ROLE AND EXPERIENCE OF TRADITIONAL HEALER IN DEMENTIA CARE IN NORTH AMERICA, AUSTRALIA AND NEW ZEALAND

Conference Track:
Respecting Tribal Sovereignty:
A Path to Accelerating Tribal Health Equity

Presented at the National Tribal Health Conference, September 26-28, 2022, Hyatt Regency Hotel on Capital Hill, Washington, D.C.

Contributing Authors

Hom Lal Shrestha, PhD¹, Lucy Shrestha, M.Sc.¹, Michael McArthur, MLIS²,

Robyn L Rowe, PhD³, Joey-Lynn Wabie, PhD⁴, Marion Maar, PhD² and

Jennifer D Walker, PhD⁵

- (1) School of Kinesiology and Health Sciences, Laurentian University, Sudbury, ON
- (2) Northern Ontario School of Medicine, Sudbury, ON, Canada
- (3) School of Rural and Northern Health, Laurentian University, Sudbury, ON, Canada
- (4) School of Indigenous Relations, Laurentian University, Sudbury, ON, Canada
- (5) McMaster University, Hamilton, ON, Canada







Gratitude & Acknowledgement

- Honored to acknowledge the land of Robinson-Huron Treaty (1850) territory and traditional territory of the Atikameksheng Anishinabek First Nation and Wahnapitae First Nation in the Greater Sudbury Area.
- Dementia Community Advisory
 Council members on Manitoulin Island









Acknowledgement and Gratitude

Elders, Knowledge-Holders and Traditional Healers

Joe and Rosalinda Peltier

Art Petahtegoose

H. Neil Monague

RN Community Researcher

Karen Pitawanakwat

This presentation's contents may be shared on other platforms.



OUTLINES

- ✓ Background
 - ✓ Methods
 - ✓ Results
- ✓ Discussion
- ✓ Conclusion
- ✓ Call to Action

GOAL

- Disseminate and share the study findings
- Initiate future discussion to develop knowledge of dementia policy, practice and intervention



Learning Objective

- Knowledge, training and experiences of traditional healers
- Policy barriers and research gaps
- Recognize and empower traditional healer as community stakeholder
- Culturally-safe dementia care: Ethical reciprocity and cultural norms and values.

INTRODUCTION

The 21st century's biggest global health crises with a new case occurring every three seconds

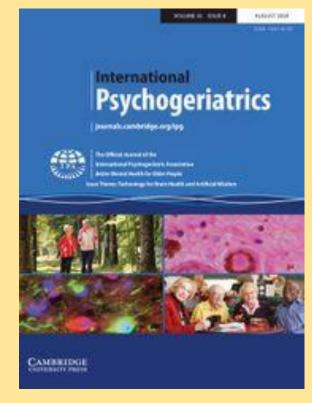
First global systematic review (2014) showed prevalence of dementia among Indigenous populations ranged from 0.5 to 20% across five countries (Warren,











Prevalence rates of dementia in Indigenous Populations



34% higher than the non-Indigenous populations in Canada.

Predict to increase First Nations population over aged 60 is 4-fold compared to 2.3 folds than non-First Nation in 2031 (Walker, 2019)



Prevalence of dementia is 3-5 times higher compared to general Australia population. Dementia rate for remote living Aboriginal and Torres Strait Islander peoples is nearly five times higher at 12.4% than compared to 2.4% in the general Australian population (Radford, et al. 2015, 2019; Smith, et al., 2008; Li, et al. 2014)



UNITED STATES
WASHINGTON, D.C.*

UNITED STATES
WASHINGTON, D.C.*

Prevalence and incidence in the American Indian/Alaska
Native populations is 14.6%
higher than in the White population (Mayeda, 2016).





Lowest prevalence rates of dementia in Indigenous Population in Bolivia

Two indigenous groups in the Bolivian Amazon have among the lowest rates (1%) of dementia in the world (Gatz, M. et al. 2022)



https://news.usc.edu/197541/some-of-the-worlds-lowest-dementia-rates-are-found-in-amazonian-indigenous-groups/

BACKGROUND

Access to culturally-safe dementia (CSDC): Paradigm Shift

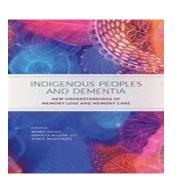
- Cultural safety and gender equity in brain health
- Two-eyed seeing framework
- Trauma-informed care, anti-racism, cultural humility

