

DEVELOPING EDUCATIONAL MATERIALS  
FOR COMMUNITY BASED DEMENTIA  
CARE  
Methodology Report

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## TABLE OF CONTENTS

<b>1.0 Introduction</b>	<b>4</b>
<b>2.0 Methods</b>	<b>4</b>
2.1 Extraction of sources from literature review	5
2.2 Environmental scan	5
2.3 Sourcing data from previous projects	5
2.4 Team discussions	5
2.5 Elder guidance	6
2.6 Community consultations	6
2.7 Teleconferences	6
2.8 Dissemination	7
2.9 Special note on language	7
<b>4.0 Discussion</b>	<b>7</b>
<b>References</b>	<b>8</b>

## 1.0 INTRODUCTION

Dementia is a growing concern in Canadian First Nations communities. First Nations communities are projected to have higher rates of dementia than the general Canadian population, and present an earlier age of onset (Jacklin, Walker, & Shawande, 2013). Indigenous cultural perceptions of dementia also differ from Western perspectives, as evidenced in Dr. Kristen Jacklin's past work, *Perceptions of Alzheimer's Disease and Related Dementias in Aboriginal Peoples in Ontario*. A clear need has emerged for evidence-based, culturally appropriate health promotional materials regarding cognitive health and aging in Indigenous communities.

The purpose of this report is to detail the methods used to develop the content for factsheets about dementia in partnership with the *First Nations and Inuit Health Home and Community Care* (FNIH HCC) program. The goal of this project is to improve health literacy concerning age-related dementias in Indigenous communities through the creation of culturally relevant health information factsheets. In the first year of work, two factsheets were generated: "What is Dementia? First Nations Perspectives and Cultural Understandings" and "Signs and Symptoms of Dementia: A First Nations Guide." In continuation of this work, the research team, under the direction of Dr. Jacklin, produced two more resources in the second year of work: "Preventing dementia in Indigenous peoples by aging well: advice from older Indigenous peoples," and "What to expect after a diagnosis of dementia: an Indigenous peoples' guide." All resources have since been well-received by local and international colleagues (see 2.8 Dissemination).

Our aim is to develop evidence-based and culturally appropriate material to inform Indigenous communities about age-related cognitive decline. The research methods that supported the development of the factsheets included: (1) updating an existing literature review to better understand diverse views of dementia in Indigenous communities in Canada; (2) the review of research findings concerning understandings of dementia in Indigenous communities in Ontario previously undertaken by Drs. Jacklin and Warry, and (3) an environmental scan to uncover any existing health promotion and knowledge translation strategies relating to dementia in Indigenous populations. The results of these reviews were consolidated and analyzed, with final key messages determined by Dr. Jacklin and her research team.

The results from this methodology also lay the foundation for future knowledge translation activities, including further development of health promotion materials for community members and caregivers, and training strategies for frontline workers.

## 2.0 METHODS

Working from within Indigenous research methodologies, the research team took a two-eyed seeing approach to the development of the factsheets. Prior to preparing the factsheets, the research team reviewed the 2012 Alzheimer Society of Canada (ASC) document titled "Person-Centred Language" (Alzheimer Society of Canada, 2012). These guidelines can be helpful when writing promotional materials in order to use language in a sensitive manner, to avoid labelling and reduce stigma-surrounding dementia. This document has been useful in guiding the use of appropriate language throughout the fact sheets. The document recommends replacing commonly used language such as "loved one" with "person / people with dementia," "family member" or "friend." In order to maintain the two-eyed seeing approach, discussions were also held with our CCNA Team 20 project Elder, Jerry Otowadjiwan. Through this process, the research team identified that the term "loved one" is commonly accepted and welcomed in the Indigenous context. The project Elder shared that caring for a person with dementia requires a lot of love, understanding and patience. We concluded, then, that this particular recommendation suggested by the ASC is problematic in the Indigenous context (see 2.9 for further details).

The literature suggests different strategies to ensure the material is presented to counter low literacy levels when delivering health information (Jones et al., 2013). Special attention was given to word selection, complex

sentences, and sentence structure. A literacy level of grade 5 was sought throughout the materials, however terms such as Alzheimer's, dementia, and Indigenous greatly impacted the readability level.

