

Developing Dementia Health Promotion Materials for Indigenous People in an Urban Northern
Ontario Community

By

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Abstract

This thesis considers health promotion materials on dementia for Indigenous people using health literacy and cultural safety as guiding frameworks. The author examined the question “How can we develop health promotion materials about dementia to meet the needs of Indigenous peoples living in urban Northern Ontario?” using two decolonized approaches to community-based participatory action research. Two-eyed seeing combines biomedical information with Indigenous knowledge to develop fact sheets. An understanding of local tribal teachings guided the research locally. Methods involved qualitative data analysis of two focus groups and five one-on-one interviews exploring the fact sheets’ appropriateness. Results suggest the need for a shared understanding of Indigenous and Western cultures; improved cross-cultural communication; the importance of grounding health promotion materials in culture; and, strategies for dementia awareness in Indigenous health literacy. These research findings can be translated to inform policy and practice through key recommendations regarding the development of health promotional materials.

Keywords: Cultural safety, health promotion, health literacy, knowledge translation, two-eyed seeing, decolonization, Indigenous knowledge, First Nations, Indigenous, dementia

Co-Authorship Statement

This thesis presents an integrated-article format according to the School of Rural and Northern Health Student Handbook 2015-2016. This thesis includes two papers prepared for academic publication.

Co-Authorship: “An approach to improve dementia health literacy in Indigenous communities.”

As the first author I contributed to the data analysis, lead manuscript development, and editing the final version. Kristen Jacklin and Wayne Warry led project development, data collection, methodological design, data analysis, and contributed to manuscript development, writing and revisions. Melissa Blind contributed to the methodological design, data analysis, and manuscript development. All authors participated in the review and editing of this manuscript.

Co-Authorship: “Exploring the appropriateness of culturally-safe dementia information for Indigenous people in an Urban Northern Ontario community.”

As the first author I contributed to the project design, data collection, data analysis, lead manuscript development, and editing the final version. Kristen Jacklin contributed to project development, methodological design, and contributed to manuscript development, writing and revisions. Sheila Cote-Meek and Birgit Pianosi contributed to the theoretical approach, manuscript development and review manuscript. All authors participated in the review and editing of this manuscript.

Epigraph

“Follow your heart and have faith in the things you do.

Things will come at the perfect time.

Blessings will come in many forms also.”

- Wiikwemkoong Community Member, Norma Peltier

Acknowledgements

The City of Greater Sudbury¹, located in Northern Ontario, is also known as N'Swakamok (where the three roads meet). The original territory belongs to the Atikameksheng Anishnawbek from the Ojibway, Algonquin, and Odawa Nations (Atikameksheng Anishnawbek, n.d.). Current experiences are owed to ancestors who contributed to the beautiful presence of an Indigenous community in this territory. Miigwetch to our ancestors and current Anishinaabek who built a foundation for Indigenous people. Future generations now have access to education, employment, and other great opportunities. Since the beginning of my journey in postsecondary education, I felt welcomed and accepted into this territory.

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¹ A Large urban population centre, with a population of 100,000 or more (Statistics Canada, 2017).

health promotion has improved my understanding of what we can do to support individuals affected by dementia and their families. Your contributions will benefit generations to follow.

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Glossary of Terminology

Throughout this thesis I used specific terminology to refer to Indigenous peoples. Whenever possible, I used the names of the tribe I am referring to, for example, Cree, Ojibway, Odawa, Algonquin, Métis, and Inuit. I used the term Indigenous if I am referring to a collective group. When referring to the Indigenous peoples of Australia I used the term Aboriginal and Torres Strait Islander people; and for the Indigenous people of New Zealand I used the term Maori.

The following is a list to help the reader identify terms similar in meaning but have different origins.

Aboriginal: a legally defined term imposed by the government of Indigenous peoples of Canada; defined under Section 35 of the Canadian Constitution Act of 1982 that consists of Indian, Inuit and Métis people (Allan & Smylie, 2015; Statistics Canada, 2013a).

Anishinaabe: Ojibway term for man (human being, man, woman or child); also, Aboriginal, Indian (Baraga, 1992; “Nishnaabe,” 2015).

Anishinaabek: also written as Anishnabeg; a term used to refer to the Anishinaabe in the plural form (Baraga, 1992).

Anishinaabe-kwe: Ojibway word for Aboriginal/Indian woman (Baraga, 1992; “Nishnaabe,” 2015).

Anishinaabemowin: Ojibway word for Indian language (Baraga, 1992; “Nishnaabe,” 2015).

First Nation: Replacing the term ‘Indian’ in the 1970’s, it refers to status and non-status Aboriginal peoples of Canada (Aboriginal Affairs and Northern Development Canada, 2010).

