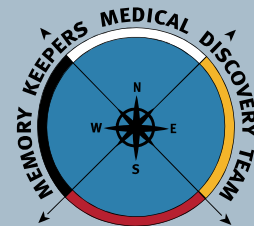


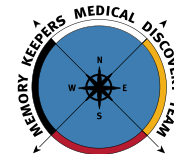
Understanding Dementia in Indigenous Populations: Cultural Safety and a Path for Health Equity

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Dementia Care 2019
Alzheimer Society Manitoba
Winnipeg, MB
March 4, 2019



Introductions and Acknowledgements



Research Team Journey



Kristen Jacklin

Wayne Warry

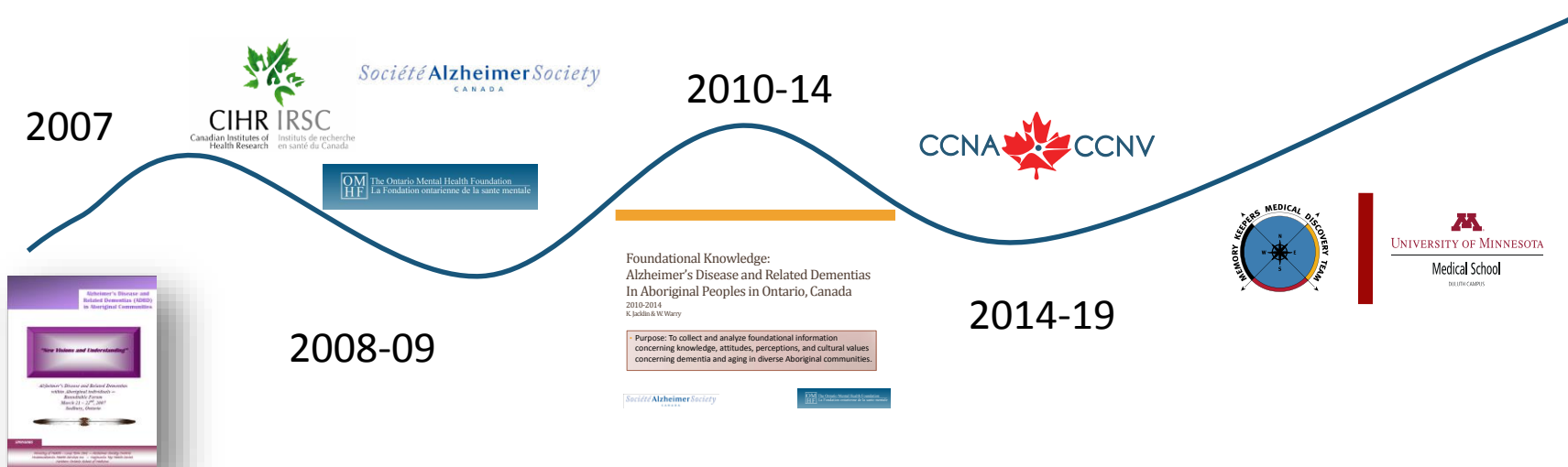
Karen
Pitawanakwat

Melissa Blind

Elder Jerry
Otowadjiwan

Sharlene
Webkamigad

Louise Jones



What is Cultural Safety?

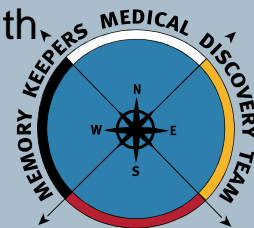
Cultural safety is a lens we look through and use to improve health policy and health care related to Indigenous populations.

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.

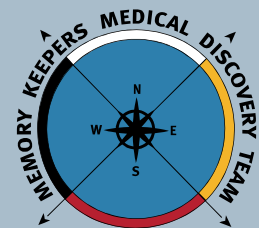
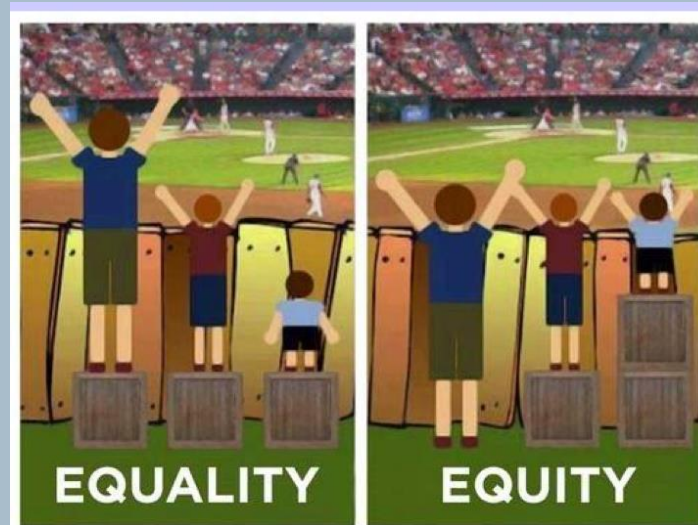
Cultural safety asks us to address structural barriers in health systems that prevent Indigenous patients from achieving health equity.



