always have to come out to the urban setting to find medical help and resources... If there was somebody that could go to them sometimes, that would be all the better for them. They would be in their own surrounding, comfortable surrounding at that... and because, a lot of times if they got to leave their reserve and come to the city it’s a big step for them.”





How can you implement this into practice?

More resources developed following the first two fact sheets are found at www.i-caare.ca/factsheets



Additional Resources

Canadian Indigenous Cognitive Assessment (CICA) Tool

A culturally-safe
dementia case finding
tool

An Indigenous-specific approach to cognitive assessment

- ▶ The CICA is a culturally relevant tool that takes language, culture and trauma into account
- ▶ May lead to earlier, more accurate diagnosis and improved health outcomes
- ▶ Leads to early supports for the person and family, caregivers and community
- ▶ The CICA has good sensitivity and specificity
 - ▶ It can pick up dementia correctly and is able to correctly identify people without dementia.

When is it appropriate to use?

- ▶ When cognitive impairment is suspected
- ▶ When there is a change in cognitive function or health status.
- ▶ The CICA is ideal for Indigenous older adults with limited access to formal healthcare services
- ▶ It can be used by formal and informal caregivers, health care providers, in the home, community, or health care setting
- ▶ It can be administered in different languages (English, Anishinaabemwin) or through translation, if the administrator is fluent in Anishinaabemwin.

Important considerations about using the CICA

- ▶ The results from this screening tool might be useful clinically, but only when the CICA has been administered in a standardized manner.
- ▶ The CICA cannot make a diagnosis
- ▶ Do not use the CICA if there have been no changes seen in a person's ability to manage day to day activities
- ▶ It should not be used to measure clinical changes over time.

The Canadian Indigenous Cognitive Assessment (CICA) materials are available online at:

<https://www.i-caare.ca/cica>

For questions about the CICA, please contact ccnateam18@laurentian.ca

P.I.E.C.E.S.
of my
Relationship

Behavior Care Planning

What is it?

- ▶ A foundational tool used for behavioral care planning
- ▶ Uncovers important details of the individual's personhood that can be incorporated into care
- ▶ Includes:
 - ▶ Guidelines for PIECES of my RELATIONSHIPS
 - ▶ A Quick Guide to...Approach
 - ▶ P.I.E.C.E.S. of my Relationships
 - ▶ P.I.E.C.E.S. of my Relationships Family Supplement

Using the PIECES of my RELATIONSHIPS Tool

- ▶ Approaching older Indigenous adults allows ample time to build trust and develop the relationship
- ▶ Understand that dementia and aging are grounded in Indigenous knowledge and culture
- ▶ Using soft and gentle tones
 - ▶ “Slow your speech, speak as slow as they walk”
- ▶ Pay attention to non-verbal cues
 - ▶ Observe, listen and be understanding

The P.I.E.C.E.S. of my Relationship materials are available online at: <https://www.i-caare.ca/practicetools>

For questions about this tool please send a message to <https://www.i-caare.ca/contact>

Resources

- Additional resources at www.i-caare.ca/
- Canadian Consortium of Neurodegeneration in Aging Team 18 – Issues in Dementia for Indigenous Populations *Website under construction* www.ccnateam18.ca
- Indigenous Inuit Home and Community Care www.hc-sc.gc.ca
- Alzheimer’s Society of Canada www.alzheimer.ca
- Alzheimer’s Association <https://www.alz.org/>
- Government of Canada www.seniors.gc.ca
- End-of-Life Care in Indigenous Communities <http://eolfn.lakeheadu.ca/>
- Overcoming barriers to culturally safe and appropriate dementia care services and supports for Indigenous peoples in Canada <https://www.nccah-ccnsa.ca/docs/emerging/RPT-Culturally-Safe-Dementia-Care-Halseth-EN.pdf>
- Wellness in Early Onset Familial Alzheimer Disease: Experiences of the Tahltan First Nation <http://med-fom-neuroethics.sites.olt.ubc.ca/files/2015/08/GTP-Wellness-in-EOFAD-s.pdf>
- RaDAR Resources for Dementia Care <https://cchsa-ccssma.usask.ca/ruraldementiacare/Resources.php>

Acknowledgements

- ▶ Special thanks to Drs. Kristen Jacklin and Jennifer Walker, my supervisors during the course of my MA study and Ph.D. study, respectively; and mentor Karen Pitawanakwat, RN, Community Based Researcher who has been actively implementing the work across Ontario.
- ▶ This work would not be made possible without the support of many community members, Elders, advisory circles, research teams, and funders of the continuous work that has been done across Turtle Island (North America) for the past 15 plus years.

Sharlene Webkamigad, RN, MA

Ph.D. Candidate in the School
of Kinesiology and Health
Sciences, Laurentian
University

swebkamigad@laurentian.ca

www.i-caare.ca

Miigwetch,
Thank you