

National Aboriginal Alzheimer's Disease and Related Dementias (ADRD) Research Network Meeting

April 15 & 16, 2010 Northern Ontario School of
Medicine, Meeting Report

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Research Network

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We would like to express our gratitude to Elder Marjory Shawande for the guidance and knowledge she has provided our network. We would also like to acknowledge all of the participants, some from nearby and some who came from great distances to share their knowledge and experience around ADRD in Aboriginal peoples.

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Thank you all!

*Sincerely,
Your Hosts,*

Kristen Jacklin and Wayne Warry

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1 Introduction

The National Alzheimer's Disease and Related Dementias (ADRD) meeting was held at the Northern Ontario School of Medicine in Sudbury, Ontario on April 15th and 16th, 2010 and chaired by Dr. Kristen Jacklin. The meeting was attended by 16 participants from across Canada (British Columbia, Alberta, Saskatchewan & Ontario) with an interest in research concerning Alzheimer's disease and related dementias in Canadian Aboriginal peoples. The aims of the meeting were (1) to bring together Canadian researchers with an interest in ADRD in Aboriginal peoples and to facilitate the sharing of knowledge and experience with research in this area; and (2) create a forum to exchange knowledge concerning ADRD between researchers, government and policy personnel and Aboriginal experts

1.1 Participants*

Sylvia Abonyi	University of Saskatchewan
Lisa Boesch	Northern Ontario School of Medicine
Elana Brief	University of British Columbia
Melissa Caibaiosai	Société Alzheimer Society Sudbury-Manitoulin
Shubie Chetty	First Nations and Inuit Health Branch,
Lindsay Crowshoe	(via video conference) University of Calgary
Wendy Hulko	Thompson Rivers University and University of British Columbia
Kristen Jacklin	Northern Ontario School of Medicine
Agnes Kanasawe	Northern Ontario School of Medicine
Lesley McBain	First Nations University of Canada, Northern Campus
Pat Montpetit	Société Alzheimer Society Sudbury-Manitoulin
Marlene Nose	First Nations and Inuit Health Branch
Jessica Pace	McMaster University
Marjory Shawande	Wkwemikong Unceded Indian Reserve
Jennifer Walker	University of Waterloo and Canadian Institute for Health Information
Wayne Warry	McMaster University

*Invitations to participate were extended to the Assembly of First Nations, the National Metis Council, the Inuit Tapiriit Kanatami and the Union of Ontario Indians. Due to unfortunate and varied circumstances at each of these organizations none were able to send a representative to the meeting. However, contacts at each of these organizations were enthusiastic and supportive of our efforts in this research area.



ADRD National Meeting Participants

1.2 Attendees

The individuals who attended the National meeting have diverse and complementary skills and interests. The group's members include researchers with both qualitative and quantitative research and analytical skill sets. Theoretical and methodological strengths within the group include narrative approaches, depth interviewing and focus groups, mapping and spatial analysis, critical theory, ethics and neuroethics, descriptive statistics, health evaluation, health systems and health transfer. The members of the group have a shared interest in community-based research and participatory frameworks that promote the development of community capacity. Research interests extend beyond Aboriginal ADRD to more broadly focus on health and aging among Aboriginal peoples. Both cultural competency/safety and knowledge transfer were raised repeatedly throughout the meeting as priorities.

1.3 Meeting Objectives:

- To identify shared priorities for National research on Alzheimer's disease and related dementias (ADRD) amongst Aboriginal peoples.
- To explore opportunities for collaboration of researchers and organizations across Canada with an interest in ADRD in Aboriginal peoples and discuss the potential for applying for research funding for a National project.

2 Overview of Research Presentations

Participants were given the opportunity to present their research to the group to provide a baseline of the types of knowledge that are available concerning ADRD in Canadian Aboriginal peoples.

2.1 Lesley McBain

Dr. McBain reported on her project “First Nations Long Term Care Facilities in Rural and Remote Communities” which focuses on work done in Northern Saskatchewan. Dr. McBain joined Dr. Deborah Morgan’s emerging Alzheimer’s and dementias study in Saskatchewan in 2003. Her work looks specifically at ADRD in the Aboriginal population of rural and remote Saskatchewan and she has a specific interest in long term care facilities, access to clinics and the use of telehealth.