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)



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Dementia in Indigenous Populations

Rates and Risk

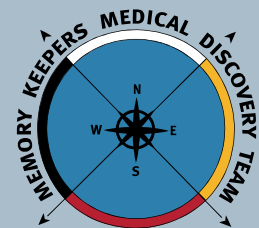


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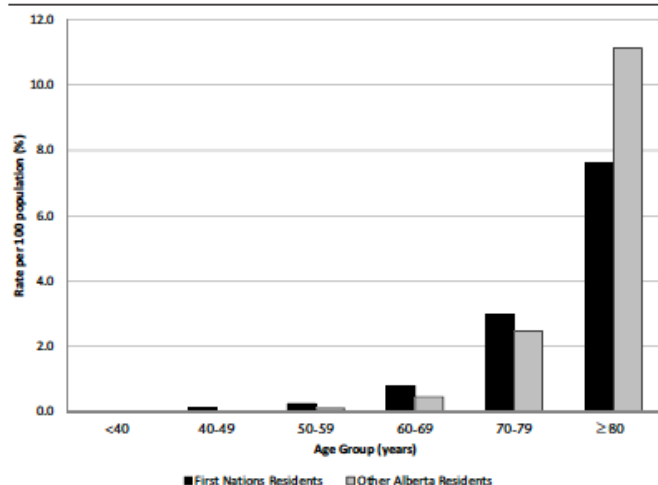
Rates of Dementia in Indigenous Populations

- 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

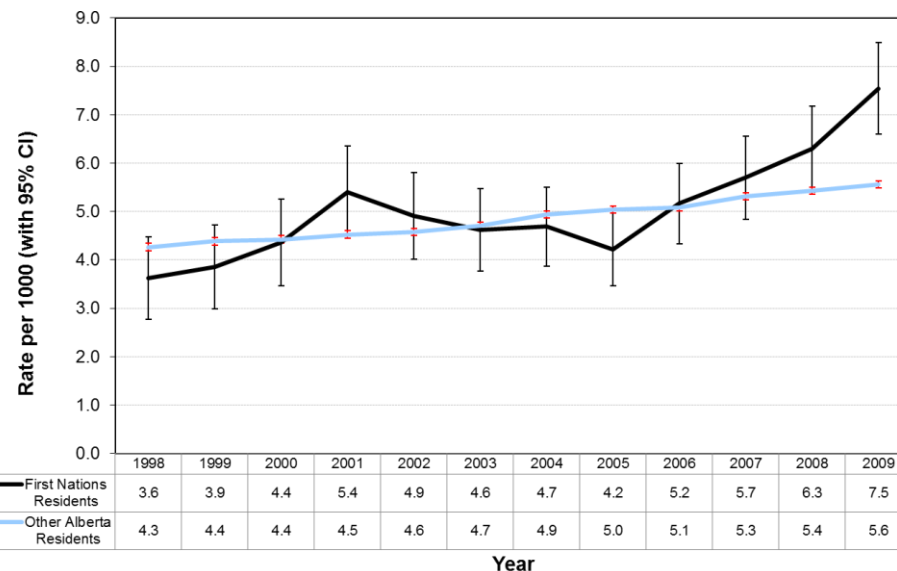
- Prevalence 34% higher in First Nations
- Dementia increasing at a faster rate in First Nations
- Average age of onset 10 years younger
- Greater proportion of males diagnosed

Figure 3. Age-specific treated prevalence of Alzheimer's disease and dementia, Alberta, 1998-2009



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.

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



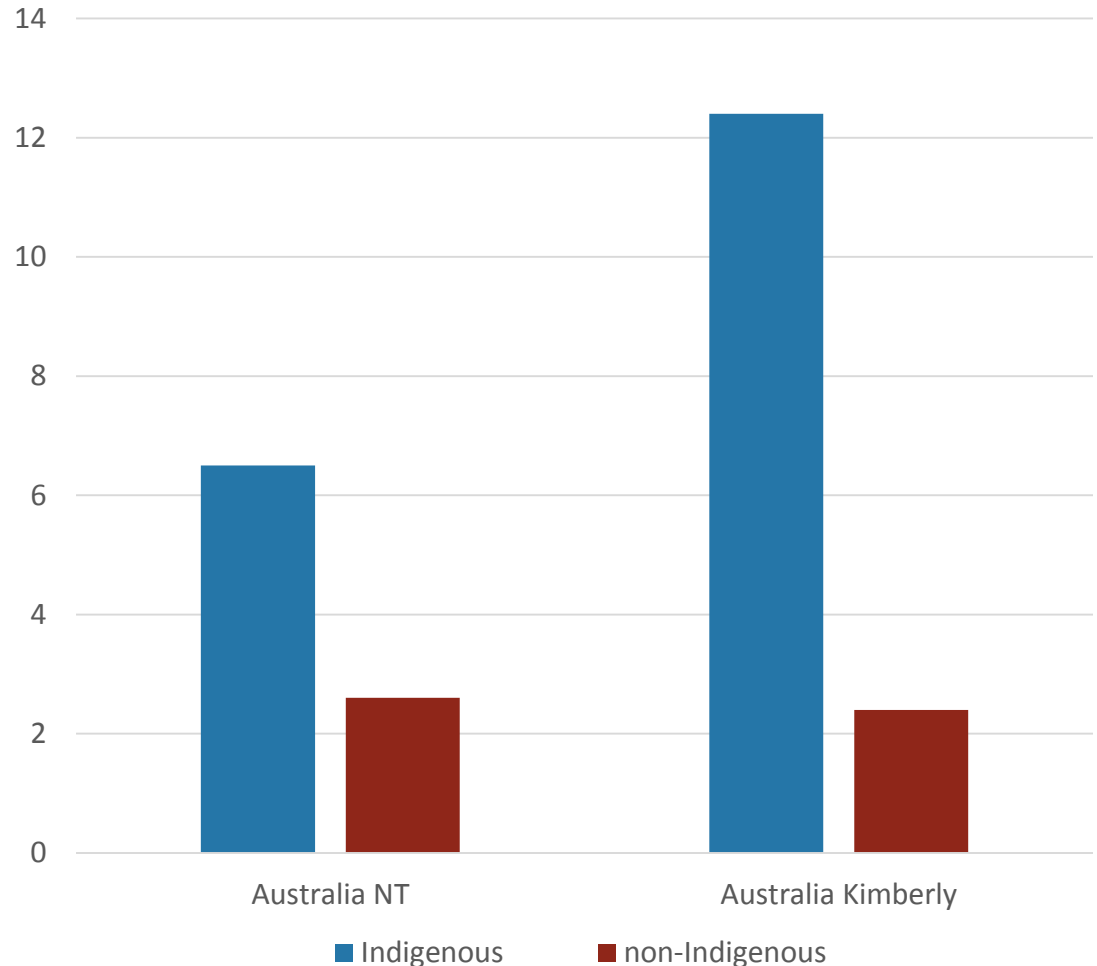
Source: Alberta Health Physician Claims Data and Alberta Health Care Insurance Plan Population Registry, Most Responsible Diagnosis of 290 or 331.0