Indian: A legal term used to depict the Indigenous peoples of North America, replaced in the 1970's in Canada by the term 'First Nation' (Aboriginal Affairs and Northern Development Canada, 2010). Using 'Indian' is problematic and offensive to some people (Smylie, Olding, & Ziegler, 2014).

Indigenous: a variable term used to identify communities, peoples and nations original to the land they occupy (Allan & Smylie, 2015). Indigenous peoples of Canada identify as First Nations, Inuit, and Métis people. They are diverse within their respective groups and across the nation, and have specific tribal affiliations such as those listed above (Allan & Smylie, 2015; Health Council of Canada, 2012).

Inuit: an Inuktitut term meaning 'people'; used to identify Indigenous peoples of Nunavut, Northwest Territories, Northern Quebec, and Northern Labrador (Aboriginal Affairs and Northern Development Canada, 2010).

Métis: a French term meaning 'mixed blood'; used to describe Indigenous peoples of mixed First Nation and European ancestry who are distinct from First Nations or Inuit. (Aboriginal Affairs and Northern Development Canada, 2010; National Aboriginal Health Organization, 2017). Métis have their own unique culture, traditions, language (michif), way of life, collective consciousness and nationhood (Métis Nation Council, 2011).

Mnaamaadziwin: an Ojibway term meaning living a good life through wholistic well-being and is the balance of your emotional, spiritual, mental, and physical health. The notion considers the life cycle and places an importance of past, present, and future (Allan & Smylie, 2015; National Collaborating Centre for Aboriginal Health [NCCAHA], 2013; Rheault, 1998).

Native: Similar to the term Aboriginal, but not widely used (National Aboriginal Health Organization, 2017). In this thesis, Native is used in N'Swakamok Native Friendship Centre.

Wewena ji bmaadziwin: an Anishinaabemowin term meaning the Seven Grandfather Teachings. See Preface for further discussion.

Preface

Sharlene Webkamigad miinwaa Waabe gegek-kwe n'dizhniikaaz, Nimkii bineshii n'doodem. Wiikwemkoong N'doonjibaa. My name is Sharlene Webkamigad, also, White hawk woman. I belong to the *Anishinaabek Nation*.

I am most at ease during rainfall or by the water, sacred gifts from mother earth. My children, E'Niigaanzit and E'jignat Nimkii Naapkawaagan, are also strengthened by the water. The colors I wear in the circle as a jingle dress dancer are vibrant and reflect my nature.

Our thoughts alone can change how Indigenous health is perceived.

Growing up on Turtle Island (what Indigenous people refer to as North America) on the *Wiikwemkoong Unceded Territory* (also known as the Wikwemikong Unceded Indian Reserve), I witnessed many health inequalities within Indigenous communities. At a young age, I became interested in what it takes to prevent chronic diseases such as diabetes, cancer, and respiratory problems. Immerging into my young adult years, I saw the importance of health promotion and disease prevention. I learned through workshops, speakers, conferences and talks with health care professionals that taking care of yourself and preventing disease is a wholistic undertaking. I learned that health promotion can be situated within the medicine wheel model.

The medicine wheel model of wholistic well-being is used by the *Anishinaabek* people of Turtle Island. Life teachings are passed on with the medicine wheel as a framework. *Mnaamaadziwin*, living a good life through holistic well-being, is the balance of emotional, spiritual, mental, and physical health. It considers the life cycle and places an importance of past, present, and future (Allan & Smylie, 2015; NCCAH, 2013; Rheault, 1998). Literature focused in Indigenous health has shifted my thinking into finding a new way to frame health in a deeper context (Health Council of Canada, 2012, 2013; Loppie Reading & Wien, 2009; Smylie, 2000). A previous paper prepared for a course in Interdisciplinary Health led me to seek the theoretical foundations of Aboriginal social determinants of health, health inequities, and structural violence. This exploration guided my search to understand the layers on layers of what a health promotion model may mean to Indigenous peoples of Turtle Island.

Furthermore, doing research helped me to reflect on my values and beliefs as an *Anishinaabekwe*. These reflections are guided by *Wewena ji bmaadziwin*, Seven Grandfather Teachings. I have included examples of my reflection in this preface because it guided my personal and

ethical conduct as a student, mother, daughter, wife, community member, nurse, researcher, and, most importantly, as an *Anishinaabe-kwe*. Understanding the *Anishinaabek* values and beliefs of *Wewena ji bmaadziwin* will help the reader identify how an Indigenous approach has helped me throughout the research.

