

TEAM 20

Issues in Dementia Care for Indigenous Populations

Fall 2015

Who are we?

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Elder
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What is Team 20?

Team 20 has two focus areas: rural and Indigenous. The Indigenous team is the only team within the CCNA investigating neurodegenerative diseases in Indigenous communities. We have received partner funding from the Institute of Aboriginal Peoples Health at CIHR to research quality of life for Indigenous people affected by age-related dementia. Led by Dr. Kristen Jacklin and Dr. Carrie Bourassa, our research will involve communities across Ontario and Saskatchewan for the next five years.

Why are we doing this?

The need for this type of research was highlighted in January 2007 when First Nations Health Authorities in the Manitoulin District supported the need to address Alzheimer's Disease and Related Dementias (ADRD) in their communities. There was a general consensus that Alzheimer's disease and dementia were becoming a health concern in Aboriginal communities, that issues around dementia in Aboriginal communities are poorly understood by health care professionals, and that there is a need to improve services and care for Aboriginal people living on and off reserve. From 2009-2013 we worked with First Nations communities and organizations on Manitoulin Island to produce the *Perceptions of Alzheimer's Disease and Related Dementias among Aboriginal Peoples in Ontario: Report of Manitoulin Island First Nations*. This project builds on that research.

What is the CCNA?

The Canadian Consortium for Neurodegeneration and Aging (CCNA) was launched in 2014 by the Canadian Institutes for Health Research (CIHR). It is a hub for research involving neurodegenerative diseases that affect cognition in aging (like dementia or Alzheimer's). CCNA teams are located across the country, each with their own independent research program.



Team 20 meets up for the first time



What is 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). Dementia might be described as "second childhood," "coming full circle," getting "closer to the Creator," or as a natural part of aging.

Karen and Kristen in Wikwemikong



Laurentian University
Université Laurentienne

What are we doing?

In Ontario we are working closely with First Nations communities and partner organizations on Manitoulin Island to...

- 1) Explore aspects of Indigenous culture, knowledge, spirituality, and ceremony that are related to improving **quality of life** in these regions.
- 2) Develop a culturally safe way for health care providers to **diagnosis** dementia in Indigenous people.
- 3) Build **capacity** and awareness about Indigenous dementia research.
- 4) Determine **how many** First Nations people have dementia, and where and how they get help. We will do this by examining administrative health data from the Indian Registry System. This data is governed by the Chiefs of Ontario.
- 5) Explore what kind of **technology** older Indigenous adults might find useful for managing dementia.



Next Steps...

Team 20 has received approval from the Manitoulin Anishinaabek Research Review Committee and the Laurentian University Ethics Review Board. We are now seeking approval from each community and assembling our advisory committee (a group of community members who will guide us on this research journey).

Get in touch...

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Meet Karen



Karen Pitawanakwat, from Wikwemikong, is our community researcher. She has worked in health care on Manitoulin Island for 25 years.

As the community researcher on previous projects, she has a great deal of experience in the field. In the past, Karen has travelled to Australia and Saskatchewan to do this work. This fall, she is attending the International Association of Gerontology and Geriatrics 2015 Conference in Chiang Mai, Thailand.

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