Understanding Dementia in Indigenous Populations: Cultural Safety and a Path for Health Equity

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Introductions and Acknowledgements
Research Team Journey

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2007  2008-09  2010-14  2014-19

Foundational Knowledge:
Alzheimer’s Disease and Related Dementias
In Aboriginal Peoples in Ontario, Canada
2010-2014

Purpose: To collect and analyze foundational information concerning knowledge, attitudes, perceptions, and cultural values concerning dementia and aging in diverse Aboriginal communities.
What is Cultural Safety?

Cultural safety is a lens we look through and use to improve health policy and health care related to Indigenous populations.

Cultural safety acknowledges that inequities have been created by and persist because of colonial policies enforced by our government.

Cultural safety acknowledges that Indigenous health care experiences and health outcomes are shaped by a collective history that has marginalized Indigenous communities, cultures and healing traditions.

Cultural safety asks us to critically look at and reflect on our health environments and our own approaches to care and examine how our own biases perpetuate inequities.

Cultural safety asks us to address structural barriers in health systems that prevent Indigenous patients from achieving health equity.

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What is Health Equity?

“Equity is the absence of avoidable, unfair, or remediable differences among groups of people, whether those groups are defined socially, economically, demographically or geographically or by other means of stratification. "Health equity" or “equity in health” implies that ideally everyone should have a fair opportunity to attain their full health potential and that no one should be disadvantaged from achieving this potential.”

(World Health Organization)
Dementia in Indigenous Populations

Rates and Risk
Rates of Dementia in Indigenous Populations

- Limited data is available to accurately represent rates of dementia in Indigenous populations.
- Small studies that are available suggest rates of dementia in Indigenous populations around the world are higher than non-Indigenous peoples and continue to increase.
- Systematic review studies suggest a high degree of variation in study designs and findings (Warren et al. 2015)
Prevalence of Dementia in First Nations in Alberta, Canada

- Prevalence 34% higher in First Nations
- Dementia increasing at a faster rate in First Nations
- Average age of onset 10 years younger
- Greater proportion of males diagnosed


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

Source: Alberta Health Physician Claims Data and Alberta Health Care Insurance Plan Population Registry, Most Responsible Diagnosis of 290 or 331.0.
Prevalence measures how many people are diagnosed with the illness

- Aboriginal Australians NT 6.5/100 vs 2.6/100 (Li et al 2014)
- Aboriginal Australians Kimberly’s 12.4/100 100 vs 2.4/100 (Flicker et al 2009)
Incidence of Dementia in a Native American Population in California
(rate of new cases being diagnosed)

Age-Adjusted Dementia Incidence Rate Per/1000 Person Yrs by Race/Ethnicity
2000-2013
(Mayeda et al 2016)
Some Risk Factors for Dementia

Age-related dementias arise from a combination of risk factors.

• Increasing Age
• Genetics
• Head Trauma
• Cerebrovascular Disease & associated factors - hypertension, stroke, smoking, obesity
• Diabetes
• Social and Economic Status
• PTSD

Indigenous Determinants of Health by Charlotte Loppie – University of Victoria
Aging Trends and Projections

- Population growth in older adults - First Nations population in Canada is expected to increase by 1.4 times between 2006 and 2030 with a disproportional amount of growth among those aged 60 and older (an increase of 3.4 times)[1].

- Projections based on only age as a risk factor suggest the number of First Nations people over the age of 60 with dementia of will increase 4-fold by 2031, compared to a 2.3-fold increase in the non-First Nations population [2].


Summary: Rates of Dementia in Indigenous populations

What to expect:

- Rates 3-5x higher than non-Indigenous population
- Rates rising more quickly
- A four-fold increase in number of Indigenous people with dementia by 2031
- Greater proportion of males diagnosed
- Younger age of onset by approximately 10 years
Indigenous Experiences and Understandings of Dementia

Six Research Sites in Ontario, Canada

health people care providers with dementia traditional caregivers knowledge keepers seniors

2009 to 2014 5 168

6 RESEARCH PARTICIPANTS

QUALITATIVE community based

6 RESEARCH SITES METHODS

ethnographic participatory action

Indigenous epistemologies

Thunder Bay Six Nations Ottawa Moose Cree Sudbury

The Ontario Mental Health Foundation
Warning: Language

- Relationship Centred
- Culturally Appropriate
What we learned:
Experiences of dementia and aging are grounded in Indigenous knowledge & culture
Cultural views of aging

I’ve watched elderly people and how they do things, to try to be like them. And we have a song that goes with that. And we sing those songs... The song goes, “When that time comes, when my hair turns white, silver, silver hair, will I be able to sound like they sound?” That’s how the song goes. “I wonder if I’m going to sound how they sound now, when I get there.”

- Elder Jerry Otowadjiwan
Normalization and Acceptance

Memory loss is often considered natural and normal by Indigenous people.