Wewena ji bmaadziwin

Mnaadendiwin (Respect): I will respect my culture, my traditions. I will respect the stories people have shared with me. I will respect every individual and not let anything harm them in the work that I do. I will not harm Indigenous people in this research. I will not generalize information. I will not stigmatize. The wholistic model of care is used to respect the person wholly. I also need to respect me by caring for me. *Nbwaakaawin* (Wisdom): I will be wise in the words I choose when I write. I know and understand the impact I could make in this world. *Zaagidiwin* (Love): Love is doing something to make a change. I love what I do. I want the next seven generations to feel loved and cared for. I need to reflect the love in my work. *Gwekwaadziwin* (Honesty): Being true to my feelings will help to make an impact. I am honest to the people I surround myself with. I am also honest with my people in what we need to do to overcome health inequalities. *Bbasendiziwin* (Humility): I am humble of my presence on Turtle Island. Mother earth cares for all people by providing means to live healthy lifestyles. The Creator has a plan for every individual, and each person must accept their intended path. *Aakdewin* (Bravery): I have to be brave to do the work that I do. To step out of my comfort zone and have a voice frames bravery. I will speak truth about what I believe in. *Debwewin* (Truth): I am true to me, my family, and my community. I will explain with full honesty what I feel and think we need to do as a collective to overcome health inequalities. I will hold up my *Anishinaabe* beliefs and values; and stand my ground as an *Anishinaabe-kwe*.

Chapter 1: Introduction

This thesis presents a knowledge translation and exchange project that responds to the need for Indigenous-specific health promotion materials related to dementia. This chapter provides the rationale for the project and reviews literature relevant to the approach; for example, cultural safety, health literacy, and health promotion. The thesis addresses the central research question: “How can we develop health promotion materials about dementia to meet the needs of Indigenous peoples living in an urban Northern Ontario community?”

This inquiry used two approaches stemming from decolonizing theory: two-eyed seeing (Martin, 2012) and a locally adapted version of tribal epistemology (*Néhiyaw Kiskêyihitamowin*) (Kovach, 2009). A local understanding of the medicine wheel was used as a guiding tool to frame participant interviews. Placed within a larger effort to address dementia care in Indigenous populations in Canada (The Canadian Consortium of Neurodegeneration in Aging [CCNA] Team 20: Issues in rural and Indigenous dementia care), this work contributed to two dementia fact sheets. These fact sheets respect the beliefs of a diverse national audience that seek to pair Indigenous cultural understandings of dementia with Western biomedical knowledge.

This research aims to understand the necessary components of culturally safe health promotion material related to dementia for Indigenous people in Canada. Drawing from researchers who study health literacy, health communication, and education (Lindeman, Taylor, Kuipers, Stothers, & Piper, 2010; Schoen, Balchin, & Thompson, 2010; Smylie et al., 2009; Taylor, Lindeman, Stothers, Piper, & Kuipers, 2012), we assess the appropriateness of dementia material developed for a national audience with a local urban Indigenous population in Northern Ontario.

The fact sheets developed with CCNA Team 20 were central to the research explored in this thesis.

The key health literacy and knowledge translation questions related to this research sought to discover: 1) the preference for communicating dementia information to Indigenous people in the City of Greater Sudbury, Ontario; 2) the role of Indigenous language in creating suitable material; and 3) the role of Indigenous oral and visual traditions of knowledge sharing in developing health promotion tools for an Indigenous audience. The importance, then, is to find ways to contribute to health literacy to improve the quality of life of Indigenous patients and families.

This research took place in a large urban population centre in Northern Ontario called the City of Greater Sudbury, which has a population of 13,405 Indigenous people (Statistics Canada, 2013b). The original territory belongs to the Atikameksheng Anishinaabek (Ojibway, Algonquin, and Odawa Nations), located 19 km west of the City (Atikameksheng Anishnawbek, n.d.). The non-official languages spoken in the Indigenous population of the City of Greater Sudbury are: Algonquin, Cree, Ojibway, among others (Statistics Canada, 2013b). Connections with older Indigenous people of the community were made through a partnership with the N'Swakamok Native Friendship Centre (N'Swakamok Native Friendship Centre, n.d.).

