

TEAM 20

Issues in Dementia Care for Indigenous Populations

Spring 2017

What has Team 20 been up to this winter?



Team 20 didn't hibernate this winter! We've been busy gathering information and spreading awareness about the importance of culturally safe dementia care in Indigenous communities. Kristen and Karen were interviewed on "The Agenda with Steve Paikin" (TVO). **Find a link on our website: i-caare.ca/videos**

- Karen Pitawanakwat**
Wikwemikong Health Centre
- Kristen Jacklin**
Northern Ontario School of Medicine
- Carrie Bourassa**
Health Sciences North Research Institute
- Jennifer Walker**
Centre for Rural and Northern Health Research (CRaNHR)
- Janet E. McElhaney**
HSNRI
- Brock Pitawanakwat**
University of Sudbury
- Wayne Warry**
CRaNHR
- Lynden Crowshoe**
University of Calgary
- Laura Warren**
Dalla Lana School of Public Health
- Elder
Betty McKenna
- Elder
Jerry Otowadjiwan
- Melissa Blind**
CRaNHR

Culturally Safe Factsheets Now Available

On March 27, 2017, we officially launched our new factsheets about dementia, memory loss, and healthy aging in Indigenous communities. These factsheets center the voices of Indigenous peoples in Ontario, including from the seven First Nations of the Manitoulin region. Graphic design was done by Design de Plume, an Aboriginal-owned agency in Sudbury. We hope that they fill a gap in health information for health care providers, older Indigenous adults, and families.

These four factsheets are freely available to download at i-caare.ca/factsheets.

WHAT IS DEMENTIA?

Indigenous Perspectives and Cultural Understandings

WHAT TO EXPECT AFTER A DIAGNOSIS OF DEMENTIA:

An Indigenous Persons' Guide

SIGNS AND SYMPTOMS OF DEMENTIA:

An Indigenous Guide

PREVENTING DEMENTIA IN INDIGENOUS PEOPLES BY AGING WELL

Advice from older Indigenous peoples



Northern Ontario School of Medicine
École de médecine du Nord de l'Ontario
בית הספר לרפואה צפונית-מזרחית



Health Sciences North Research Institute
Institut de recherches d'Horizon Santé-Nord

CCNA
Canadian Consortium on Neurodegeneration in Aging



CCNV
Consortium canadien en neurodégénérescence associée au vieillissement



Laurentian University
Université Laurentienne

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"There is no word that has been identified to mean dementia in Aboriginal languages. Instead, Indigenous languages have words that describe the symptoms or state of mind."

*What is Dementia:
Indigenous
Perspectives and
Cultural
Understandings*

(i-caare.ca/factsheets)

Team Members on the Move



(top left): Dr. Carrie Bourassa, (centre): Dr. Jennifer Walker, (bottom left): Dr. Janet McElhaney.

We have exciting news! Team 20's Dr. Carrie Bourassa has been busy this winter. She moved from First Nations University of Canada to Health Sciences North Research Institute (HSNRI) in Sudbury. She has also assumed the position of Scientific Director for the Institute for Aboriginal Peoples' Health, Canadian Institutes of Health Research (CIHR).

Dr. Jennifer Walker, Senior Research Associate at CRaNHR, has also made exciting moves. As Laurentian University's first Canada Research Chair in Indigenous Health, she was awarded a CIHR grant to validate the Canadian Indigenous Cognitive Assessment (CICA) in three provinces with CCNA Team 20 colleagues.

Dr. Janet McElhaney, Vice President of Research & Scientific Director at HSNRI, also secured a CIHR grant with co-applicants from CCNA Team 20. Her work seeks to empower caregivers supporting older Indigenous adults with dementia.



(Photo courtesy of Anishinabek News) Dr. Jennifer Walker and Dr. Janet McElhaney at the announcement of their CIHR grants with federal government and Laurentian University representatives.

"This will be a major contribution to the quality of front-line health care provided to aging Indigenous populations and will form a solid foundation for ongoing surveillance of dementia rates. I look forward to working with communities in Ontario, Alberta and Saskatchewan, on this very important research initiative."