“The code talks about... it's more of a natural thing. It's not looked at as a disease, you know. Some people go back that way, and this is how they're going back to the Creator.”
- Knowledge Keeper, Six Nations

Yeah, so ah you know it, “abnormal” does not mean [pause] “abnormal is the normal to us, it's part of the human family” everything is, maybe they're the normal, I don’t know, how do we know, (laughs). Yeah they don’t hide anything. They carry the spirit of a little child, they laugh at inappropriate times or speak up in an inappropriate times........ [Knowledge Keeper, Thunder Bay]

“It’s normal”
“It’s Natural”
“It’s part of the circle of life”
“Coming full circle”

Since memory loss is not always associated with illness, Indigenous people may not access health and social services in the early stages of dementia.
Teachings from the languages

• There are no specific words for “dementia” in Indigenous languages in the communities included in the research.

• There are gentle or humorous descriptions of being confused, forgetful, or mixed up.

• Inability to remember also did not mean that memories were lost. In Manitoulin Island communities, the term ngwosh kaa ni we ga kendung was used to describe memories as “buried” or “covered” for the time being, but not lost.

“The older people they always refer to that term of going back into their childhood, but they use the Anishnaabe word for that, and that term is “keewayabinoocheeaway.” That’s returning back to childhood.”

- Older Adult, Thunder Bay
Perceptions of memory loss in aging are deeply affected by spiritual beliefs and practices.

The loved one was often viewed as coming full circle or experiencing their second childhood as they returned to the Creator.

Visions were viewed as the result of being closer to the spirit world, and were not to be confused with hallucinations.

“Elders with dementia [are] in a time of preparation to leave this physical earth. When the Elder with dementia is not making sense in conversation or talking about another place or time that is not being experienced by all those listening, their spirit is actually travelling and amongst their next life (after life experiences/on the other side). These experiences are verbally passed on in stories and not considered hallucinations but a real part of what we know as the circle of life.”

– Anishinaabe Expert Language Group Manitoulin Island
“We were somewhere and somebody was asking her about like seeing people that are dead or gone and they were acting as if it was a bad thing. And it's something that it's a sign of dementia and for me that is clearly not a sign of dementia. That's an expected behaviour and it's expected in little ones and in older people and I found it irritating and demeaning to have to explain it and for them to just dismiss it as a sign of dementia. Because I expect her to be able to see um, people who have gone on, I expect her to be able to see things that aren't accepted in the mainstream. So that was one point of irritation. I can’t remember who asked that question but to me that was a culturally insensitive question.

Well not even just elderly too, we look at it as a better ability to be able to have that connection and we talk about the points of, of life and that when you get close to the, the portal or the time of change the birth, death area. The closer you are to both birth and death the more your able to see and experience so we don’t dismiss it we accept it and we use it and were actually happy when that happens.”

- Caregiver, Six Nations

Participants easily linked their culture and spirituality to self care in old age, caregiving practices and healthy living/lifestyles.

Self Care: “I just pray to the Creator to take care of me, to look after me, help help me out, just pray that’s all. Light cedar, smudge, or make cedar tea, make Indian medicine.” (Person with Dementia Thunder Bay)

Caregiving: Ah, I think what made it easier or more natural is that being Aboriginal that’s one of the traits is family care.. (Six Nations Family Caregiver)

Healthy Living:
Oh yes because you can’t participate in them [spiritual activities] if you drink or do drugs. Mhm – and uh, um, (pause) I don’t know what it does, dancing, not only lifts your spirit but uh, I guess brings up the whatever you need in your mind to need what do you call those things? Um, like the serotoninins and...chemicals, yeah to bring em up. (Ottawa Older Adult)
Loved ones, caregivers, and knowledge keepers talked about balance a lot. The rise in dementia was viewed as a symptom of being out of balance due to historical changes in diet and lifestyle, disconnection from the land and culture, trauma, intergenerational trauma, and unresolved grief.

this Elder said to me, “you’re out of balance,” you know? When I first went to him for help all he said was, “you’re out of balance,” so I think that Alzheimer’s is being out of balance, for me anyways. So that’s why I look at it not being able to function in a balanced way to your thoughts your feelings and your actions and acceptance.

- Older Adult, Manitoulin Island
Impact of Residential Schools

“Being around the kids is actually healing for the elderly too, because you have the kids and they’re engaging in new things with you all the time, so that’s good for the memory so, and because of a lot of the residential schools incidents too, that has also affected the family dynamic so you find a lot of grandparents just isolate themselves so families are not there doing their role as a grandparent's roles...eh? Which actually keeps you young...” (JP01 Traditional Healer Manitoulin)
Generalizability?