CSDC is an emerging challenges worldwide

Recognition: Traditional healers as stakeholder in dementia care (WHO, 2018)

Marginalized catalytic role of TH on CSDC to generate knowledge for health policymakers and community partners











The global voice on dementia

DEMENTIA – AN EYE OF INDIGENOUS ELDER

"It's not looked at as a disease, you know. Some people go back that way, and this is how they are going back to the Creator" – Knowledge Keeper, Six Nations (Jacklin, 2019)

"Keewayabinoocheeaway. That's returning back to childhood." – Elder, Thunderbay (Jacklin, 2019)

TALK OF "MEMORY LOSS" IS LESS APPROPRIATE THAN SAYING "MEMORIES ARE BURIED." (Jacklin, 2019)

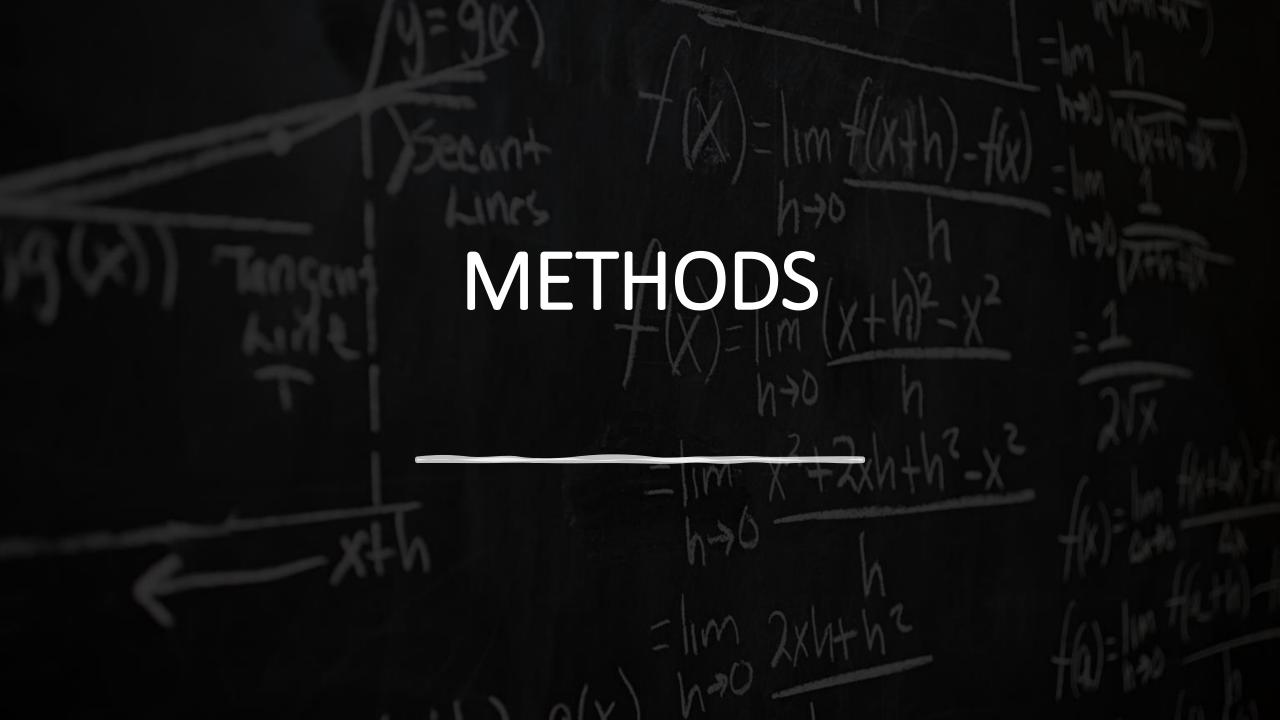
Objective

- Understand the roles and experiences of traditional healers
- Explore and mapping the potential integration of traditional healing and medicine in dementia care into mainstream health care system
- Identify policy barriers and research gaps

Research Questions

- 1. What is known about traditional healers' roles and experiences surrounding dementia care within Indigenous populations in North America, Australia, and New Zealand?
- 2. What strategies have been recommended and evaluated to integrate traditional healing and medicine into health care system (culturallysafe dementia care?
- 3. What are the policy barriers and research gaps?

Objectives and research questions reflect to map the key concepts that underpinning a research area (Arksey & O'Malley, 2015).