Background

Indigenous People in Canada: In 2011, the National Household Survey showed there were roughly 1.4 million Indigenous people in Canada (Statistics Canada, 2013a). This is a population that identifies as First Nations, Inuit, and Métis people that are diverse within their respective

groups and across the nation (Health Council of Canada, 2012). To elaborate, First Nations people are status and non-status Indigenous peoples in Canada (Canada, 2004). Nearly 23.6% (201,000 people) of the Canadian First Nations population live in Ontario (Statistics Canada, 2013a). There are 618 First Nations communities in Canada (Aboriginal Affairs and Northern Development Canada, 2015); each community is unique with distinct values, beliefs, and dialects. The second group of Indigenous peoples is the Métis population. The highest number of Métis (19%, 86,015 people) are in Ontario (Statistics Canada, 2013a). This population also has its own unique culture, traditions, way of life, and nationhood (Statistics Canada, 2013a). The third group of Indigenous peoples are Inuit. In 2011, Statistics Canada reported the Inuit population to be 59,445 (Statistics Canada, 2013a). The highest number of Inuit, roughly 45%, live in Nunavut (Statistics Canada, 2013a). Like any Indigenous peoples, Inuit comprise several different regions, languages, dialects, and cultures. Collectively, Indigenous people experience the poorest health of any group of people in Canada (Health Council of Canada, 2012; Royal College of Physicians and Surgeons of Canada, 2013).

The number of Ontarians aged 65 years and older is expected to double over the next two decades (Sinha, 2012). Older adults make up a low proportion of the Canadian Indigenous population, representing 5.9% of the total Indigenous population in 2011 (Statistics Canada, 2013a). In 2003, Canstats Bulletin reported that Indigenous older adults aged 55 and over are the most rapidly growing demographic in Canada (as cited in Lanting, Crossley, Morgan, & Cammer, 2011). As with the non-Indigenous population, the older-adult age group of the Indigenous peoples of Canada is projected to increase rapidly. There is a projected growth of the Indigenous population aged 65 years and over from 4.7% in 2006 to 14.5–15.4% by 2031 (Malenfant & Morency, 2011). As an illustration, Malenfant and Morency projected in 2011 that

“the number of First Nations people aged 60 and older is expected to increase in number by 3.4 times from 54,165 in 2006 to 184,334 in 2031” (as cited in Jacklin, Walker, & Shawande, 2013, p. e39). Aging is the most significant factor in the development of dementia.

The increasing number of older Indigenous adults is a concern for health care providers who will need to respond to age-related health care needs. In Canada, the number of people with Alzheimer’s disease and related dementias is projected to more than double to 1,125,184 over the next 30 years (Alzheimer's Society of Canada, 2010). There have been very few Canadian studies that address the prevalence and incidence of dementia in Indigenous people (Warren, Shi, Young, Borenstein, & Martiniuk, 2015). However, one study suggests that the age-standardized prevalence of dementia in First Nations in Alberta in 2009 was 7.5 per 1,000, compared to non-First Nations, which was 5.6 per 1,000 (Jacklin, Walker, & Shawande, 2013). Furthermore, Walker and Jacklin suggest that there will be a fourfold increase in the number of First Nations people over age 60 with dementia in 2031; non-First Nations populations will see a 2.3-fold increase (Walker & Jacklin, forthcoming 2017).

It has been anticipated that the aging population (whether Indigenous or not) will present serious challenges and demands for caregivers, communities, the current and future health care system, and society (Bourassa, Blind, Jacklin, Oleson, & Ross-Hopley, 2017; Del-Pino-Casado, Frias-Osuna, & Palomino-Moral, 2011; Vitaliano, Young, & Zhang, 2004). In the past decade, policy makers in Canada have been encouraging older adults to age-at-home so that they will have the ability to live in their own communities for as long as possible (Lilly, Robinson, Holtzman, & Botorff, 2012; Chief Public Health Officer, 2010). Although this is potentially a reasonable solution, there is acknowledgment that the aging-in-place movement could have unintentional

adverse effects for family members who care for older adults (Lilly et al., 2012). For example, caregivers sometimes face alienation, isolation, and lack of support from their community and health care system (Bourassa et al., 2017).

Dementia, Aging, and Caregiving in Indigenous Communities: Dementia is an umbrella term for a variety of brain disorders with symptoms such as memory loss, problems with judgement and reasoning, and changes in mood and behaviour, as well as issues with brain function that can affect a person's ability to function at work, in relationships, or in everyday activities (Alzheimer Society of Canada, 2010; Warren, Shi, Young, Borenstein, & Martiniuk, 2015). Research suggests that there are specific health behaviours of Indigenous people concerning dementia, aging, and caregiving that are distinct from the general population. First, memory loss and forgetfulness may be viewed as normal signs of aging amongst Indigenous people (Jacklin & Walker, 2012; Jacklin et al., 2014c; Lanting et al., 2011; Pace et al., 2013). This belief may lead to the acceptance of early signs and symptoms of dementia and therefore delay care. Second, Indigenous people have an overall sense of caring for the elderly that can occur with or without signs of illness (Best Start Resource Centre, 2010). Third, Indigenous people view caregiving holistically, describe the caregiving relationship as reciprocal, and experience caregiving across the lifespan. In brief, Indigenous people may experience caregiving differently, not simply due to poorer health profiles, but because of their perspectives on caregiving (Healthy Balance Research Program, 2006).