Dementia described in other Indigenous studies:

“For us it was an accepted, accepted part of our culture...you call memory loss, we once again go back to the full circle – a baby once again” Secwepemc British Columbia (Hulko et al 2010)

“back to the baby stage” Cree Grandmother’s in Saskatchewan (Lanting et al 2011)

Circle of Life: ...part of her life was just part of the circle of life; she became a little child again. Minnesota Chippewa (Boss et al. 1995)

Speaking about colonization: “It’s no wonder our brains became sick, our minds became sick and I became very angry” Secwepemc British Columbia (Hulko et al 2010)
There is a Need for Appropriate and Safe Care Strategies for Older Indigenous Adults
Communication & Cross-Cultural Care: lost in translation

Western/Biomedical Care Approach
- Direct questions
- Authoritarian tones
- Fast-paced
- Technical language
- English
- Focus on physical symptoms
- Patient-practitioner disassociation

Indigenous Care Approach
- Indirect
- Gentle or soft
- Taking time
- Descriptive
- Indigenous Language
- Physical, Mental, Emotional, Spiritual
- Relationship centred
Relationship Development

Relationships with health care providers were deemed important to participants. A lack of access (talked about next) was a major impediment to this.

Continuity of Care: was seen to foster relationship develop and trust. With a longer term relationship with a provider Indigenous people were more willing to engage in an honest medical history and more likely to respect and follow advice of the physician.

Lack of Continuity of Care was the norm and resulted in:
- Issues of under and over diagnosis
- Frequent medication changes
- Mistrust resulting in poor adherence to advice and medications
Organizational, Policy and Individual Barriers to Health Equity in Dementia Care

Access to Culturally Appropriate Care
- **Diagnosis**
  - Cognitive screening and assessment
- **Treatment and Care**
  - Long Term Care Programs
  - Hospital settings
  - Respite
- **Health promotion**
  - Prevention
  - Education

Access to Services
- **Mal-distribution of health care resources**
  - Family physicians
  - Indigenous providers
  - Home care/LTC/Respite
- **Indigenous Health Policy and Interjurisdictional Issues**
  - NIHB – Transportation, medications & supplies
- **Provincial Policies**
  - Referrals and diagnosis

Knowledge Gaps
- **Training**
  - Community workers – dementia training
  - Physicians and HCPs – Indigenous Cultural Safety Training
Summary of Research Findings to Inform Culturally Safe Dementia Care for Indigenous Peoples

1. Dementia and aging are grounded in Indigenous knowledge & culture
   • Dementia and aging are accepted
   • Indigenous knowledge and culture positively impact the dementia experience
   • Colonialism and cultural continuity mediate experiences with dementia

2. There is a need to develop and support appropriate and culturally safe care strategies for older Indigenous adults
   • Communication/Cross-Cultural Care
   • Relationship Development

3. Organizational, policy and individual barriers can work to prevent health equity in dementia care but can be addressed by improving:
   • Culturally appropriate care
   • Access to Services
   • Training
Dementia and Aging are grounded in Indigenous Knowledge & Culture.

Appropriate Care Strategies for Older Indigenous Adults are Needed.

Address Organizational, Policy and Individual Barriers to Health Equity in Dementia Care.

Indigenous Determinants of Health – Colonial Legacy.

Relationship Development

Advocacy

Critical Self-Reflection

Health Promotion & Education

Diagnosis & Treatment

Caregiving

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

Who I am

My name is _____________________. What is yours?

Is this the name you use most often?

Where are you from?

Where were you born?

Who are your parents?

Have you ever raised or taken care of an animal? What did you call them? What was their name?

Who is it in your life who comes to help you do what you need to do?

Is there anyone who is the leader, who everyone in the family listens to, who is trusted to look after all of your affairs?

Is there anyone who comes around to take you on outings?

Who is it that tells you not to climb up steps to reach up high on your own?

PREVENTING DEMENTIA IN INDIGENOUS PEOPLES BY AGING WELL
Advice from older Indigenous peoples

The Path of Dementia

Canadian Indigenous Cognitive Assessment (CICA)
COGNITIVE ASSESSMENT SCREENING TOOL
Learn More at the Conference:

1. Culturally Appropriate Resources for Indigenous People with Dementia: Dr. Melissa Blind and Karen Pitawanakwat, RN
   - Monday 1:15-2:30 PM
   - Tuesday 10:45-noon

   - Monday 3-4:15 PM
Learn More From Our Website Hosted by I-CAARE:
www.I-CAARE.ca
Key Summary Points

• Evidence suggests that dementia is a significant health issue for Indigenous populations that is likely to continue to increase in magnitude.

• Globally, Indigenous people experience a health equity gap that extends to the rates of dementia and access to appropriate care. Specific Indigenous determinants of health are likely factors in the elevated rates.

• While research on this topic is slowly increasing, there are still significant gaps in our knowledge of how to best prevent, treat and care for dementia in diverse Indigenous populations.

• Cultural understandings of dementia need to be respected and considered in our approaches to care. Not doing so continues a process of colonization.

• Cultural safety is a framework that can be applied to our individual care efforts and at the organizational level to ensure we are providing appropriate and effective care to Indigenous clients.
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Please Visit
www.I-CAARE.ca

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Helpful References


• Brascoupe S, Waters C. 2009. Cultural safety: Exploring the applicability of the concept of cultural safety to Aboriginal health and community wellness. *Journal of Aboriginal Health* 5:6-41