- Joanna Briggs Institute (JBI)
- Protocol Development
- PCC Framework
- Stakeholder Consultation
 - Elders
 - Knowledge-holders
 - Traditional healers









Step 1: Protocol Development



Protocol is the plan or method of systematic scoping review



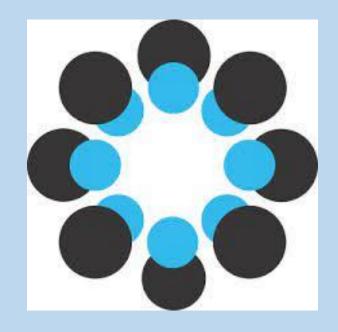
Developed to refined research questions and inclusion/exclusion criteria



Aligned with PCC (participant, concept, and context) Framework

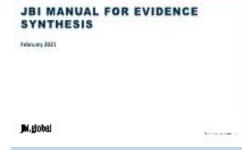


Registered in the Open Science Framework in Montreal









Step 2: Search Strategy

OVID MEDLINE, PSYCINFO, CINAHL & EMBASE English peer reviewed research article/literature published in

2000 to 2020

Initial Search Keywords in MeSH (dementia* or alzheime* or alter* behav* or memory care or cognitive* impairment*).mp Involved NOSM Academic Librarian Used Zotero and Covidence





Geographic limitation

 Keywords and subject headings used to limit North America, Australia and New Zealand Indigenous populations

Language

Database-specific filter for English only

Chronology

Database-specific filter for 2000-2020



Search Strategy: JBI PCC Framework (Inclusion/Exclusion Criteria)

| PCC Framework | Inclusion | Exclusion | Exclusion Justification |
|------------------|--|--|--|
| Participants | Traditional healers and Grandmothers Group in dementia care | Caregivers | |
| Content | Traditional healing and medicine in dementia, senile, and memory care, AD, head or brain injury. Role and experiences, Potential integration of dementia care into health care system policy barrier and research gaps | Mental and psychiatric disorders, Parkinson's disease, schizophrenia, and epilepsy | Focused on traditional healing and medicine in dementia-related diseases through traditional healers and Grandmother Groups. |
| Context | Indigenous communities of North America: First Nations, Metis, Inuit, Cree, American Indian/Native Indian, Alaska Native and Hawaii Native), Australia: Aboriginal and Torres Strait Islander, and New Zealand: Maori | Asia, Africa, Europe, and South America | Relevant studies were not found in databases search (CINAHL, EMBASE, MEDLINE and PSYCINFO) |

Step 3: Select Relevant Studies

Inclusion Criteria

Studies with all design types:

experimental and quasiexperimental, quantitative, qualitative, mixed-methods designs, arts-based, phenomenology, grounded theory, etc.

Exclusion Criteria

- Expert opinions, editorials, commentary articles, research news,
- Gray literatures
- Publications in other languages than English

Involved Independent Reviewers for the relevant studies (titles, abstract and full text for extraction)

Step 4: Chart Relevant Data

- 1. Title
- 2. Authors and Year
- 3. Journal volume, issue, and pages
- 4. Type of article
- 5. Geographical Region Indigeneity Community
- 6. Participants (age/sex/number)
 Sample size
- 7. Purpose
- 8. Method
- 9. Intervention
- 10. Key Findings

Step 5: Synthesize and Report Results

Based on Covidence data analysis
Apply 22 Items of JBI PRISMA Extension Check-list
(JBI, 2020).

- Abstract
- Introduction
- Review Questions
- Inclusion Criteria (PCC Breakdown)
- Methods
- Results (PRISMA-ScR Flow Chart with 22 items)
- Discussion
- Conclusions and Recommendations
- References
- Conflict of Interest and Acknowledgement
- Appendices

Step 6: Local Community Stakeholder Consultation Zoom Circle Gathering/Meeting held on May 18, 2021

Purpose:

Gathering to interpret and meaning of the results:

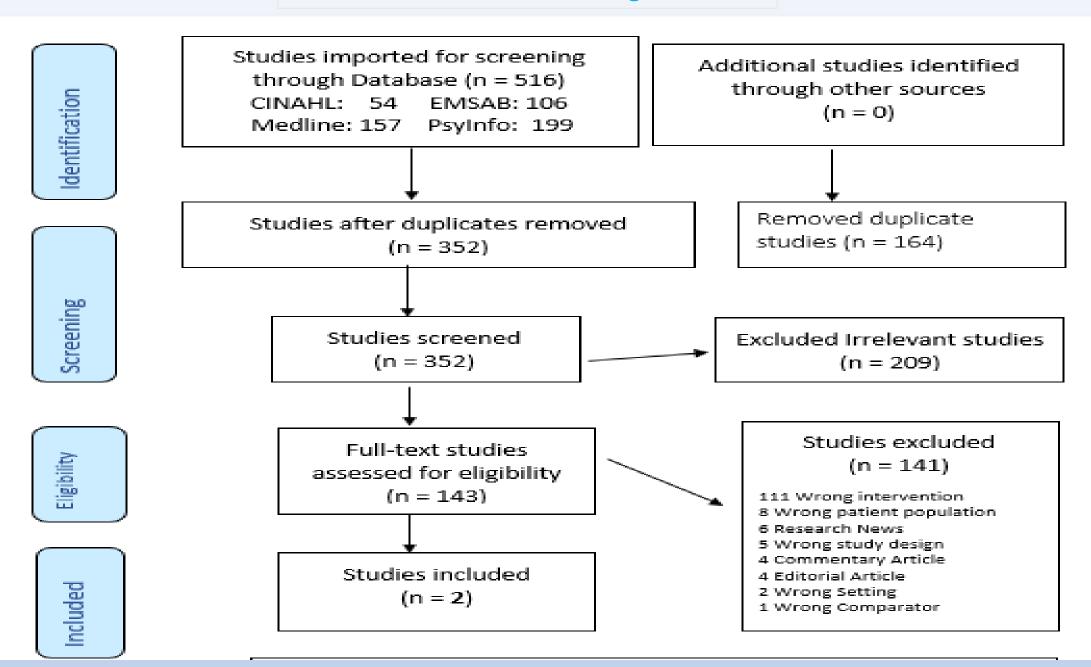
- What important questions did this review set out to answer?
- What answers did we find and what questions remain?
- Why are the results important and how can they be used at a community level?

Four Elder knowledge holders and a Community Researcher shared their knowledge are meaningful.

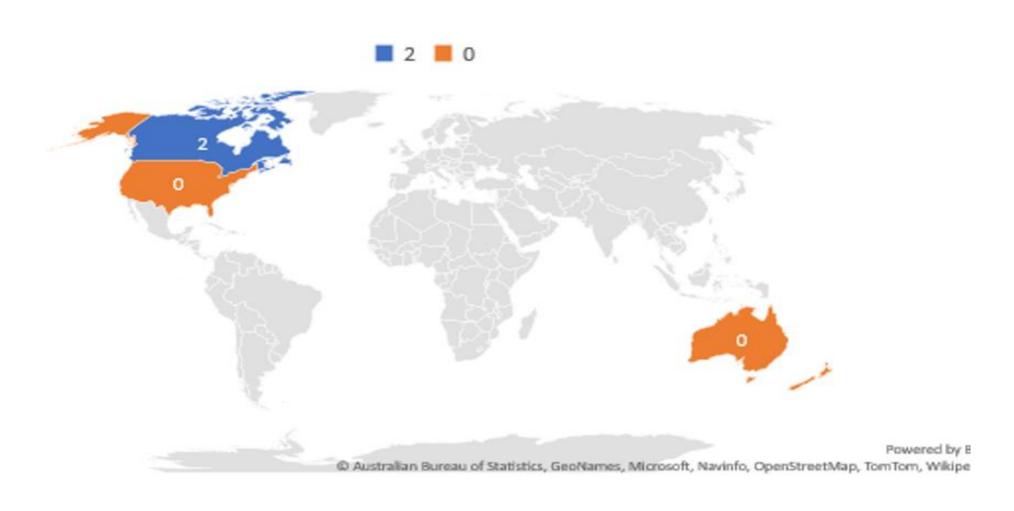
- To guide locally conceptualize the interpretation
- To validate and adopt the proposed model 1 and 2 culturally safe dementia care integration roadmap