Source: Jacklin K, Walker J & Shawande M (2013) Canadian Journal of Public Health

Prevalence of dementia in Indigenous populations: Australia

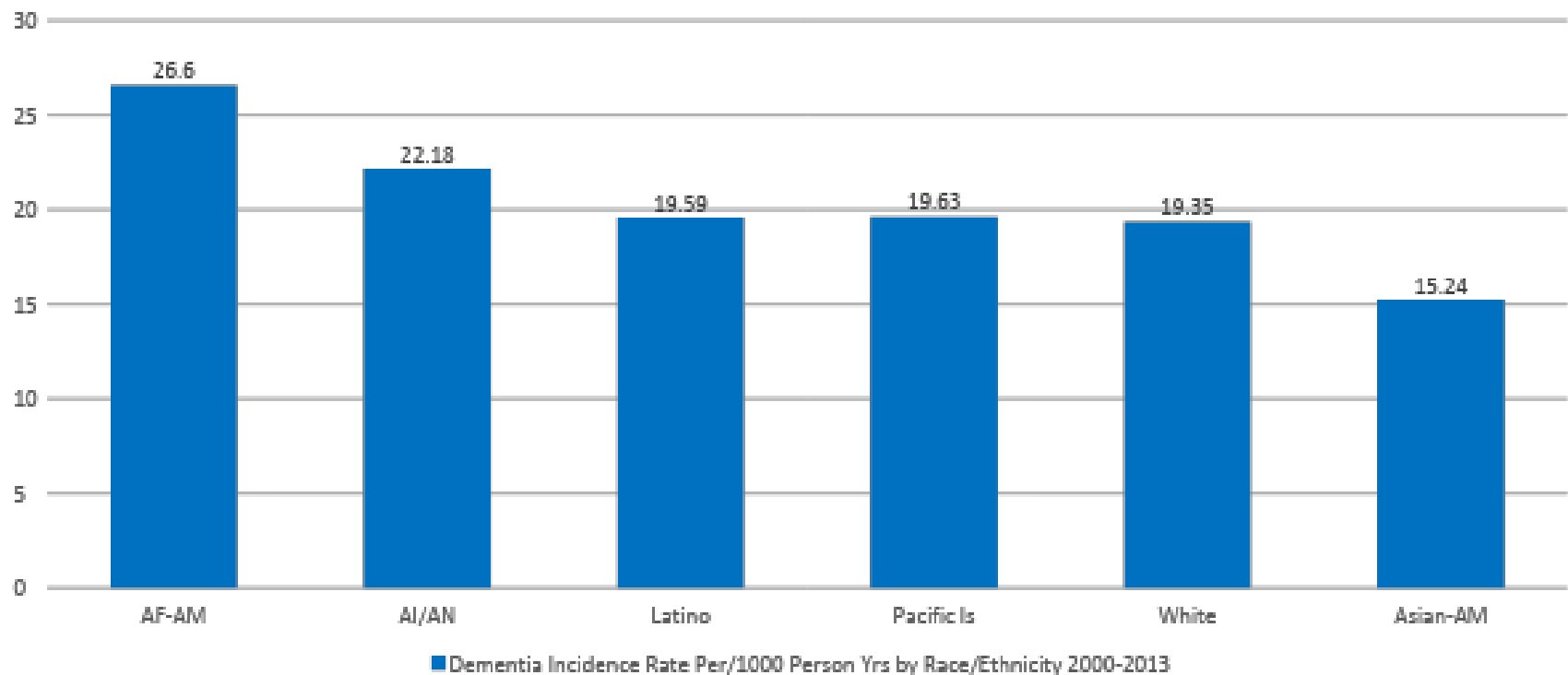
Prevalence measures how many people are diagnosed with the illness