Culture, life experiences, and religious beliefs may affect Indigenous peoples' understanding of aging, dementia, and perceptions of the caregiving role (Hayter, Vale, & Alt, 2008; Luong, Rauters, & Fingerman, 2014). The cultural concept of the person influences the adaptation of

older adults in specific ways, such as whether they reside with offspring, whether they provide for others, or expect to be provided for, and the values they place on different types of social liaisons (Fingerman & Pitzer, 2007). For the Indigenous caregiver, giving meaning to life may include having positive interactions with the person with dementia. The caregiving role may help to sustain important cultural values such as the importance of relational care in an Indigenous language, intergenerational relations, reciprocity, love, and an understanding of the circle of life (Jacklin, Pace, & Warry, 2015).

Pace (2013) argues that an appropriate understanding of personhood is important when developing culturally safe dementia care, such as fact sheets. Furthermore, a discussion of the concepts of person-centred language and personhood are necessary to maintain the respect and recognition towards Indigenous people, older adults, and caregivers. There are variations in the form and function of personhood: egocentric (personal history, accomplishments), sociocentric (family, clan, lineage, community), ecocentric (environment, ecology), and cosmocentric (ancestors) cultural configurations of the self (Kirmayer, 2007). The Alzheimer Society (2012) puts forth personhood as the first principle in the support of person-centred language:

“A standing or status that is bestowed upon one human being by others in the context of relationship and social being. It implies recognition, respect and trust”
(Alzheimer Society of Canada, 2012, p. 2).

When applied to the Indigenous context, there have been debates regarding the concepts of person-centred care and personhood (Morhardt & Spira, 2013), which are egocentric, focus on the individual, and may contradict with Indigenous ways of life. However, care for older adults in the Indigenous context is ideally provided by the family and grounded in traditional values

(Jacklin et al., 2015), thus supporting sociocentric and relational care that is grounded in values of collectivism, love, reciprocity, and the understanding of the circle of life. Peoplehood, a concept developed in the 1980s by Robert K. Thomas, identifies four factors that imply how Indigenous people behave: language, sacred history, ceremonial style (formerly religion), and land (Holm, Pearson, & Chavis, 2003). It is more applicable to utilize terms that are congruent with an understanding of peoplehood as this resembles the Indigenous ways of life far better than personhood does.

Refocusing on the local applicability of this study, an understanding of the medicine wheel as a holistic model can assist with how peoplehood is used in Indigenous health promotion. It is a common belief amongst the Anishinaabek and other Indigenous peoples that one person alone cannot survive without the support of family members, neighbors, and community members. Elements from personhood and person-centred care can be used to identify how to deliver care to the individual, but this approach should be adapted to include other aspects of the support system (loved ones, elders, community members).

A discussion with this project's Indigenous advisory group (IAG) regarding language such as loved one(s), older adult, and caregiver revealed that these terms are supported. Language supportive of peoplehood and relational care is used to ensure the unique values of Indigenous peoples, such as those listed above, is encouraged. IAG members identified that the language was acceptable to Indigenous community members when an explanation of the term was given. Love, one of the Seven Grandfather Teachings, is an essential component of the care provided to a person with dementia. The action of love is giving part of yourself to another. Therefore, using the term "caregiver" is more appropriate in the context of Indigenous care than the more recent

“care partner”. This study resonates with the community preferences in using the terms loved one(s), older adult (when aged 55 and up), and caregiver.

Structural Health Inequalities. Concerns over the influences of health care culture has led researchers to focus on structural violence as a framework to identify health care inequities. Researchers have identified that the silencing of Indigenous voices occurs in the mainstream health care system (Kurtz, Nyberg, Van Den Tillaart, Mills, & Okanagan Urban Aboriginal Health Research Collective, 2008). Structural violence describes how social structures such as economics, politics, law, religion, and culture can stop individuals, groups, and societies from reaching their full potential (Farmer, 2004; Farmer, Nizeye, Stulac, & Keshavjee, 2006); thereby increasing the gap between an ability to fulfill basic needs and the actual fulfillment of these needs (Ho, 2007).

Clearly, structural violence has made its impact through an accumulation of Indigenous health inequalities. Specific policies enacted within the Canadian health care system heighten structural inequalities, including: the Constitution Act of 1867, the Indian Act of 1876, and the Non-Insured Health Benefits (NIHB) program (Allan & Smylie, 2015). In addition, current health care services for Indigenous Canadians have limited accountability, fragmented delivery, jurisdictional ambiguity, poor access, and institutional barriers to care (Jacklin, Pace, & Warry, 2015; Wien & Loppie Reading, 2009). As a result of structural violence, the delivery of health care services to Indigenous peoples in Canada is continuously fluctuating (Kurtz et al., 2008; NCCAH, 2013).