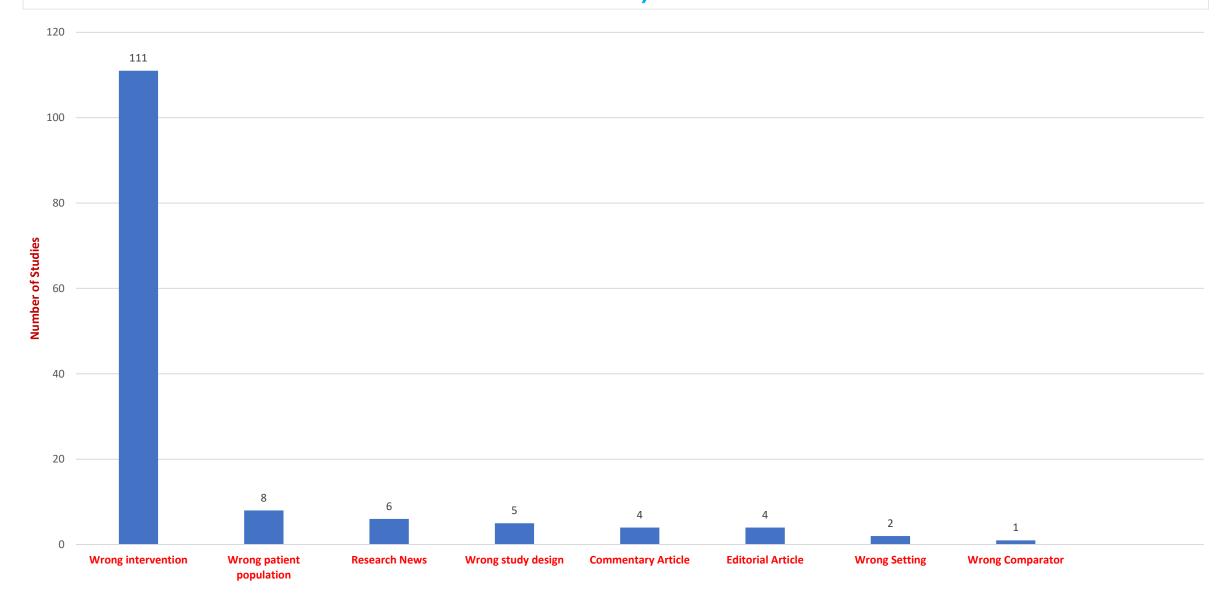




Studies in North America, Australia and New Zealand



Reasons for Ineligible Studies in Canada, United States, Australia and New Zealand (2000-2020)



• Of 143, two studies (2000-2020) met all inclusion criterion but minimal.

- No CSDC policy and practice in place on health care system
- Potential to develop knowledge of CSDC for policymakers and community partners for health policy, practice and research

KEY RESULTS

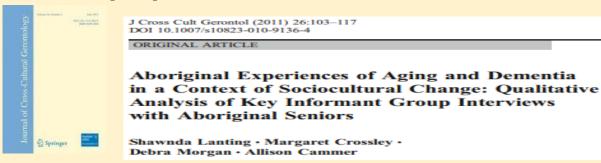


> Can J Aging. 2012 Sep;31(3):257-70. doi: 10.1017/S0714980812000207. Epub 2012 Jul 25.

Formal dementia care among first nations in southwestern Ontario

Sara A Finkelstein 1, Dorothy A Forbes, Chantelle A M Richmond

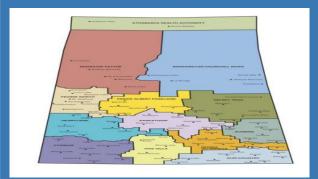
Traditional healer illustrates how physician rejecting the validity of traditional healing and alternative medicines, making it challenging to have collaborative care for people with dementia due to mistrust.



The notion of culturally-competent care, Grandmothers Group (considered as traditional healer) urged essential of visual language and translation services in remote memory clinic.



Addressed
Research
Question 1:
Role and
Experience of
Traditional
Healer



Ontario

- Traditional healer's role additionally recognizes investigating and determining the cause of dementia and treating symptoms.
- Worked with client, family member or caregiver closely and spend much more time to build mutual trust for collaboration and partnership

Saskatchewan

- Role and experience as community health care worker
- Engaged educational session and social gatherings on ageing, dementia, cognitive decline and caregiving in remote Saskatoon Community Memory Clinic.





Addressed
Research
Question 2:
Strategies for integration of culturally safe dementia care



Ontario

- Created Culturally Appropriate Dementia Resources and Care
- Traditional healer encouraged his clients to seek out Western medicine and strove to work in partnership with Western health care practitioners.
- Personal support worker, collaborated with traditional healers for her client with dementia and whatever traditional healer say, she must do. For example, if the client wants their house cleaned out with a seed of the sage, she goes in and cleans their houses out.