2.2 Elana Brief

Dr. Brief spoke about her work with Early Onset Familial Alzheimer’s disease (EOFAD) related to a genetic mutation in a specific First Nation in British Columbia. Elana’s talk, “Reductionism and Holism in Alzheimer’s Disease: Bridging Medicine and Wellness in a Remote First Nations Community” focused on understanding and promoting First Nations wellness in the context of EOFAD. The goals of Dr. Brief’s work include determining how First Nations understand EOFAD from both medical and holistic frameworks, how culturally relevant resources affect understanding of EOFAD and its prediction, diagnosis and care, and sources of stigma and shame related to EOFAD in the community. Dr. Brief works at the National Core for Neuroethics and the Clinic for ADRD at the University of British Columbia.

2.3 Jennifer Walker

Dr. Walker presented information about the Canadian Institute for Health Information (CIHI) and its goals which include: to support decision and policy makers in their work; to collect data that can be used to improve health services; to promote standards for national health information; to maintain health databases and registries; and to conduct analysis related to health care. CIHI is a trusted collaboration in understanding First Nations, Inuit and Métis health and has an interest in providing support to improving Aboriginal health in Canada. Dr. Walker also spoke about the CIHI Home Care Program and Home Care Reporting System.

2.4 Wendy Hulko

Dr. Hulko presented information from her project “Memory Loss and Memory Care for Secwepemc Elders”, conducted in collaboration with decisionmakers from the local health authority and three Secwepemc Nation communities. Her interests focus on the perspectives of First Nations communities on dementia, ascribed meanings and desired relationships with the healthcare system. Her work uses constructivist grounded theory and an Indigenous worldview and involved sharing circles with Elders and interviews with older adults with memory loss. In the Secwepemtsin language, the closest word to dementia translates as “the lights went out” and “being out of mind” [translation of dementia from Latin] is not necessarily considered to be a negative thing. Cultural revival efforts and working with Elders to do traditional storytelling were considered to be positive interventions.

2.5 Jessica Pace

Jessica Pace reported on her project “Constructs of Cognitive Health and Illness in Canadian Aboriginal Communities” which shares goals of understanding knowledge, attitudes, beliefs and behaviors related to ADRD in Aboriginal communities with Jacklin and Warry’s broader project. Jessica’s research will consider broader views of aging and how culture shapes the experience of becoming old in Aboriginal communities. She will also identify how ADRD impacts the expected health course of aging. Jessica will consider the subjective experiences of people with dementia, what it means to grow old in an Aboriginal community, identify the factors that indicate the coming of old age and what constitutes successful/healthy aging.

2.6 Kristen Jacklin and Wayne Warry

Drs. Jacklin and Warry spoke about a project they are leading in Ontario: “ADRD in Aboriginal Peoples in Ontario” funded by the Alzheimer’s Society of Canada and the Ontario Mental Health Foundation. This project builds on the recommendations for research and priority areas of concern discussed at the “Alzheimer’s Disease in Aboriginal Communities Roundtable” in 2007. Their research considers cultural understandings of dementia in diverse Aboriginal communities and factors influencing health care needs and access to care for Aboriginal peoples in Ontario. The research will contribute to the creation of culturally appropriate screening and health promotion tools in the future. The research is being conducted in partnership with seven Aboriginal communities in Ontario representing urban, rural, remote, locations and culturally diverse Aboriginal groups.



Dr. Kristen Jacklin & Dr. Wayne Warry

2.7 Marlene Nose

Marlene Nose of the First Nations and Inuit Health Branch of Health Canada spoke about the Canadian Homecare Association and the ways that it has been developed in collaboration with First Nations and Inuit organizations across Canada. This program provides funding to communities and allows them to design resources based on their needs. Out of 698 Aboriginal communities eligible for funding, 605 First Nations and 52 Inuit communities are fully implemented. Those communities who do not receive funding are usually very small and remote and do not deliver other health services. There is an Indian and Northern Affairs homemaking piece, as well as a Health Canada homecare piece. Integration is needed since management of two programs within two different government branches can create significant barriers. Marlene presented data and statistics about the program, but the key issues she identified were related to the needs of communities and the actions that are needed to improve their experience with home care.

2.8 Lindsay Crowshoe

Dr. Crowshoe is a family doctor and an academic at the University of Calgary with a background in Fetal Alcohol Syndrome. He conducts qualitative research to better understand illness perspectives but has not been involved in any formal research on dementia. Dr. Crowshoe is interested in the notion of culture and cultural competency as it applies in psychometric testing. He spoke about peoples' exposure to traditional community and a life of traditional ceremony and the cognitive demands, requirements, expectations and support that is needed to achieve a complex world view. He also spoke of how people with cerebral palsy who partake in ceremonial practice do fairly well in achieving the components that are part of ceremonial activities because of the large involvement of memory. Dr. Crowshoe sees people from his own community and notes that they generally do not do well in a western context and educational system, but thrive with community support when they come to the table to be part of a ceremonial group. He wonders if there is a protective factor that ceremonial activity can provide for people with brain injuries. Communities are not always aware of the infrastructure of resources for people with dementia. As far as interventions, the application of traditional world views and practice may offer a protective effect or may act as a surveillance tool to understand where people are on a cognitive level that is more culturally attuned to specific communities. Dr. Crowshoe works in the city of Calgary at an Aboriginal Health Centre called Elbow River Healing Lodge where the patient population is younger, often homeless and very ill from a multidimensional point of view.

