Canadian Conference on Dementia: Indigenous Health Research
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I would first like to take the opportunity to acknowledge that the land on which we gather is the traditional and unceded territory of the Huron-Wendat People.
Learning Objectives

1. Understanding the importance of spirituality in Indigenous health research, particularly related to aging and dementia;

2. Identify innovative research and training practices that can be adapted/modelled;

3. Identify and utilize the research results presented, particularly given the paucity of data relating to Indigenous people living with/experiencing dementia and/or aging in place.
Indigenous Health Research can be defined by any field or discipline related to health and/or wellness that is conducted by, grounded in, or engaged with First Nations, Inuit, or Métis communities, societies, or individuals and their wisdom, cultures, experiences, or knowledge systems, as expressed in their dynamic forms, past and present (CIHR, 2017).
Indigenous Community-Based Research

- Indigenous Community-Based Health Research Lab (Morning Star Lodge) – guided by an Elder
- Research priorities established by the community or through a community research advisory board
- Research agreements with all Indigenous partners
- Full engagement, capacity building
- Mentorship of undergraduate and graduate students is a priority
- No hierarchy in the lab – everyone is a mentor/leader (reciprocal learning)
- Elders and community partners are central to training and mentorship
  - academic training is only one aspect of learning
Morning Star Lodge Projects Relating to Dementia

- Canadian Consortium on Neurodegeneration in Aging (CCNA) Team 20: Indigenous Stream
- The Centre for Aging and Brain Health Innovation (CABHI): Testing locally developed language apps to reduce caregiver stress and promote "aging in place" as it relates to dementia in Indigenous populations
- AGEWELL: Rural/Remote Indigenous Technology Needs Exploration (RRITE)
Team 20: Indigenous Stream

Project Objectives

• Research Focus 1: Access to Culturally Safe and Relevant Dementia Care for Diverse Indigenous people in Canada

  • What are the pathways to dementia care for Aboriginal people? And, what is the lived experience of Indigenous patients with dementia and their caregivers navigating these pathways?

  • What aspects of Indigenous culture contribute to quality of life for people with dementia and their caregivers (e.g., language use, ceremony, music, prayer, cultural roles of elders, Indigenous medicine)?
Unequal access to health and social services is one of the top five problems facing Indigenous people. The health of people living in rural and remote communities is worse than the health of people who live in cities. Indigenous communities want culturally safe and relevant care.

Findings of the CCNA Team 20: Indigenous Stream
There is a lack of local medical services and a shortage of health care practitioners in rural and remote regions of Canada.

The rate of dementia occurring in Indigenous adults in Saskatchewan is increasing.

Findings of the CCNA Team 20: Indigenous Stream

Canadian Consortium on Neurodegeneration in Aging
Testing locally developed language apps to reduce caregiver stress and promote "aging in place" as it relates to dementia in Indigenous populations

**Project Objectives**

- To examine the application of language-based apps to persons living with dementia and their effect on quality of life, caregiver stress, and the promotion of “Aging in Place” in the context of Indigenous populations and,

- To examine the accessibility of language services and programs to cultural survival and retention within Indigenous communities.
How are participants’ views changed about using language to introduce technology?

Can protective factors such as language use serve as an intervention in dementia patients who have experienced loss of language through the historical trauma?

Audio and video recordings are used to collect the interview and observation data.

Nvivo will be used to categorize and sort the data, followed by a qualitative data analysis using CCDA/NAKPA

Testing locally developed language apps to reduce caregiver stress and promote "aging in place" as it relates to dementia in Indigenous populations
Indigenous Data Analysis Method

- Data analysis done with the Collective Consensual Data Analytic Procedure (CCDAP)
- Qualitative data analysis method streamlined and adapted as an Indigenous data analysis method
- Renamed in ceremony
  - NATAWIHOWIN ACIMONA KEKEH MOSAH KIN KEHK PAHPISKIT TASCIKEWIN ASTACHIKOWINA (Cree for Medicine/Healing Stories Picked, Sorted, Stored) (NAKPA)
- Panel of community members, CRAC members, research team members, and experts, sort the data together through general consensus
- Interview quotes are placed in columns based on their similarity
- Major themes develop in each column
Project Objectives

1. Explore technology user needs for Indigenous older adults in rural locations.
2. Qualitatively examine needs for technology to enhance the wellbeing and support independence of Indigenous older adults requiring dementia care.

- Identify compatibilities between technologies and Indigenous communities’ user needs.
Technology user needs of Indigenous seniors can be different due to many historical and cultural factors.

Lack of culturally safe technologies for use by older Indigenous adults.

Lack of access to reliable internet services in rural and remote regions of Canada.

Few have the high-speed access needed to use Information and Communication Technologies (ICTs), such as Telehealth. This is called the “digital divide”.

Rural and remote Indigenous communities are open to technology for health and dementia care.
Indigenous communities want culturally relevant technology to help older people living with dementia and their caregivers. Technology that is developed with, rather than for Indigenous communities, is more likely to make a positive impact on the health of older adults.
Defining Technology User Needs of Indigenous Older Adults Requiring Dementia Care

Defining Technology User Needs of Indigenous Older Adults Requiring Dementia Care

Main Findings

- The internet is beneficial
- Technology is inevitable
- Recognized the value of technology
- Know about Telehealth, but not the details
- Lack on computer use
- Unstable internet access in/around Indigenous communities
- Problems around technology infrastructure in/around Indigenous communities
- Personal security concerns
Defining Technology User Needs of Indigenous Older Adults Requiring Dementia Care

**Novel Concept**

**TRIPLE DIVIDE**
- Infrastructure challenges
- Exacerbating comfort with and exposure to technology
- Lack of culturally safe technologies
Overall Conclusions

• Indigenous research priorities established by the community or through a community research advisory board
• Unequal access to health and social services
• Indigenous communities want culturally safe and relevant care
• Rates of dementia much higher in Indigenous Peoples
• Indigenous communities want culturally relevant technology such as mobile apps, web-based apps, and use of devices such as tablets to help older people living with dementia and their caregivers
• Triple Divide
  • Infrastructure challenges
  • Exacerbating comfort with and exposure to technology
  • Lack of culturally safe technologies
MIIGWETCH/THANK YOU!
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