Health care professionals working within Indigenous communities face many challenges in the delivery of dementia services. These challenges can be attributed to: a lack of culturally

appropriate resource materials and services (Finkelstein, Forbes, & Richmond, 2012); stigma, suspicion, and mistrust of the health care system; complex needs of individuals and families; not enough professional staff to meet the needs of older adults and their caregivers; short-term programs; little to no support or respite for caregivers (Alzheimer Society London and Middlesex, 2011); and limited information regarding the prevalence and incidence of dementia amongst the Indigenous population (Jacklin et al., 2013). Buchignani and Armstrong-Esther (1999) argue that although there are complex needs for Indigenous people with dementia, there is also significant underutilization of mainstream services due to deeply embedded mistrust of the health care system. Indeed, a group of caregivers of Indigenous people with dementia expressed an overwhelming and deep aversion to residential care facilities (nursing homes) and there is a deep reluctance by Indigenous caregivers to use mainstream services as there is a lack of culturally appropriate services or services in Indigenous languages (Jacklin et al., 2015). Furthermore, another group of researchers found that 69% of respondents from First Nations communities would prefer to remain living in their community right up to their death if community health care services and support were available and adequate (Habjan, Prince, & Kelly, 2012).

Research has shown a lack of basic dementia care resources and Indigenous-specific dementia care literature does not exist (Finkelstein et al., 2012). Caregivers, older adults, nurses, personal support workers, and researchers often request Alzheimer's and age-related dementias health promotion materials targeted to the Indigenous peoples in Canada, but none exist (Jacklin et al., 2014; Pace, Jacklin, & Warry, 2013). As a result, health care workers often create their own or adapt mainstream resources to make them more culturally appropriate (Finkelstein et al., 2012). Similarly, caregivers, service providers, and community workers feel strongly that dementia

initiatives must be driven by the community and that the community must be engaged at all levels to be successful (Smith et al., 2011). For example, a study called the “Perceptions of Alzheimer’s Disease and Related Dementias among Aboriginal Peoples in Ontario”, herein referred to as the Perceptions Project, focused on the perspectives of dementia in six communities in Ontario (Jacklin, Warry, & Blind, 2014a, 2014b, 2014c, 2013; Jacklin, Warry, & Dietrich, 2013; Pace, Jacklin, & Warry, 2013): Sudbury, Thunder Bay, Ottawa, Six Nations, Moose Cree First Nation, and a combined group of Anishinaabek First Nations on Manitoulin Island (see Figure 1). This study focused on the perceptions of Indigenous older adults, persons with dementia, caregivers, and traditional healers. Findings from all six communities have harmoniously identified a need for educational material that is appropriate and reflective of the Indigenous culture.

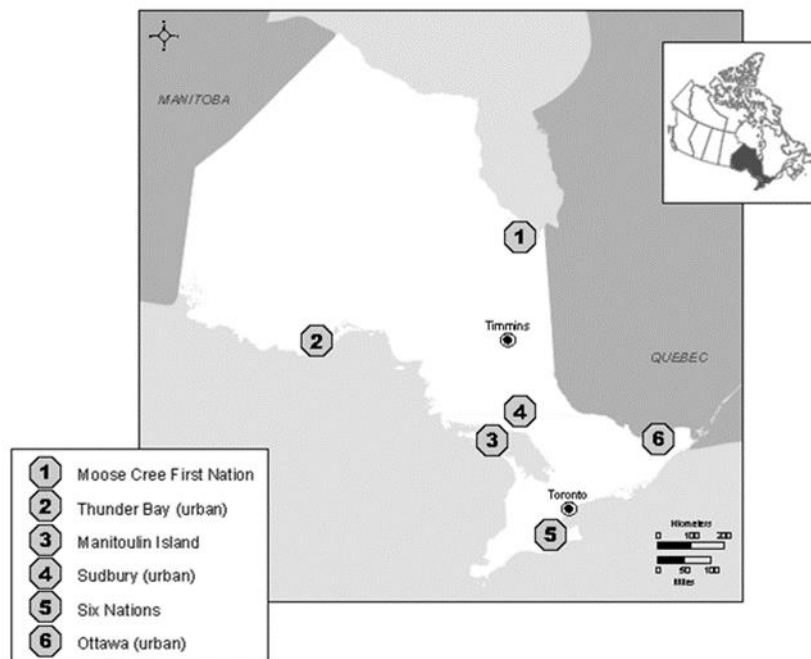


Figure 2. Partner Research Sites in Ontario, Canada (Jacklin et al., 2015)

