

Aging, Dementia and Cognitive Decline: Perspectives of an Aboriginal Community in British Columbia

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Introduction

Researchers have identified dementia as one of the most significant medical challenges in the 21st century due to its prevalence, high direct and indirect costs, and burden on both the individual and society (Wimo et al., 2007). The Canadian Study of Health and Aging (CSHA) reported the prevalence of dementia in Canadians over the age of 65 at 8.0%. Limited existing data from North American Aboriginal groups suggest a 4.2% prevalence rate, at least as generalized from the Cree in Manitoba (CSHA Working Group, 1994 and Hendrie et al., 1993).

Hendrix and Cloud-Lebeau identify three belief systems used for understanding the disease among First Nations groups (2006):

- (1) a combination of biomedical and lay models,
- (2) the belief that dementia is part of normal aging,
- (3) the belief that behaviors are a means of communication during transition to the next world.

Some North American Aboriginal groups view dementia-related cognitive decline as a necessary transition to death (Downs, 2000). The perspectives held in a population help shape coping mechanisms and views about when medical treatment should be sought by individuals and their community. Indeed, some North American Aboriginal groups use "white man's medicine" for "white man's diseases" (e.g., diabetes, hypertension) and traditional medicine for other conditions, including behavioral and emotional problems (Hendrix & Cloud-Lebeau, 2006).

The purpose of this study was to investigate concepts of brain health, aging and dementia in a North American Aboriginal community in British Columbia (BC). We explored the perspectives of members of this community because of the novel PS-1 gene mutation associated with early onset familial Alzheimer Disease (EOFAD). Our goal is to bridge existing science and social divides that can compromise care in regions and communities such as this by gaining an understanding of culturally-relevant views on aging and dementia.

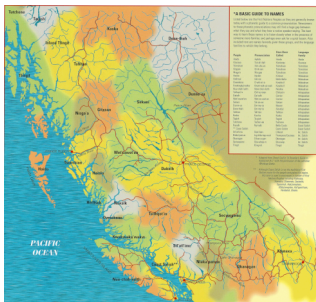


Figure 1: Map of the First Nations of British Columbia. Courtesy of the Government of British Columbia (<http://www.bced.gov.bc.ca/abed/map.htm>)

Methods

Participant-guided discussions were carried out in the community to explore:

- (1) concepts of brain health,
- (2) values and coping mechanisms, and
- (3) resources for health care and research.

Participants were recruited through the local nursing station and during an annual health fair in the region. Discussions were audio taped and analyzed for emerging themes using a grounded theory approach. We also obtained expert opinions from local health care providers.

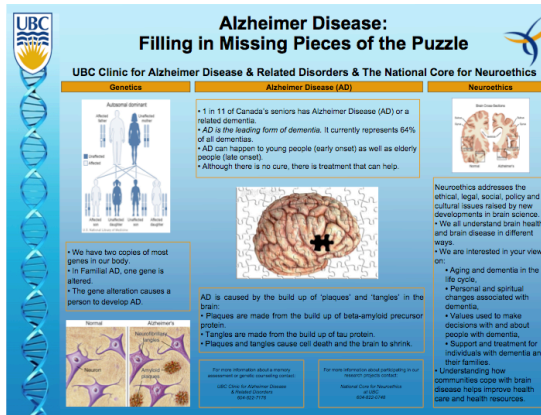


Figure 2: Educational material presented at the community's health fair

To ensure a culturally sensitive study, we sought feedback on our methods and instruments from experts who have lived in or worked with the community. Permission to carry out the study was given by the band chief prior to our arrival. An important component of our work was to provide educational material on Alzheimer Disease (AD) and dementia during the health fair (see Figure 2). Tailored information on the genetics of AD, genetic counselling and neuroethics created by the authors was also provided.

Results

	Participants	Gender	Average Age
Community member focus groups	10	60% female 40% male	48 years
Health care professionals meeting	6	100% female	N/A

Table 1: Participant demographics

Concepts of brain health and dementia

> Overall, AD is viewed as a medical condition. Community members generally seek diagnostic and therapeutic care from providers trained in Western medicine.

"My great grandfather died of that because they said he went crazy but actually I think he had dementia"

- > Symptoms (forgetfulness, wandering, restlessness, sporadic violence) were recognized as part of the disease.
- > Several participants reported that community members had exhibited symptoms well before the age of typical onset for late-onset AD consistent with EOFAD (before 60-65 years).
- > Traditional medicine is sometimes pursued to mitigate memory loss. One participant identified herbal treatments as responsible for a family member's stability in early stages of the disease. Another reported that elders did not take medications.
- > Participants associated genetic and environmental factors of the disease. Possible environmental factors identified were contaminated food supply (especially fish), air quality, and effects of shut down mines in the area.

Values and coping mechanisms

- > The entire community is involved in caring for people diagnosed with AD. Primary caregivers usually make decisions (in conjunction with health care professionals) about sending family members to long-term care facilities. Elders are involved in the decision-making process if the patient has no family.
- > The community has developed unique ways to manage symptoms. Caregivers have sent letters to community members asking them to help monitor patients who wander.
- > Caregivers reported anxiety about the transfer of elderly band members to long-term care facilities outside the band's territory. Two factors accounting for this are: (1) the disorientation it causes and, (2) the sense that duty of care by the community is abrogated.

"Those elders showed us what to do since we were small. And then this is how we go back repaying them? By sentencing them to a home that we don't really know nothing about... for being natives, that's hard for us to see one of our natives go into someone else's territory in order to survive when it should be within our own traditional territories.. There's an invisible line there, you cross them, you are crossing a lot of people"

Resources for health care and research

- > The community expressed a strong desire for a local long-term care facility. Currently, people are sent to facilities 700 km away. Despite having available infrastructure for establishing a local facility, ensuring continuous staffing would remain a significant problem.
- > Support groups, community forums and workshops were all mentioned as ways to help educate the community about AD, care for affected community members, and mitigate stigma.
- > Further education about symptom recognition and management is desired.

"a big community meeting... [where someone] explains the disease to the community and the symptoms – the early stages and all that – right to the end, that way when... like we do have some members of the community who have that and we can say ok, well this person has this... so that way they don't treat them differently but this will keep them interactive with everybody around them."

Conclusions

Members of this community in British Columbia understand AD as a medical condition and generally seek Western medicine to treat it. In this first study phase, we learned that some forms of alternative therapy are used, mostly in early stages of the disease. The community has developed unique mechanisms for managing symptoms such as wandering. Caregiver burden is prevalent. Ideas about traditional territorial boundaries and duty to care for elders cause particular anxiety in the context of long-term care. Better local resources for education emerged as top priorities. Ongoing work will expand the existing knowledge base, the development of effective programs for outreach, and promote informed health policies for members of the North American Aboriginal communities.

References & Acknowledgements

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The authors would like to thank members of the National Core for Neuroethics, the Alzheimer Society of British Columbia, the health care team and experts who helped us prepare for our work in community.

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Supported by the North Growth Foundation and the Canadian Institutes of Health Research- Institutes of Neurosciences, Mental Health and Addiction (CIHR-INMHA) CIHR CNE #85117.