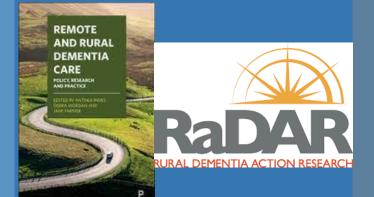
Saskatchewan

- No strategy developed for the integration of culturally safe dementia care.
- Focused on traditional and culturally grounding health care for the ageing illness and dementia.
- Emphasized color visual image and culturally appropriate translation for evoking Elder's interest and engaging them in assessment process.





Addressed
Research
Question 3:
Policy
barriers and
research
gaps



Ontario

- Failing to collaboration and mistrust.
- The traditional healer described how physicians might not accept the validity of traditional healing and alternative medicines, making it difficult to have collaborative client care with dementia.

Saskatchewan

The notion of culturally competent healthcare, the Grandmothers strongly urged the importance of visual language and translation services in the healthcare environment.

"I think it is very important to have a translator. This Elderly man went to the doctor and when he went home, he said to his son that a horse was on his liver. Son phoned the nurse and asked what his diagnosis was, and she said it was cirrhosis of the liver. Close but you need a translator."

GUIDANCE FROM LOCAL STAKEHOLDER CONSULTATION (ELDER, KNOWLEDGE-HOLDER, TRADITIONAL HEALER)

- Dementia:
 - Social and humanitarian issues
- Traditional teachings/ways of life
 - Food, diet
 - Technology distractions
- Social interaction between traditional healer and physician/geriatrician/ neurologist



- Communicating local languages loves-one with dementia through language translator/interpreter
- Validated community dementia care model 1 and 2 as an integrated roadmap to access CSDC in locally.

- Canadian Government cocreated distinction-based Indigenous health
- The Open Dialogue on Indigenous Health Legislation, held on February 23, 2022. This legislation has yet to be approved.
- 5 dialogue sessions held:
- Our Shared Past and the Legacies of Colonialism
- Honoring Relational Health
- Starting a Fire Together
- Youth Reflections
- Carrying the Fire on Together
- Elder Leroy Little Bear also offered a keynote address called "Interrupting Toxic Stress"
- impact of colonialism on the physical and mental health of Indigenous peoples.

INVITE ALL VOICES ACCESS to MOND ceremonies INDIGENOUS BUT DID NOT RELINQUISH OUP Indigenous LEGISLATION SOCIAL INDIGENOUS MODELS HEALTH OF CARE OMBUDSPEOPLE PROTECT against RACISM & HATE

DISCUSSION

Combination of biomedical and traditional healing: unique example of medical pluralism in dementia and memory care

Both studies reflect Indigenous ways of knowing were marginalized in the health care system, e.g., cognitive assessment training for traditional healers and Grandmother group.

Canada: Many studies focus on caregiving for people with dementia in diverse Indigenous communities

USA: Traditional healers are not omitted from research and reflect underdeveloped relationships with Indigenous populations and people with dementia.

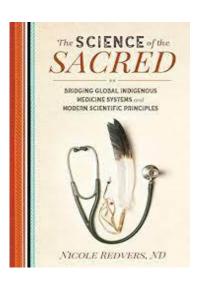
Australia: Involved Aboriginal researcher and community leaders in Modified Kimberly Indigenous Cognitive Assessment New Zealand: Nurtured relationships with Elders in Maori community, e.g., biocultural model of dementia care