Looking beyond Canada, culturally appropriate dementia resources for Indigenous populations have been developed in Australia, and include: materials for the Indigenous and Torres Strait Islander people, such as a brochure titled “Look After Your Brain, a Guide to Dementia for Indigenous People”; a book titled *Meet Dementia, the Bad Hawk That Steals* (Alzheimer’s Australia, n.d.); and, a poster titled “The Snake Eating Away at Your Memory” that was developed by Australian Indigenous community workers in the Kimberly region of Western Australia (Dwyer, 2013). Another example from Australia is “Looking Out for Dementia,” a multimedia resource consisting of a DVD, a training flip chart, and a community awareness poster, aimed at improving the understanding of dementia within Indigenous communities (Lindeman et al., 2010). An evaluation of this resource shows that good intercultural communication enhanced the effectiveness of the resource materials as the materials reflected the diversity of the local languages, images, and participants, and the resources validated the Indigenous cultures by enhancing engagement and providing opportunities to develop health vocabularies where there are no existing translatable terms (Taylor et al., 2012).

Reinforcing findings from the Australian researchers, this research aims to improve the relationship between the health care recipient and health care provider by bridging the knowledge gap through culturally safe health promotion materials. Supportive policies and programs must consider the cultural context, respect holistic paradigms, support family/community networks, and support intergenerational care (Healthy Balance Research Program, 2006). However, few attempts have been made to increase the understanding of the interrelationships among literacy, language, culture, and health in Indigenous communities (Smylie, Williams, & Cooper, 2006). Through increasing Indigenous peoples’ awareness of dementia using culturally appropriate resources, this study’s products aim to change attitudes,

awareness, and understanding, and improve outcomes for caregivers and persons with dementia (Taylor et al., 2012).

The next section discusses cultural safety, health literacy, and health promotion in the development of culturally appropriate fact sheets relating to dementia.

Cultural Safety

Cultural safety moves beyond cultural sensitivity to an analysis of the power differentials inherent in health service delivery, institutional discrimination, and the need to fix these inequities through education and system change at the micro, institutional, and macro levels (Browne & Smye, 2002; Hart-Wasekeesikaw, 2009; Health Council of Canada, 2012). The term cultural safety originated in New Zealand when Maori people were dissatisfied with nursing care in the 1980s (Browne & Smye, 2002; Health Council of Canada, 2012). This model, originally developed by Dr. Irihapeti Ramsden, highlights how colonial, historical, and sociopolitical factors have led to health disparities in Indigenous communities (Allan & Smylie, 2015; Gerlach, 2012). As a result of health disparities in Canada, the Aboriginal Nurses Association of Canada has highlighted cultural safety as one approach to improve health outcomes (Hart-Wasekeesikaw, 2009).

Many frameworks for cultural safety address structural inequalities in health care delivery (Allan & Smylie, 2015; Gerlach, 2012; Hart-Wasekeesikaw, 2009; Kurtz et al., 2008; Loppie Reading & Wien, 2009). Many Indigenous people have suggested that cultural education should be provided to health care workers, and multiple health professional organizations and training programs have endorsed the adoption of cultural safety (Kurtz et al., 2008). Cultural safety can

be established when health care providers adapt to communication styles of Indigenous people, involve individuals in decision-making, ensure understanding of information and instructions, and accept beliefs formed by views alternative to the medical field (National Aboriginal Health Organization, 2008). Furthermore, the concept encourages health care providers to acknowledge cultures different from their own, examine their own culture, history, lived experiences, beliefs and attitudes, and proceed in a personal analysis of power relationships and practice (DeSouza, 2008). For example, to improve health outcomes, nursing education core competencies for Indigenous nursing were developed for faculty members and students. These competencies include postcolonial understanding, communication, inclusivity, respect, Indigenous knowledge, mentoring, and supporting students for success (Hart-Wasekeesikaw, 2009). Another example of the implementation of cultural safety is the accredited Indigenous Cultural Competency Training Program, which is offered online for physicians, counsellors, and psychotherapists (Allan & Smylie, 2015). Many health care providers follow ethical standards when it comes to culturally safe care; however, practices may be unintentionally discriminatory and attitudes may still come from a lack of awareness of historical and colonial policies that have shaped Indigenous health (Kurtz et al., 2008). It is crucial therefore to understand the role of cultural safety in health care delivery.

Efforts to improve cultural safety within the health care sector are also reflective of the Truth and Reconciliation Commission's Calls to Action (2015), where recommendations for health include providing cultural competency training and skill-based training in intercultural competency.