2.9 Community Perspectives (Sudbury-Manitoulin Island)

2.9.1 Melissa Caibaiosai

Melissa Caibaiosai works with the Alzheimer's Society of Sudbury-Manitoulin. She noted that most of the First Nations families visited by the Alzheimer's Society are not sure what Alzheimer's Disease is. The Alzheimer's Society tries to provide as much information as possible but the materials they have available are often culturally inappropriate and can be challenging to ensure that the information is understood. Interpretations of dementia vary across families. Families who are more traditional often do not see memory loss as a medical issue, while more modern families do identify memory loss as a medical problem. Families have indicated that people with memory loss are seen as normal, but requiring more care from more hands – the patient is embraced within the family. One of the challenges faced by the Alzheimer's Society is understanding why First Nations people are not using mainstream services. This may be because dementia has not yet reached a crisis state in these communities or it may represent the presence of adequate

family and community support. Knowledge transfer and the linking of services have been identified as important issues.

2.9.2 Agnes Kanasawe

Agnes Kanasawe spoke of community meetings attended by the research team on Manitoulin Island where stories were elicited from Elders. These groups spoke about fear of the disease, and were generally unfamiliar with the disease, its causes and manifestations. They were concerned about who would care for seniors who were afflicted and spoke of the return to a second childhood in old age. The Elders explained how the lifecycle moves from babies to youth to adults to elders and elders then spill back over to the baby stage. Memory loss is seen as a normal progression of aging in the communities, therefore no red flags go up that would cause people to seek medical help. Family members take care of their senior relative until the end, though it was noted that some people choose to leave (to pass on) before they need to be taken care of.



Marjory Shawande Presents to the Group

2.9.3 Marjory Shawande

Marjory Shawande discussed lifecycle challenges including the loss of spiritual beliefs (residential schools, Jesuit mission survivors abused within the church), the importance of the spiritual doorway on the medicine wheel when working with people and how different health care approaches can use different doorways in the medicine wheel when discussing health (medical model = physical doorway, psychiatry = mental doorway) and how healing is often focused on returning balance to the spiritual area. There is a need to take a holistic approach since mental illness may stem from untreated trauma in other realms (accident, abuse) and can effect the entire being. If trauma goes untreated it will resurface later and will manifest itself in the brain. Mental illness can often go unnoticed because it is in the brain, even though a patient may not be doing things like they used to or may be forgetful, people just assume that it is normal. Stress affects mental capacity and prevents people from functioning optimally. Ageism can occur, but it is the norm to accept changes in an older person such as forgetfulness and slower pace of movement and activity.

3 Issues Discussed

3.1 Perceptions of Dementia

- Western ideas about Alzheimer's disease have been imported into communities by clinicians before anyone has had the chance to think about what the cultural interpretations might be.
- It is not necessarily a good thing for doctors to give everyone a biomedical diagnosis or to impose western notions of dementia.
- Generational changes may be impacting traditional perceptions of memory loss and care patterns for seniors.
- As more women carry out more responsibilities outside of the home and more people migrate to urban centers, seniors who stay behind in the community may face a gap in care.
- Tolerance and acceptance of a family members' dementia may change to more of a burden because of the care required. It may cease to be considered as a normal part of aging which may lead to problems that the family will need to solve.

3.2 Diversity

- Perceptions of dementia may vary across Aboriginal groups in Canada.
- Diversity must be recognized in research as it may impact the development or implementation of interventions and educational tools.

3.3 Causes

- Early Onset Familial Alzheimer's Disease (EOFAD) is a problem in one BC First Nation. This type of Alzheimer's disease is caused by a specific gene mutation.
- In this community, people have heard about the genetic causes, but they also wonder about chemicals from food and industries on the land.
- In communities on Manitoulin Island, Ontario there is a significant belief that the environment impacts the development of ADRD including the physical layout, cultural aspects of the environment, changes from past to present, and the presence of chemicals in food.
- Among some BC Elders, dementia is considered to be the result of social and environmental factors (social determinants of health) and the idea of it being a brain disease is not considered to be important. Elders who talked about causes of memory loss in later life identified social and environmental causes.
- Changes in life expectancy play a role in the development of dementia because many Aboriginal people did not live as long in the past.