- Aboriginal Australians NT 6.5/100 vs 2.6/100 (Li et al 2014)
- Aboriginal Australians Kimberly's 12.4/100 vs 2.4/100 (Flicker et al 2009)



Incidence of Dementia in a Native American Population in California (rate of new cases being diagnosed)

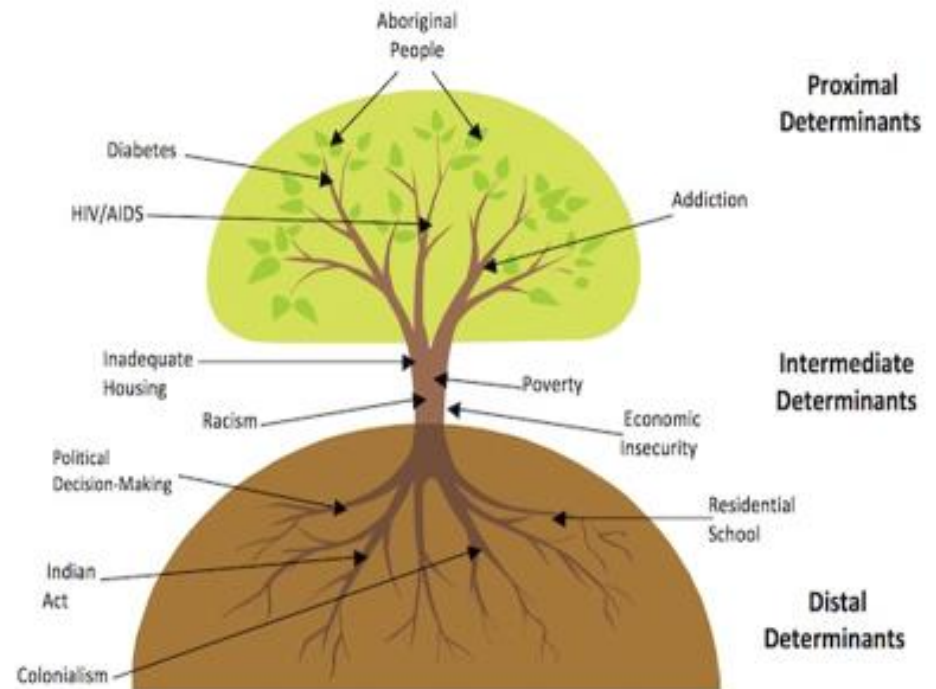
Age-Adjusted Dementia Incidence Rate Per/1000 Person Yrs by Race/Ethnicity
2000-2013
(Mayeda et al 2016)



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].

[1] E. Caron Malenfant and J. Morency, "Population projections by Aboriginal identity in Canada, 2006 to 2031," Statistics Canada, Ottawa, 2011.

[2] J. D. Walker and K. M. Jacklin, "Current and projected dementia prevalence in First Nations populations in Canada," in *Indigenous peoples and dementia: Experiencing and understanding memory loss and memory care in three settler nations*, Vancouver, UBC Press, in press.

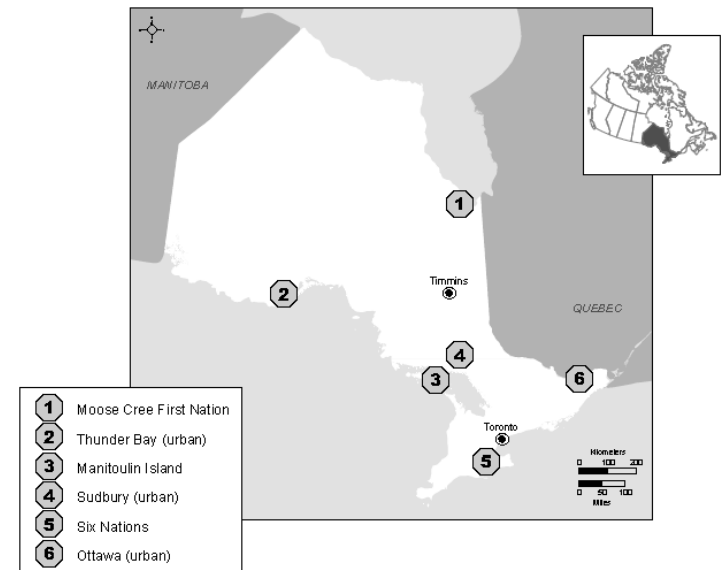
Summary: Rates of Dementia in Indigenous populations