We paid particular attention to the perception of how dementia is viewed in the communities as reported in the literature and community reports. When speaking of dementia, individuals only describe the symptoms of forgetfulness and memory loss, and do not present words or terms that signify 'dementia.' In other words, 'dementia' is not a term commonly used by First Nations people. Yet, this needed to be balanced by the fact that it is widely recognized by health care providers working with First Nations people.

Team members met to discuss the results of their investigations and through discussion, distillation of key concepts and consensus prioritization began to determine what information should be included in the factsheets. Draft factsheets were reviewed by Drs. Jacklin and Warry with final drafting of the factsheets by Dr. Jacklin. In the end, we drew key ideas primarily from Canadian literature and from study data, and used international literature as a validity check against significant Canadian findings.

## 2.1 EXTRACTION OF SOURCES FROM LITERATURE REVIEW

Members of the research team reviewed the updated literature review *Trends in Alzheimer's Disease and Related Dementias among First Nation and Inuit* (Jacklin & Walker, 2012), and identified key white and grey literature sources. This literature review focused on the incidence, prevalence and rates of dementia among Indigenous people; the detection, screening and diagnosis of the illness; dementia risk factors and co-morbidities; the cultural considerations in diagnosis and care; and, prevention and awareness campaigns targeted at Indigenous people. This activity was undertaken through a parallel and complementary research study in Dr. Jacklin's research lab funded by the Canadian Consortium on Neurodegeneration in Aging (CCNA).

## 2.2 ENVIRONMENTAL SCAN

We undertook an environmental scan of health promotion materials. We reviewed health promotion materials related to dementia and other health topics. Materials reviewed focused on Alzheimer's disease and age-related dementias from Canada, United States, New Zealand, and Australia. Topics of focus included prevention, awareness, signs and symptoms, and care.

We also reviewed Indigenous specific health promotion materials from Canada focusing on health topics such as asthma, tuberculosis, diabetes, cancer, influenza, nutrition, and HIV. These materials were assessed for readability, design, visuals, colour, and the overall presentation of the information.

## 2.3 SOURCING DATA FROM PREVIOUS PROJECTS

The research team returned to the data from Drs. Jacklin and Warry's 2009-2013 project, *Perceptions of Alzheimer's Disease and Related Dementias among Aboriginal Peoples in Ontario*, and elicited participant experiences and stories concerned with prevention and what to expect following diagnosis. Key quotes from participants have been used throughout the resources, and themes from this work shaped the remaining content. Lived experience was prioritized. Drs. Jacklin and Warry's multi-sited study included interviews with seniors, persons with dementia, caregivers of persons with dementia, Traditional knowledge keepers in the communities, as well as health care workers, physicians and specialists. An initial review of the study reports focused the primary themes of the factsheets. After the initial review, the research team looked in-depth at the transcripts from people with dementia, caregivers, seniors, and Traditional knowledge keepers in all six community data sets.

## 2.4 TEAM DISCUSSIONS

The research team members worked primarily independently, but scheduled regular full team brainstorming sessions to finalize content:

- September 14, 2014
- November 11, 2014

- December 10, 2014
- February 6, 2015
- March 9, 2015
- April 30, 2015
- June 8, 2015
- November 9, 2015
- December 11, 2015
- January 7, 2016

## 2.5 ELDER GUIDANCE

The research team worked closely with Elder Jerry Otowadjiwan to develop and refine the resources, particularly the Medicine Wheel and Life Cycle Models associated with “Preventing Dementia in Indigenous Peoples by Aging Well: Advice from Older Indigenous Peoples.” Elder Otowadjiwan is a life-long resident of Manitoulin Island, Anishnaabemowin language specialist, Fourth Degree Midewin, and Mishomis.

## 2.6 COMMUNITY AND STAKEHOLDER CONSULTATIONS

Consultations were held with various community stakeholders throughout the project. Revisions from these consultations were incorporated in final versions of the resources.