3.4 Stigma, Shame and Acceptance

- In communities on Manitoulin Island, Ontario memory loss is seen more as a natural part of the lifecycle and is generally expected and accepted.
- The idea of shame fits in with older understandings of Aboriginal cultures where there is a strong moral component to illness. Within this understanding, illnesses are not necessarily caused by germs and viruses but by interpersonal relationships.
- In some BC First Nations there is more stigma associated with ADRD because of the unique occurrence of Early Onset Familial Alzheimer's Disease.
- In this case only one family is afflicted with dementia which raises questions in their community: Why only that family? What has that family done wrong?
- This situation is similar to a community (Behchoko), where there is a genetic predisposition to night blindness. In this community people have created a story to explain the incidence of night blindness. The story is about a hunting trip during which a male hunter scratched the eye of a lynx that he was hunting. In payment for this act, all of the future children of this man would suffer from vision problems. This story helps to deflect shame.

3.5 Prevention

Prevention and education of both physical and cognitive preventive measures were identified as an important area for consideration.

3.5.1 Physical Activity

- Routine physical activity can result in improvements in people's current mental capacity.
- In the past, people in Northern communities were always active while learning traditions; they wouldn't just sit down and talk, they would talk as they were doing something in the kitchen or in the bush.
- Today people are more sedentary, we need to promote self care and keep people engaged and active in the community (get people to pick their own herbs, environmental therapy, etc.).

3.5.2 Cognitive Stimulation

- In many cases there is no access to cognitive stimulation and no on-going learning for Aboriginal seniors.
- We need to implement interventions so that individuals feel connected to each other and the world at a cognitive level and participate in enough cognitive activity to keep their minds active.
- Oral tradition, storytelling and participation in ceremony may be ideal sources of cognitive stimulation.

3.6 Screening

- A standard tool for evaluating cognition is the mini mental status exam. However, mainstream cognitive evaluation tools are often culturally inappropriate and modifications need to be made to make these more suitable for use in an Aboriginal context.
- Some people have attempted to make alterations to standard mainstream assessment tools, either formally or informally.
- Narrative, storytelling and oral tradition approaches may be useful tools that could be used to understand where people are cognitively and could be developed into tools to apply to a larger population.

3.7 Support and Resources

- We need to identify the resources that can be pulled together for interventions for people with dementia and their families and caregivers.

3.8 Housing and Long Term Care

- In northern Saskatchewan there are severe housing issues including insufficient housing and crowding that are being compounded by new events like increasing longevity.
- In BC Aboriginal people are reluctant to go to [mainstream] long term care because it reignites residential school trauma, yet few communities have been able to build their own Elders lodge.
- Part of the funding that FNIHB provides is for respite care, but the bulk of the burden still falls back on families and more support is needed for respite care.
- The key to care for dementia patients is not to build more institutions, but to provide supports that keep people at home with their families for as long as possible.

3.9 Treatment and Interventions

- We need to think of multi-staged interventions that have the potential for long term effects by re-engaging people in traditions and getting them to use their minds in ways they were used in the past.
- In the short term you can see improvements in people's memory when they are in the early stages if they actively use their minds.

3.10 Information, Education and Knowledge Transfer

- It would be helpful to develop and distribute relevant information that would help communities make better decisions around care, whether it is a seniors lodge or better home care.
- This would give communities and families better options and there would not be an automatic default to institutional care.
- Knowledge transfer is a big issue. Pamphlets are often used, but can be inappropriate because many people cannot read them.
- Videos can be an effective alternative to pamphlets and other printed material. Videos allow people to see and hear the things they need to learn.
- Videos are very good tools because they are based on stories, and there is the possibility to provide subtitles in several Aboriginal languages.
- Videos may be a good idea as part of a national initiative to explain Alzheimer's disease and issues related to the condition that could be filmed across the country.
- Two models for videos exist: the Alzheimer's Society of Toronto created a culturally relevant film a decade ago in ten languages and Neil Henderson has made a video in the United States about dementia in Aboriginal populations.

- However, based on what we have discussed in this meeting, it can already be identified that a national video would be difficult to create in a way that was meaningful across the board.
- We need to be careful not to impose a disease model by sending out a video.
- Videos are not the only method of knowledge translation.