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



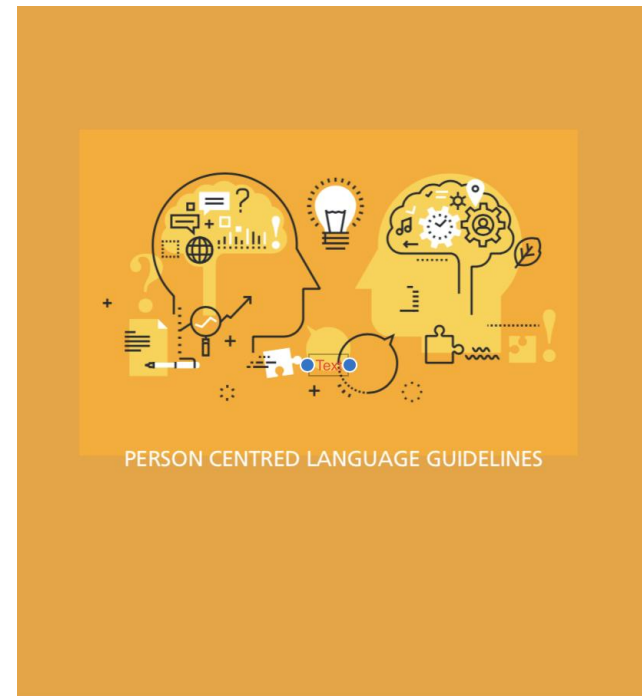
A word cloud summarizing research findings from the Dementia Care Research Network. The words are arranged in a circular pattern, with larger words indicating more frequent or significant findings. The colors are primarily blue and red.

Participants: 168 participants (2009 to 2014).
Research: 6 research sites.
Methods: Qualitative methods (ethnographic, participatory, action).
Themes: Health people, care providers with dementia, traditional caregivers, knowledge keepers, seniors, community based, Indigenous epistemologies, Thunder Bay, Six Nations, Ottawa, Manitoulin Island, Moose Cree, Sudbury, First Nation.

Société Alzheimer Society
CANADA

Warning: Language

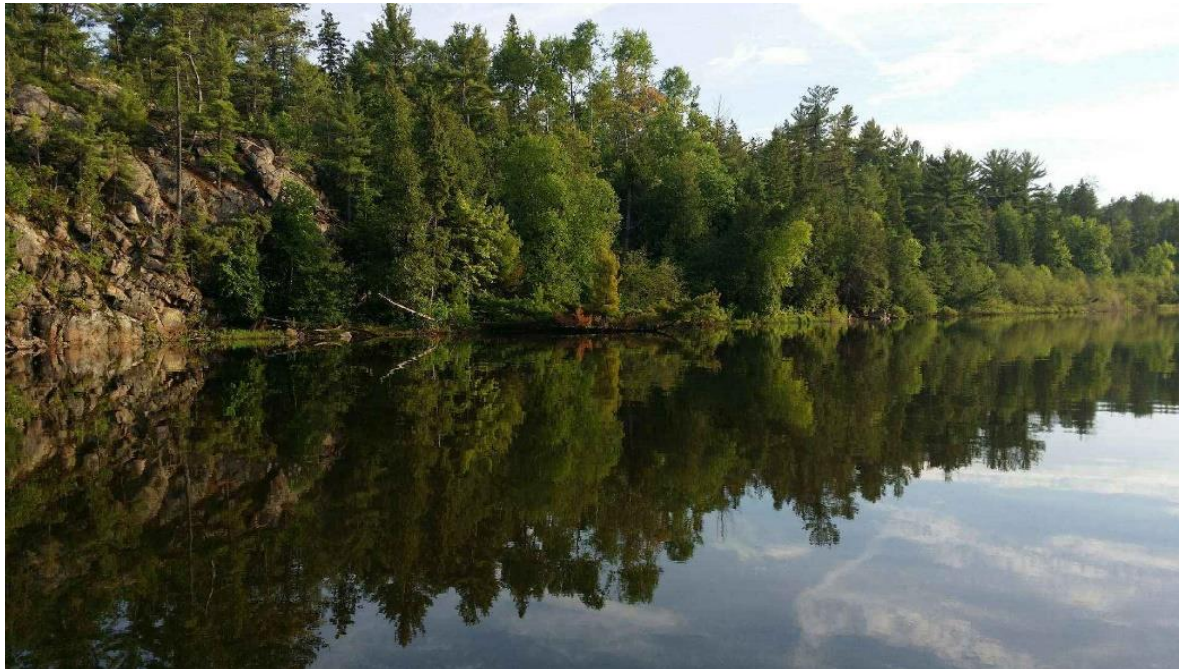
- Relationship Centred
- Culturally Appropriate



Alzheimer Society

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



Elder Jerry Otowadjiwan
Wikwemikong Unceded
Indian Reserve, ON

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

"It's normal"

"It's Natural"

"It's part of the circle of life"

"Coming full circle"

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]

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

“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

- 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.

Spirituality

“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

- 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.

Visions as strength

"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 main stream. 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

Further Reading: Henderson, J. N., & L. C. Henderson. (2002). Cultural construction of disease: A "supernormal" construct of dementia in an American Indian tribe. *Journal of Cross-Cultural Gerontology*, 17: 197-212.

Culture and Spirituality are Medicine

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 serotonins and...chemicals, yeah to bring em up. (Ottawa Older Adult)

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

Balance / Out of Balance

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

- 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.