- Consultations with a Community Advisory Group in the Manitoulin region were conducted for development of “Preventing Dementia in Indigenous Peoples by Aging Well: Advice from Older Indigenous Peoples” in spring of 2016.
- “What is Dementia? First Nations Perspectives and Cultural Understandings” and “Signs and Symptoms of Dementia: A First Nations Guide,” were presented to an Anishnaabemowin Language Speakers Group from the Manitoulin region in spring of 2016.
- Sharlene Webkamigad, a Master’s student working with the team, conducted focus groups with Indigenous caregivers of people living with dementia to confirm adaptability to an urban context in Sudbury, Ontario, during winter of 2016.
- Review by the North East Behavioural Supports Ontario Medical Advisory Committee, December 8, 2016 to verify medical accuracy of information. Content was reviewed by five behaviour specialists, a credentialed professional gerontologist, two psychiatrists, a nurse practitioner, two family physicians, and two physicians specializing in care of the elderly.

## 2.7 TELECONFERENCES AND WEBINARS WITH HEALTH CANADA

Teleconferences were conducted to discuss development of the products with key partners at FNIH HCC on the following dates:

- November 3, 2015
- December 7, 2015
- January 12, 2016
- April 6, 2016
- July 11, 2016
- January 19, 2017

Materials were presented to Health Canada and community partners via formal webinar:

- Developing First Nations Dementia Factsheet Material: Health Funding Contribution Agreement HQ150013  
Presenters: Dr. Kristen Jacklin & Dr. Wayne Warry  
June 4, 2015
- Developing Educational Materials for Community-Based Dementia Care: 1516-HQ-000028  
Presenters: Dr. Kristen Jacklin & Dr. Melissa Blind  
January 23, 2017

## 2.8 DISSEMINATION

- “What is Dementia? First Nations Perspectives and Cultural Understandings” and “Signs and Symptoms of Dementia: A First Nations Guide” have been copyrighted and published online through the Indigenous Cognition and Aging Awareness Research Exchange (Jacklin, 2015).
- “What is Dementia? First Nations Perspectives and Cultural Understandings” and “Signs and Symptoms of Dementia: A First Nations Guide” were presented at the International Association of Gerontology and Geriatric 2015 Congress in Chiang Mai, Thailand (Webkamigad et al., 2015).
- All resources were presented at the 2016 Alzheimer Association International Conference in Toronto, Ontario (Webkamigad et al., 2016).

## 2.9 SPECIAL NOTE ON LANGUAGE

The research team employed specialized culturally safe language throughout the factsheets. Instead of “person with dementia” or “person diagnosed with dementia” the term “loved one” is used. Throughout this work, Elder Jerry Otowadjiwan was consulted to make sure that work was done in a good way. Elder Otowadjiwan shared teachings about love with the research team. He shared that a person with dementia is someone who needs a lot of love and will need to be reminded that they are loved. And whether or not their caregiver is someone who loves them, the act of providing care is a loving act, and somebody, somewhere loves this person. Using the term loved one reminds readers of how the person with dementia should be respected and treated. Community advisory groups, participants in Webkamigad’s thesis work, and community partners all reacted well to loved one and found it appropriate in an Indigenous context.

The term caregiver is also used instead of the more recent “care partner.” This is because to provide care is to offer a valued gift to another. Caregiver was also preferred by all of the community stakeholders and participants consulted throughout the development process.

## 4.0 DISCUSSION

Throughout development, it became apparent that Indigenous-specific health promotional materials for cognitive health and aging are not readily available in Canada. None were captured in the environmental scan, and the literature was still in early stages. Participants in Webkamigad’s thesis work questioned why they had not previously seen resources like these, and after every presentation, the research team fielded requests for copies of the resources, even in plain text.

Dissemination has been received positively, both locally and internationally, and the research team has been fielding requests from colleagues and health care workers for further information and more resources. The team has launched the Indigenous Cognition & Aging Awareness Research Exchange (I-CAARE.ca) to consolidate multiple projects in this research area. Currently, the team is developing culturally safe training curricula for health care providers regarding cognitive health and aging in Indigenous communities, based on the in-depth findings summarized in the resources available at this time.

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