3.11 Traditional Activities

3.11.1 Traditional and Community Life

- There is a lot of remembering and cognitive stimulation involved when participating in traditional activities and ceremony.
- When people talk about bringing back traditional lifestyles and how they lived in the past, it is everything that we tell people now – the mind, body, and spirit plan (Alzheimer Society of BC).
- Some communities want to bring back BINGO using cognition, healthy food, social interaction, and exercise by walking to the community centre.
- Removing a person with dementia to a long term care centre can actually be more damaging because it takes them away from familiar places, ceremonies and the memories attached to them.
- Isolation is a concern. As people age there is the potential for them to become isolated as opposed to maintaining their engagement with the community.
- Anything we can do to foster these community activities to keep people involved is going to have positive long term effects.

3.11.2 Oral Tradition and Storytelling

- Working through an oral tradition framework is an area that should be explored for dementia interventions. Social stories and a narrative approach are useful ways of doing so.
- Loss of oral culture was one specific thing that was mentioned by the Elders as an issue that can impact dementia.
- Elders storytelling can be used as an intervention with health care providers to help them become more culturally safe.
- Social stories are a robust way to try to understand the domains of brain functioning in a more inclusive and multi-connected way.
- Social stories are a very good way to add on to traditional psychometric testing.
- Songs and mental maps, especially those from youth or childhood are some of the last memories that a person with dementia will lose. Even in later life people are usually able to draw maps from memory of the route that they took from their home to a familiar place.

4 Priority Topics

4.1 Basic Research

- Base line research needs to be done and epidemiological data needs to be gathered to establish what is known about dementia and what data and information is lacking.
- We need better surveillance of dementia through home care, statistics and surveys.
- Basic documentation of the prevalence of dementia and the types of dementia in different places is lacking. What types of dementia are we dealing with?
- How is dementia perceived in different Aboriginal cultures across Canada? What are the similarities and differences in perceptions of dementia across cultures?
- What is unique about Aboriginal cognition (i.e. medicine wheel, Indigenous ways of understanding the aging process)?
- How can we produce research that is relevant to diverse communities?

4.2 Tools, Resources & Support

- Identify the tools and resources that exist to support health care professionals working with dementia patients at the community level. Determine what is needed to improve services and support.

4.3 Cultural Relevance & Cultural Safety

- Identify what health care professionals working with Aboriginal peoples know about dementia and what they know about cultural safety. How can we ensure that these two components are brought together?
- In what ways are mainstream clinical perspectives culturally relevant? What might a more holistic model look like?
- Culturally relevant clinical practice guidelines need to be established around dementia.

4.4 Interventions & Prevention

- How can we promote healthy aging and prevention of dementia in Aboriginal communities in a culturally safe way?

- Why is the number of people on disability on the rise in Aboriginal communities?

4.5 Knowledge Translation & Education

- Identify the level of knowledge that Aboriginal people have about dementia and determine if educational interventions are needed or if extant interventions need to be modified so they are culturally appropriate.
- We need to be aware of the risks of imposing a biomedical model of dementia on Aboriginal communities.
- Better assessment tools are needed as is training for caregivers, families and professionals.
- Improved health promotion tools need to be developed. We need to consider the development of an educational video about dementia.

4.6 Historical Context & Trauma

- What are the dementia-related health impacts of residential schools?
- What are the impacts of other trauma on dementia and dementia care?
- How are genetics impacting dementia in Aboriginal communities?
- What impact has relocation had on mental health and dementia among Aboriginal people?

4.7 Traditional Life & Culture

- Are there differences in the perception, development or experience of dementia between Aboriginal people living a more traditional versus a more contemporary lifestyle?
- Does participation in traditional cultural activities such as ceremony impact the development or experience of dementia? Does culture have a protective effect?
- Are Elders involved in ceremony and are they connected with youth?

4.8 Life Course

- How does childhood and cumulative life experience affect dementia in later life?



Dr. Wendy Hulko Presents to the Group

5 Next Steps

- Reach out to other Canadian provinces and Territories and expand our network.
- Begin prioritizing research needs and interests to create funding proposals
 - Begin with small funding proposals to hire a coordinator for the network
- Begin sharing our research findings and network through knowledge translation activities especially special journal issues, conferences, and through existing networks such as the ASC Aboriginal Advisory Group, the Canadian Dementia Knowledge Translation Network, and the NEAHRs.
- Outreach to International colleagues and explore the potential for an International Indigenous Dementia Research Network
- Create a webpage for the network with public and member access
- Begin to inventory existing resources: short annotated biographies and lists of major papers and resources that network members use.