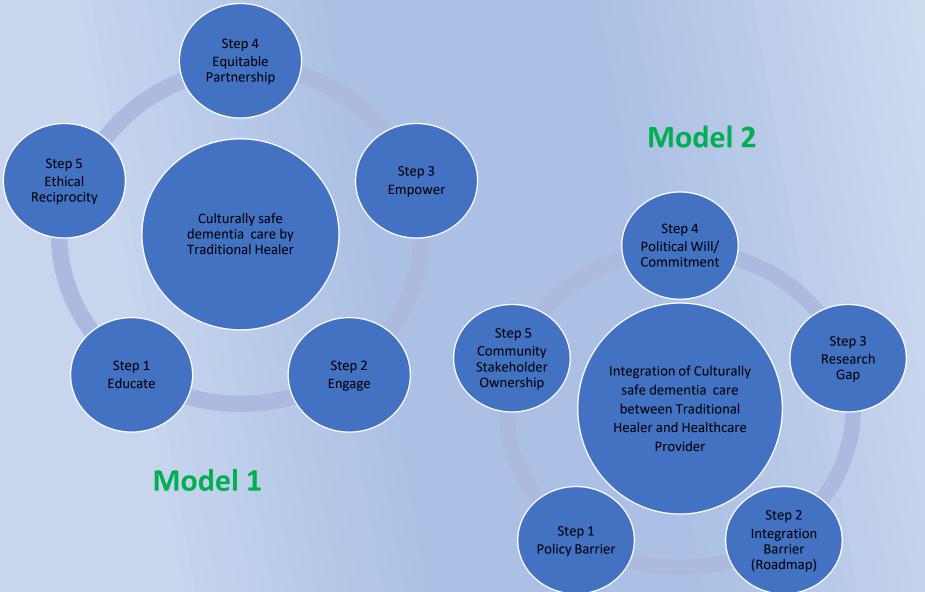
CONCLUSION

Inclusiveness is Key to Health Equity and Diversity

- Building evidence-based dementia care
- Integration of Indigenous traditional healing and Western medicine in dementia Pathways to culturally-safe dementia care
- Implications for policy, practice and research
 - Marginalized engagement and empowerment
 - Policy advocacy for community partners and policymakers
- Federal Indigenous health care policy (legislation) must be recognized and empowered traditional healer as community stakeholder and "gate-keeper" for the dementia navigation, assessment, research intervention and prevention.
- Traditional medicine and science can coexist with mutual respect and understanding for the benefit of Indigenous and non-Indigenous patients worldwide (Redvers, 2020)



Call to Action: Culturally-safe Dementia Care Roadmap



Endorsed, validated and adopted model 1 and 2 of five steps

Develop an integration roadmap of culturally-safe dementia care for traditional healers, local health care providers and community advisory groups or councils to establish a culturally-safe dementia care model.

TAKEAWAY MESSAGES

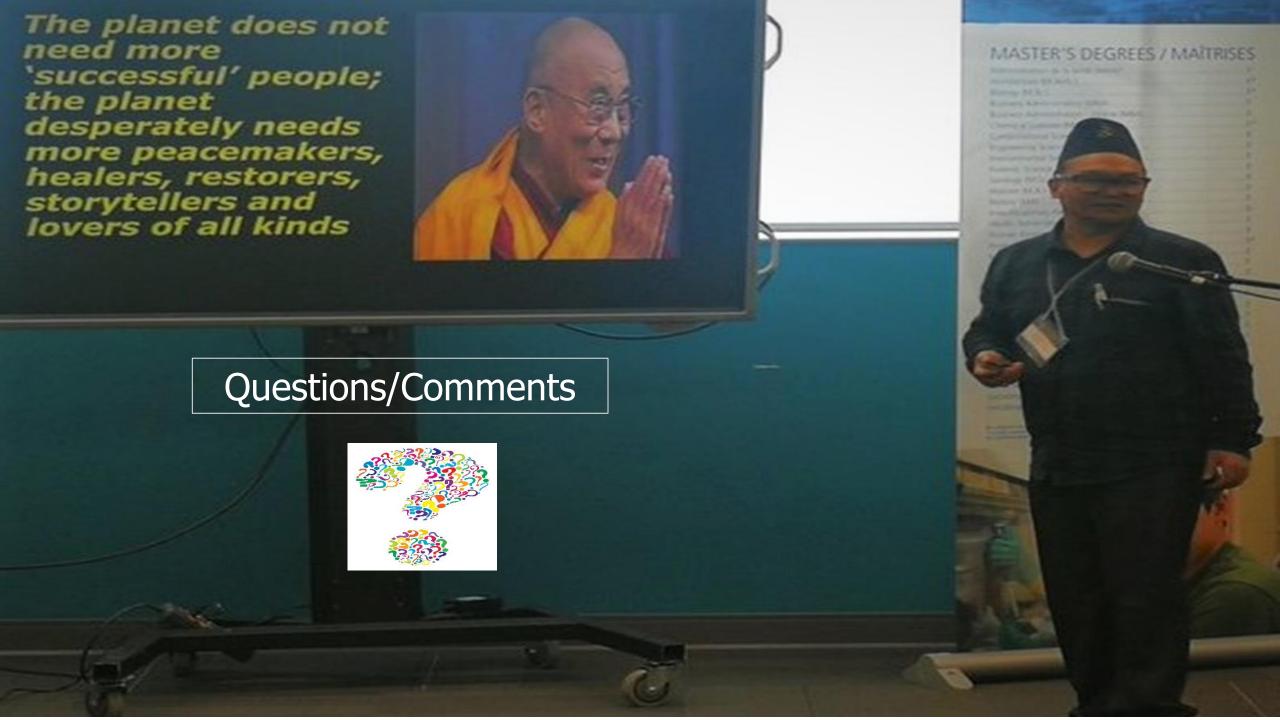
- Recognize, honor, educate, engage and empower
 Traditional healer as community stakeholders and valued partners in dementia care, assessment and prevention.
- Knowledge of culturallysafe dementia for health policy and practice





