DEVELOPING FIRST NATIONS DEMENTIA FACTSHEET MATERIAL: METHODOLOGY REPORT

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INTRODUCTION

The purpose of this report is to detail the methods used to develop the content for the *First Nations and Inuit Health Home and Community Care* (FNIH HCC) factsheets about dementia. The goal of this project is to improve health literacy concerning age-related dementias in First Nations communities through the creation of culturally relevant health information factsheets. Our objectives for year 1 of the work have been the creation of factsheets for community health care providers that focus on First Nations cultural understandings of "What is dementia?" and "Early warning signs and symptoms of dementia."

Our aim is to develop evidence-based and culturally appropriate material to inform First Nations 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. The factsheets will be presented to the FNIH Home and Community Care regional offices and Partners Committee in June 2015 for feedback.

The reviews produced 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.

METHODOLOGY

In order to inform the development of the factsheets, we undertook the following activities:

1. We analyzed an updated version of a previous literature review titled: *Trends in Alzheimer's disease and Related Dementias among First Nation and Inuit* (Jacklin and Walker, 2012) that was contracted by FNIH Home and Community Care.
    - 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. We analyzed six community reports and findings on Alzheimer's disease and related dementias in Aboriginal Peoples in Ontario (Pace et al., 2013, Jacklin et al., 2014 , Jacklin et al., 2014b, Jacklin et al., 2013b, Jacklin et al., 2013a, Jacklin et al., 2014a).

    - 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 reports focused on cultural understandings of dementia and the early warning signs and symptoms associated with dementia. After the initial review, the research team looked in-depth at the transcripts from people with dementia, caregivers, seniors, and Traditional knowledge keepers in three out of the six community data sets.

3. 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.

SUMMARY OF RESULTS

1. MAJOR THEMES IN THE LITERATURE REVIEW

INDIGENOUS CULTURAL UNDERSTANDINGS OF DEMENTIA/WHAT IS DEMENTIA?

Dementia in Indigenous populations has been described in a number of different ways: as "childlike" benign behaviours; "madness" or aggressive behaviours; or as a "sick spirit" suffering from the consequences of colonization and loss of connection to land and traditional relationships (Arkles et al., 2010). Dementia may not be recognized as a medical condition in many Indigenous communities. In fact, some reports stress that cognitive impairment and dementia can be perceived as part of the Creator's plan for a person's ultimate learning (Griffin-Pierce et al., 2008). Contrary to Western conceptions, dementia may be valued by the person experiencing it, if the symptoms are seen to be communication with the spiritual world (Henderson and Henderson, 2002). In terms of defining or "labelling" the illness, the word dementia is not easily translated into Indigenous languages (Hulko et al., 2010, Lanting et al., 2011).

EARLY WARNING SIGNS/SYMPTOMS OF DEMENTIA

Very little is discussed in existing published studies concerning early warning signs of dementia in the context of Indigenous experiences. Many studies report that dementia is under-diagnosed or diagnosed late in Indigenous populations. Many studies reported that forgetfulness is thought to be a natural part of the experience of growing older and other symptoms (such as visions) may not be problematized when viewed as communication with the spiritual realm (Henderson and Henderson, 2002). However, other studies suggested that Indigenous peoples sometimes viewed symptoms (anger, arguing, aggression) as problematic and were distinguishing between natural aging and illness related aging brought on by adoption of Western lifestyles and food (Smith et al., 2011, Hulko et al., 2010).

2. MAJOR THEMES IN THE COMMUNITY REPORTS

INDIGENOUS CULTURAL UNDERSTANDINGS OF DEMENTIA/WHAT IS DEMENTIA?

Indigenous cultural understandings of dementia differ from Western understandings of dementia in that many Indigenous people accept memory loss and confusion as a normal part of the aging process. In the interviews people with dementia, caregivers, seniors, and traditional knowledge keepers, described forgetfulness and memory loss as part of "getting older", "old age", or having a "seniors' moment."

Many participants also commented that people who are experiencing memory loss may be "going back to childhood", entering "second childhood", or "going full circle". In the circle of life, babies and elderly people are seen as being closer to the Creator. It was acknowledged that individuals entering the later stages of life may be more connected to the spirit world and see or hear things that other people may not. It was also widely accepted that elderly people may exhibit certain child-like behaviours and will need more personalized care as they age. Participants also shared that during this time a person's long-term memories may be more prevalent and they may speak more of their childhood or youth by "remembering things from the past".