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

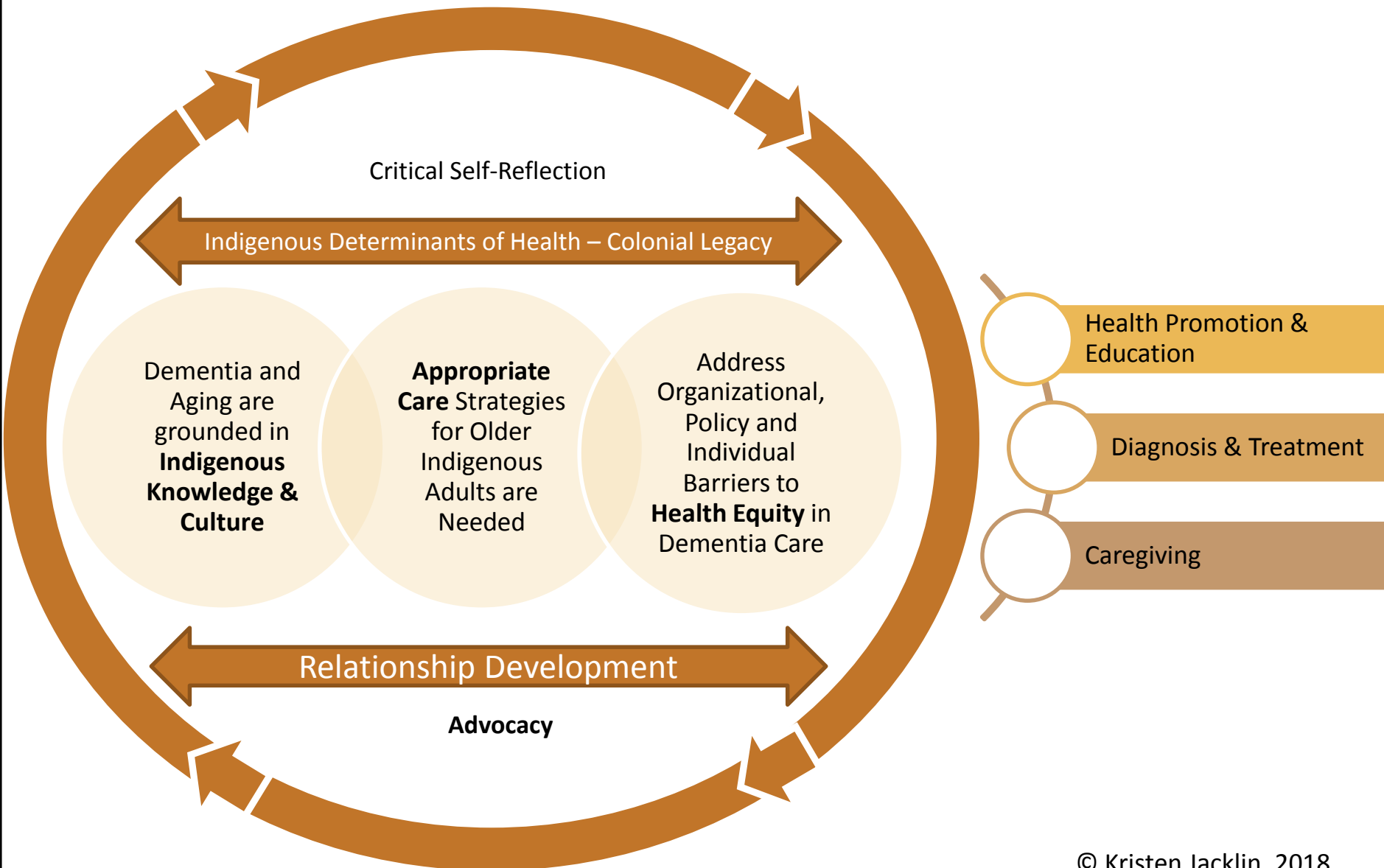
Training

- 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

Knowledge Base for Culturally Safe Dementia Care in Indigenous Populations



Research to Practice: Improving Care

WHAT IS DEMENTIA?

Indigenous Perspectives and Cultural Understandings

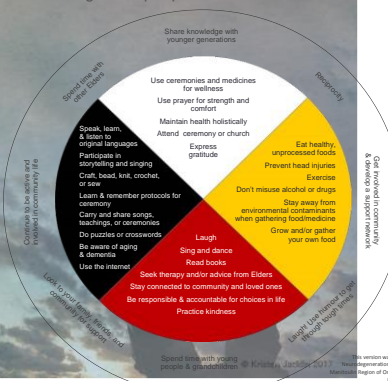
SIGNS AND SYMPTOMS OF DEMENTIA: An Indigenous Guide

PREVENTING DEMENTIA IN INDIGENOUS PEOPLES BY AGING WELL

Advice from older Indigenous peoples

WHAT TO EXPECT AFTER A DIAGNOSIS OF DEMENTIA: An Indigenous Persons' Guide

PREVENTING DEMENTIA IN INDIGENOUS PEOPLES BY AGING WELL



The Path of Dementia

DIAGNOSIS: Getting an accurate diagnosis as early as possible can rule out causes of memory loss not due to dementia and can help you access care that you need. Having a family member or friend with you for diagnosis is helpful.

CONNECT WITH A DOCTOR OR NURSE YOU TRUST: It will be important for you to be under the care of a doctor or nurse regularly. If you live on-reserve you should be referred to the Home and Community Care Program, off-reserve you should be referred to provincial Home Care services. If you speak an Indigenous language it is extra important to let your doctor or nurse know and to have someone with you who can translate.