Dr. Jennifer Walker

The Kind Words Corner

*"We view end of life living as a part of the circle of life. Whatever conditions that elderly person has don't become them. **They're still who they are.**"*

Karen Pitawanakwat, on TVO's The Agenda



Kristen presents about the importance of training health care providers in culturally safe dementia care at the Chiefs of Ontario Annual Health Forum.

Words Matter: Loved One & Caregiver

You will notice that instead of "person with dementia" we use **loved one**. In our work, we spend time with Elder Jerry Otowadjiwan to make sure that it's done in a good way.

Elder Jerry shared teachings about love with us. He shared that a person with dementia is someone who needs a lot of love and will need to be reminded that they are loved. And whether or not their caregiver is someone who loves them, the act of providing care is a loving act, and somebody, somewhere loves this person. Using the term **loved one** reminds us of how we should be treating and respecting a person with dementia.

The community advisory group, participants and community partners reacted well to **loved one** and found it appropriate in an Indigenous context.

We also use **caregiver** instead of the more recent "care partner." This is because to provide care is to offer a valued gift to another. **Caregiver** was also preferred by community stakeholders and participants.



Kristen and Elder Jerry Otowadjiwan in Wikwemikong, August 2016. As Project Elder for Team 20's Ontario work in the Manitoulin area, Elder Jerry has been instrumental in making sure that work is done in a good way.

Elder Bill Antoine, a member of the Anishinaabe Language Expert Group, reminded us that there are words caregivers can use to make older adults feel comfortable, wanted, and good, like:

***gzaagidwin** (to love)*

***gzaagin** (I love you)*

"Memory care and brain health is a life long journey that involves the whole community, especially younger generations. For example, playing with kids and youth can keep older Indigenous adults active. Older adults have a role in teaching youth how to age and grow in a healthy way."

Preventing Dementia in Indigenous Peoples by Aging Well: Advice from older Indigenous peoples

(i-caare.ca/factsheets)

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Members of the North East BSO staff and Team 20 staff meet up to work on **PIECES of my Relationships** for the first time in Summer 2016.

From left: Emily Piraino, Louise Jones, Karen Pitawanakwat, Bob Spicer, Melissa Blind, and Roxanne Makela.

Let's talk about "PIECES of my Relationships"

This past summer, Team 20 began working with North East Behavioural Supports Ontario (BSO). BSO provide services and training to long term care homes and home care agencies for older adults all across northeastern Ontario, including Manitoulin. One of the tools that they use is called **PIECES of my Personhood**.

PIECES is used to get to know a loved one so that when BSO staff are providing services, they can be sure the person is comfortable and safe. It also helps staff plan fun activities and make sure the person gets to eat, sleep, and visit the way they want to. BSO recognized that this tool was not culturally safe for Indigenous people, so Team 20 and the BSO are developing a new tool, **PIECES of my Relationships**. The Anishinaabe Language Expert Group rephrased the questions and translated them into Anishinaabemowin.

This bilingual tool will be brought to focus groups this spring to make sure it works for as many people as possible. Once focus group feedback has been incorporated, the BSO will begin training staff to use it. Indigenous loved ones will then have the option of using the old or the new tool.

Next Steps

This spring, we are piloting the Canadian Indigenous Cognitive Assessment with older Indigenous adults in the Manitoulin region in English and in Anishinaabemowin. Once piloting is complete, we will start reliability testing.

Visit i-caare.ca/cica to learn more.

Kristen, Karen, and Melissa will also be presenting about CCNA Team 20's work at the International Association of Geriatrics and Gerontology World Congress in San Francisco, California in July.

Meet Rhonda



Rhonda Trudeau, from Wiikwemkoong Unceded Territory, is our Community Research Assistant. She also works in finance and admin support at the health centre.

She has been a vital part of Team 20 for a year, assisting our Community Researcher, Karen Pitawanakwat. While supporting Team 20, Rhonda has enjoyed connecting with neighbouring community members, our advisory group, and our expert Anishinaabe language speakers.

TEAM 20

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