More medicalized explanations of dementia behaviours and symptoms are put forward by Indigenous participants once dementia starts to progress. In certain cases participants attributed memory loss to an event, such as the loss of a loved one, or past trauma, such as a head injury. Phrases such as "old timer's disease", "my mind goes on me", "breakdown of thoughts", "sickness of the mind", "brain not working right", and "losing one's mind" were used to describe the loss of balance between the mind, the body, and spirit.

Early Warning Signs/Symptoms of Dementia

Participants brought forward the following early warning signs and symptoms associated with dementia:

- Forgetfulness, including not being able to recognize people, places, or objects; repeating stories; misplacing objects;
- Impaired judgement, including not understanding instructions; not understanding cause and effect; sense of time is off;
- Changes in mood and personality, including emotional outbursts; easily upset or frustrated; withdrawn from family, friends, or favourite activities; increased fear, paranoia or distrust of others; compulsive behaviour;
- Changes in hygiene, including forgetting to brush hair, teeth; not interested in washing or getting cleaned up;
- Getting lost, this may include wandering or pacing;
- Seeing or hearing things that nobody else can, including connections with people who have passed; hallucinations;

These and other major themes from the community reports, environmental scan, and literature review were analyzed and prioritized leading to the development of the two factsheets.

3. MAJOR THEMES IN THE ENVIRONMENTAL SCAN

INDIGENOUS CULTURAL UNDERSTANDINGS OF DEMENTIA/WHAT IS DEMENTIA?

Many of the resources developed by Alzheimer's organizations described dementia as an irreversible disease affecting the brain, causing deterioration of memory and the ability to think. Dementia also causes behavior and emotional changes, which may interfere with the person's social and work life.

The only Indigenous specific fact sheet and brochures that we identified were developed for Aboriginal and Torres Strait Islanders in Australia and were found in the website *Understanding Alzheimer's Educate Australia* (Australia Alzheimer's, 2010). In the brochure titled, "Look After Your Brain, A Guide", dementia is defined as "a disease of the brain that makes it difficult for you to remember, think and plan. You get sicker over time. As dementia gets worse you may find it hard to keep doing the things you used to do each day." A poster titled "the snake eating away the life of your memory" was developed as part of the Indigenous Dementia Services Study in Australia (Indigenous Dementia Services Study, 2013). This poster raises awareness about dementia to Indigenous people in the Kimberly region of Australia, highlighting risk factors and signs of dementia. The poster relates dementia to "a snake inside the brain that is said to be eating away a person's memory."

EARLY WARNING SIGNS/SYMPTOMS OF DEMENTIA

Short-term memory loss affecting day-to-day abilities is the first early warning sign of Alzheimer disease and related dementias listed by the four organizations reviewed (Alzheimer's Association, 2015, Alzheimer's New Zealand, 2012, Australia Alzheimer's, 2010, Canadian Alzheimer's Society, 2015). Other early warning signs of dementia that are commonly identified by dementia advocacy organizations include: 1) problems with language, words, speaking, writing, and understanding what is said to them; 2) difficulty performing/completing/managing familiar complex or new tasks and taking longer to do so; 3) withdrawal from usual/social/work activities due to lack of initiative or loss of social skills; 4) changes in mood, behavior and personality with unpredictable behavior and 'mood swings'; 5) challenges in planning or solving problems, with impaired/decreased/poor judgement; 6) confusion with time or place/ disorientation in time and space; and 7) misplacing things.

CREATION OF FACT SHEETS

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.

Prior to preparing the fact sheets, 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". Following discussions with our CCNA Team 20 project Elder, Jerry Otowadjiwan, 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 First Nations context.

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.

The factsheets have been prepared without symbols or specific cultural references. Future work of our team will consider how the material can be adapted to First Nations across regions. In this first stage, we have created generic factsheets outlining cultural understandings of dementia and early warning signs and symptoms associated with dementia for front-line workers. In the future, these factsheets can be tailored to different audiences, for example, First Nations seniors and community members, leadership, persons with dementia and family caregivers.

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