TREATMENT: It is important to stay well by being active, getting enough sleep, and eating well. All of these can slow the dementia. Your doctor might also suggest medications to use. There is no cure for dementia, but there are medications that have been shown to slow the progression in some people. If you try these medications, it is important to be in regular contact with your doctor about side effects. Some people also use plant-based medicines, ceremony, or spiritual practices to help with the symptoms. *—*

TRANSITIONS: Now you, your caregivers and loved ones will be focussed on your comfort and preparing for your transition out of this life. As you come full circle, it is important that your loved ones understand and are able to carry out your final wishes to help make your transition as gentle as possible.



EARLY STAGES: You are noticing some memory problems but are still very healthy. It is important to stay physically and socially active. You can still be independent. Many people use humour to talk about changes.

PLAN FOR THE FUTURE: This is the time to talk to family, trusted friends or health care providers about how you can be supported. What changes need to be made to your house to help you stay independent? Where do you want to live when you can no longer live on your own? Is there someone you trust as your caregiver? Someone you trust to make financial and medical decisions for you?

GETTING EXTRA SUPPORT: At this time, you might want to get extra support for everyday routines and needs. Explore community services such as Friendship Centres, Aboriginal Health Centres, Elder's Centres, and Home Care Programs.

life are challenging. Many people say that there can be days with moments of frustration and anger, and other days that are peaceful and joyful. You may need help remembering household routines and names. You may find yourself repeating stories or getting lost in time. Whether you are living on or off-reserve you should now have home care services in place. It is important to have someone with you at appointments to help

Some people start to forget more important tasks, like turning off the stove, or putting on mittens when it is cold outside. Sometimes you may leave the house and forget to tell someone where you are going. You and your caregivers should talk about making sure that you, your loved ones, and your home are safe and that you have a system in place to keep track of you when you go out. This might include

You will need more support in everyday routines. You may wish to spend more time with loved ones. You will still have many stories to share and wisdom to pass on. It is important to continue to communicate however you can. Your caregivers and health care providers will help you prepare your transition to the next place.

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Continuous Assessment (CA)

CA)



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?

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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

2. Adapting and Validating a Culturally Appropriate Cognitive Assessment Tool: The Canadian Indigenous Cognitive Assessment (CICA): Dr. Melissa Blind and Karen Pitawanakwat, RN

Monday 3-4:15 PM

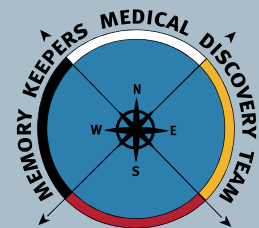


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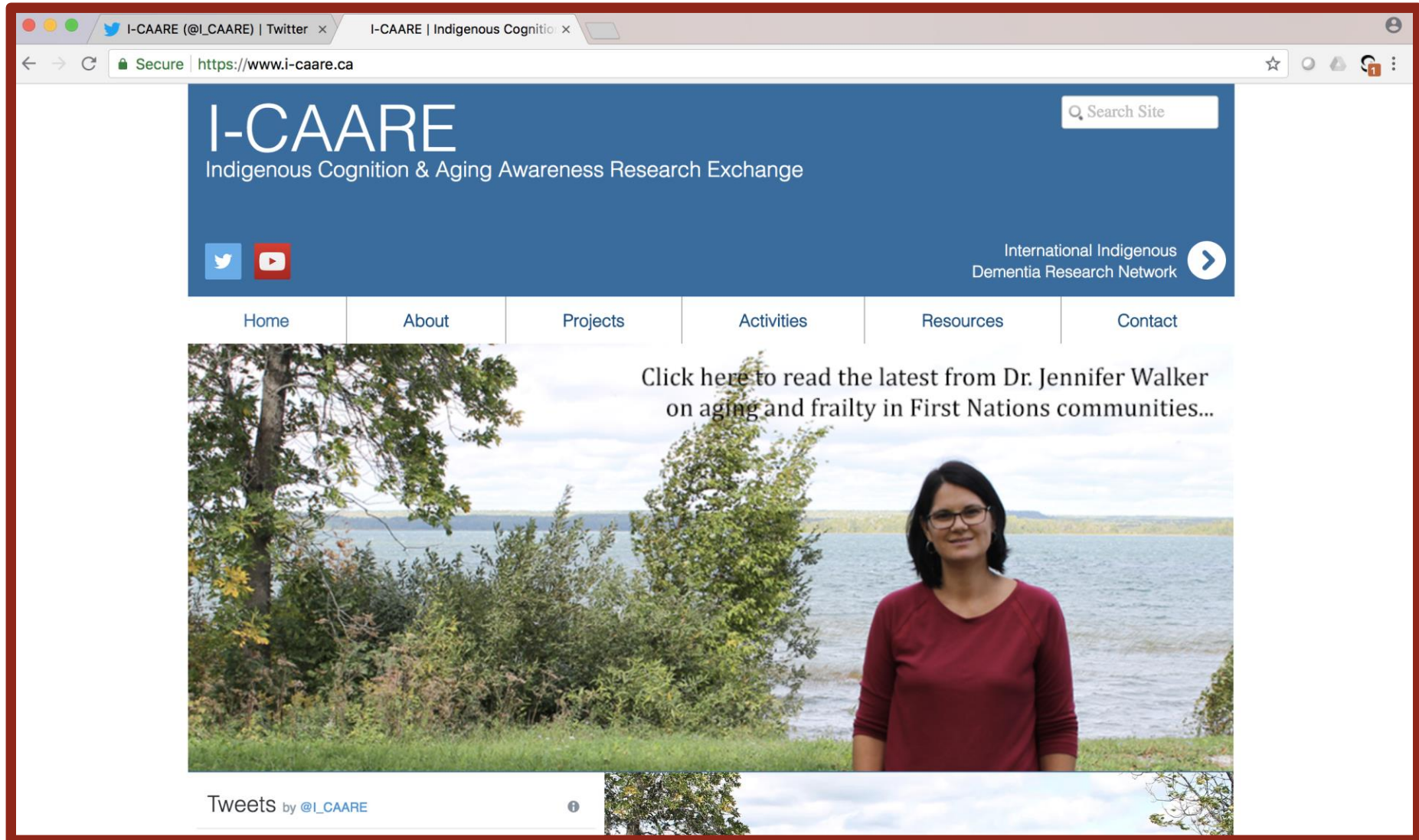
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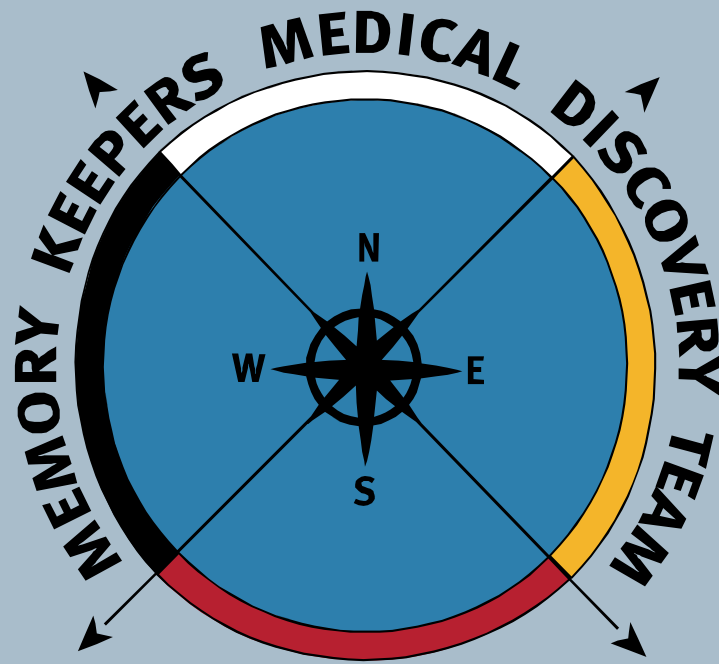
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Key Summary Points

