

First Nations, Inuit, and Métis understandings of dementias and healthy aging

There is little research on Indigenous Peoples' understandings about dementia. The existing research suggests their perceptions range from traditional to biomedical.

Some Indigenous people did not consider dementias as a major health concern because symptoms and behaviours aligned with their cultural understandings of aging, with dementia viewed as a normal part of this process, or because they faced more pressing health conditions. Others considered symptoms of dementia from a spiritual perspective – as a way of communicating with the supernatural world, with ancestors, or as a vision that brings individuals closer to the creator. Still others viewed dementia as a mysterious sickness, a hex, or bad medicine. In most of the existing studies, dementia was seen as a new disease brought about through lifestyle changes resulting from contact with White settlers.

There is also little research on Indigenous understandings of healthy aging. The limited research shows that First Nations, Inuit, and Métis peoples view health holistically. They emphasize physical, mental, emotional and spiritual components as well as relationships at many levels. First

Nations, Inuit and Métis people preferred to age in place with the support of family, friends and community members.

Several studies found that in First Nations communities, informal caregivers were culturally valued and had a positive view of their roles. Institutionalized caregiving was seen as problematic because it interrupted the important role of Elders in their community and raised concerns about continuity of care and cultural safety.

Knowledge sharing about dementia in Indigenous communities

Different groups of people have different knowledge to share about dementias and different knowledge needs and gaps. Indigenous people with dementia and their caregivers need culturally appropriate information about dementia prevention, symptoms, and care to provide optimal care and promote health and well-being. They also need information about how to navigate the healthcare system and available supports and services in the community.

Healthcare providers need information to build their capacity to diagnose and manage patients with dementia, especially in rural and remote communities where they often lack access to physicians and specialists. They also need information to help build trust and address racism and discrimination in the healthcare system and

improve communication with Indigenous dementia patients and their families.

Indigenous communities need community-based dementia education programs and resources to help reduce the stigma and stress associated with the disease, support community caregiving, and ensure community members can interact with people who have dementia with compassion, ease, and confidence.

Policy makers and program developers need information to inform the development of effective dementia policies, programs, and services. They need information about First Nations, Inuit, and Métis understandings of dementia to help reduce stigma and promote family and community caregiving. They also need information about interventions that have been effective in preventing dementia and caring for dementia patients in Indigenous communities.

One challenge is that most resources are designed for the general population. Existing resources for Indigenous people focus on First Nations. They do not account for the different understandings that First Nations, Inuit, and Métis people have of dementia. They also don't account for different perspectives of healthy aging or preferences for cultural approaches to dementia care. These barriers to knowledge sharing can result in reduced access to dementia-related information and care.

Knowledge sharing is a key to delivering effective dementia care. Knowledge exchange can be supported through:

- Building relationships between patients, caregivers, and healthcare providers,
- Improving communication and coordination across the dementia interest parties, and
- Incorporating culture into services and education resources.

Some ways to develop meaningful relations include healthcare providers:

- Taking the time to explain medication and treatment plans,
- Connecting in a deeper and spiritual way,
- Considering the impact of trauma on clients (patients and their caregivers), and
- Having a respectful, caring and supportive approach.

Communication and coordination can be improved by increasing cross-cultural communication skills. Examples include using a two-eyed seeing approach and consulting with Elders to ensure dementia resources are useful and acceptable. It would also be helpful to bring more services and information closer to home. This could be accomplished by shifting resources from acute care

to community and long-term care services. Better integration of health services would improve communication between on and off-reserve health practitioners and health institutions.

Culture shapes Indigenous people's perspectives on dementia, healthy aging, and preferences for caregiving. Incorporating culture into health services and dementia resources can help with knowledge exchange. Examples of this approach include:

- Using a culturally sensitive, holistic, client- and family-centred approach that recognizes the importance of spirituality;
- Prioritizing Indigenous knowledge in the development of health promotion materials;
- Emphasizing Indigenous Peoples' relationship-centred concepts and approaches to dementia care, which focus on family and community involvement;
- Using strategies that draw on the strengths of First Nations, Inuit, and Métis communities, including the role of Elders;
- Using communication styles and modes preferred by First Nations, Inuit, and Métis people, as these differ across populations; and
- Using language that accounts for literacy and education levels.

Communicating health information to Indigenous people in culturally appropriate ways can lead to more effective knowledge translation. This, in turn, can help reduce health inequalities.

Research needs

More research is needed to fill many of the information gaps about dementia in Indigenous populations. Research priorities should be set with input from interested parties, including people with dementia and their caregivers. Examples of priority research topics for Indigenous populations include:

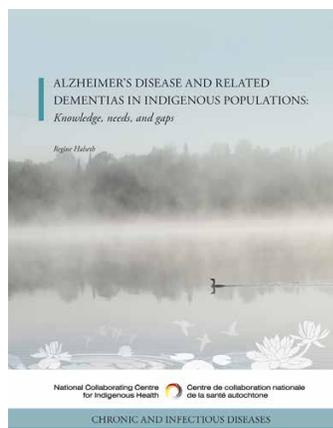
- Indigenous interpretations and understandings of dementia;
- Effective dementia prevention and intervention activities;
- Culturally responsive caregiver activities; and
- Inclusion of Indigenous medicine and ceremony in care.

There is also a need to track progress on the recently developed national dementia strategy, including better data on groups affected in different ways by dementia, including Indigenous Peoples.

Note: the longer version of this report lists dementia education, tools, and resources.



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La version française est également disponible sur le site Web ccnsa.ca sous le titre : *La maladie d'Alzheimer et les démences apparentées chez les populations autochtones : connaissances, besoins et lacunes*.

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