Culturally Safe Dementia Care: Working with Secwepemic Elders and Nurses to Improve Care in First Nation community in British Columbia (Hulk, et al. 2021).

https://learningcircle.ubc.ca/2014/09 /19/september-18-research-circleculturally-safe-dementia-careproject/



Works Cited in this Presentation

- Canadian Academy of Health Sciences. (2019). Improving the quality of life and care of persons living with dementia and their caregivers. Ottawa (ON): The Expert Panel on Dementia Care in Canada, *CAHS*. https://www.cahs-acss.ca/wp-content/uploads/2019/01/Report.pdf
- Joanna Briggs Institute [JBI] (2015). The Joanna Briggs Institute Reviewers' Manual 2015: Methodology for JBI Scoping Reviews. University of Adelaide: The Joanna Briggs Institute.
- Moher D, Shamseer L, Clarke M, Ghersi D, Liberati A, Petticrew M, et al. (2015). Preferred reporting items for systematic review and metaanalysis protocols (PRISMA-P) statement. *Syst Rev.* 4(1) 1.
- Nyanchokaa, L. *et al.* (2019). A scoping review describes methods used to identify, prioritize and display gaps in health research. Journal of Clinical Epidemiology. 109, 99-110. https://www.jclinepi.com/action/showPdf?pii=S0895-4356%2818%2930754-6
- Peters MDJ, Godfrey C, McInerney P, Munn Z, Tricco AC, Khalil, H. Chapter 11: Scoping Reviews (2020 version). In: Aromataris E, Munn Z (Editors). JBI Manual for Evidence Synthesis, JBI, 2020. https://synthesismanual.jbi.global. https://synthesismanual.jbi.global. https://synthesismanual.jbi.global. https://synthesismanual.jbi.global. https://synthesismanual.jbi.global. https://synthesismanual.jbi.global.
- Peters, M. et al. (2015). Guidance for conducting systematic scoping reviews. International Journal of Evidence-Based Healthcare. 13 (3), 141-146.
- Reading, C. (2018). Structural determinants of Aboriginal Peoples' Health. In: Margo Greenwood, Sarah de Leeuw and Nicole Marie Lindsay. (Editors). *Determinants of Indigenous Peoples' Health: Beyond the Social*. (pp. 3-17). Toronto/Vancouver: Canadian Scholars' Press Inc.
- The Global Alzheimer's and Dementia Action Alliance (2018). https://www.gadaalliance.org/
- Tricco, A. (30 July 2020). JBI Live Webinar: How to conduct and report your scoping review: latest guidance. {YouTube}. https://youtube.com/watch?reload-9&v=5Db5JILJDRG.
- Walker, J. & Jacklin, K. (2019). Current and Projected Dementia Prevalence in First Nations in Canada. In: Wendy Hulk, Danielle Wilson, and Jean E.Baluster (Eds.). *Indigenous peoples and dementia New understandings of memory loss and memory care* (pp. 24-40). Vancouver: UBC Press
- Warren, L.A., *et al.* (2015). Prevalence and incidence of dementia among indigenous populations: a systematic review. *International Psychogeriatrics*, 27(12), 1959-1970. Retrieved from https://journals-scholarsportal info.librweb.laurentian.ca/pdf/10416102/v27i0012/1959_paiodaipasr.xml
- World Health Organization [WHO] (2018). Towards a dementia plan: a WHO guide. https://apps.who.int/iris/handle/10665/272642. License: CC BY-NC-SA 3.0 IGO