- 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

- Truth and Reconciliation Commission of Canada. 2015. Truth and Reconciliation Commission of Canada: Calls to Action. *Truth and Reconciliation Commission of Canada*
- Jacklin K, Walker J, Shawande M. 2013. The emergence of dementia as a health concern among First Nations populations in Alberta, Canada. *Canadian Journal of Public Health* 104:e39-e44
- Henderson JN, Henderson LC. 2002. Cultural construction of disease: A "supernormal" construct of dementia in an American Indian tribe. *Journal of Cross-Cultural Gerontology* 17:197-212
- MacDonald JP, Ward W, Halseth R. 2018. Alzheimer's disease and related dementias in Indigenous populations in Canada: Prevalence and risk factors, National Collaborating Centre for Aboriginal Health, Prince George, BC
- Gracey M, King M. 2009. Indigenous health part 1: Determinants and disease patterns. *The Lancet* 374:65-75
- Hulko W, Camille E, Antifeau E, Arnouse M, Bachynski N, Taylor D. 2010. Views of First Nation Elders on memory loss and memory care in later life. *Journal of Cross-Cultural Gerontology* 25:317-42
- Lanting S, Crossley M, Morgan D, Cammer A. 2011. Aboriginal experiences of aging and dementia in a context of sociocultural change: Qualitative analysis of key informant group interviews with Aboriginal Seniors. *Cross Cultural Journal of Gerontology* 26:14
- Jacklin K, Pace JE, Warry W. 2015. Informal Dementia Caregiving Among Indigenous Communities in Ontario, Canada. *Care Management Journals* 16:106-20
- LoGiudice D, Flicker L, Thomas J, Almeida O, Lautenschlager N, et al. 2004. Kimberley Indigenous Cognitive Assessment Tool. Western Australian Medical Centre for Health & Aging
- Jones L, Jacklin K, O'Connell ME. 2017. Development and use of health-related technologies in Indigenous communities: Critical Review. *Journal of Medical Internet Research* 19:e256
- Jacklin K, Blind M, Jones J, Otowadjiwan J, Warry W. 2017. *Dementia care with older Indigenous adults: A focus on culturally safe and appropriate care. June 29, 2017. Canadian Intellectual Property Office, Registration #1141638.* <https://www.i-caare.ca/factsheets>
- 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
- Baker AC, Giles AR. 2012. Cultural safety: A framework for interactions between Aboriginal patients and Canadian family medicine practitioners. *International Journal of Indigenous Health* 9
- Browne AJ, Varcoe C. 2006. Critical cultural perspectives and health care involving Aboriginal Peoples. *Contemporary Nurse* 22:155-68