Additionally, one approach tied to provincial, territorial, and national policy initiatives to improve the health of Indigenous people of Canada is to have health services and programs directed by the Indigenous communities themselves (Allan & Smylie, 2015). A great example of

this autonomy is the Indigenous community-directed approach by the First Nations Health Authority in British Columbia, which defines the following seven directives to establish a new health governance relationship:

1) Community-driven, nation-based program, service, and policy development; 2) increased First Nations decision-making and control in health program and service philosophy, design, and delivery; 3) improved services that incorporate Indigenous ways of knowing; 4) fostering meaningful collaboration and partnerships between First Nations and non-First Nations organizations, as well as within communities; 5) developing human and economic capacity; 6) being without prejudice to First Nations' interests; and 7) functioning at an accountable, transparent, high operational standard (Allan & Smylie, 2015, p. 32).

There are lessons to be learned from other Indigenous health care stakeholders regarding cultural safety that can be applied in the dementia field. As noted in previous research regarding dementia, cultural safety is at the core of priorities to break through structural inequalities. For the dementia field it began when local Indigenous community representatives, Indigenous and non-Indigenous health care providers, and others involved in services for Alzheimer's disease and age-related dementias (ADRD) in Ontario met in Greater Sudbury to discuss ways to improve services to Indigenous people on- and off-reserve (Sutherland, 2007). The four priority areas arising from the 2007 roundtable discussion included: cultural sensitivity training for mainstream service providers; training in ADRD for Aboriginal service providers; culturally appropriate educational materials; and establishing partnerships with the Alzheimer's Society (Sutherland, 2007). The roundtable has led to collective efforts from a group of researchers who

are utilizing cultural safety frameworks to deliver effective, Indigenous-specific health services and care in dementia (Alzheimer's Association, 2016; I-CAARE, 2016a).

In addition to local efforts, national and international efforts to respond to Indigenous dementia care needs have been increasing alongside working groups committed to improving specific care and quality of life of Indigenous people with dementia and their caregivers (Canadian Consortium of Neurodegeneration and Aging [CCNA-CCNV], 2015; I-CAARE, 2016a). Adding to the Canadian arena of dementia research in Indigenous communities, the International Indigenous Dementia Research Network is committed to research of ADRD in Indigenous people (I-CAARE, 2016b). These establishments all have a common goal: to improve the experiences of Indigenous people and their caregivers when faced with ADRD.

Health Literacy and Cultural Care

Literacy, one of the 12 determinants of health (Public Health Agency of Canada, 2013), is seen as “an ideological construct, knowable as it is defined and practiced by different social and cultural groups...is constructed and enacted within social, cultural, and political contexts” (Smylie et al., 2006, p. S22). In Canada, health literacy is defined as “the ability to access, comprehend, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course” (Public Health Agency of Canada, 2014, n.p.). As a determinant of health, literacy has been shown to improve health outcomes of Indigenous peoples (Korhonen, 2006).

Indigenous conceptualizations of health literacy and cultural safety build on Indigenous understandings and perspectives (Smylie et al., 2006). First, Indigenous conceptualizations of

literacy can be seen as avenues of sharing information, whether it is through storytelling by an elder, or a health care worker from the community who understands the language and symbols of the materials. As observed by Taylor et al. (2012), the use of local languages, images, and participants can enhance the effectiveness of resource materials. To improve Indigenous health, health care providers can address cultural safety and health literacy by considering the languages, cultural and social influences, education levels, reading skills, language-comprehension skills, listening skills, background knowledge, concepts of health-related topics, numeracy skills, emotional and physical factors, and the individual's level of comfort in the health setting (Korhonen, 2006). Second, health care providers must understand the preferences of health communication. As health care providers search for effective ways to communicate with Indigenous peoples, it is important to deliver literature with clear communication that is locally and culturally relevant. Understanding the signs and symptoms of dementia or when to seek a diagnosis can increase health literacy, as it becomes more than a skill but also a demonstration for living a healthy lifestyle. Therefore, it is important to encourage proper avenues of health communication and culturally appropriate care when working with Indigenous people. This research therefore aims for improved health literacy to contribute to improvements in the determinants of health.

It is imperative to recognize that researchers have suggested working “in partnerships with community members to uncover multiple literacies; and build on these through building capacity in the community, developing literacy programs, and advocating for public policies that reflect community-defined aspirations” (Smylie et al., 2006, p. S25). To understand multiple literacies in Indigenous health, the researchers looked at the rainbow/holistic approach to Aboriginal literacy (George, 2003). This framework is a result of various literacies, namely: metacognition,

oral communication, differentiation, functional skills, 21st century skills, spiritual literacy, and critical literacy (George, 2009). Each literacy is connected to a different color of the rainbow: red, orange, yellow, green, blue, indigo, and violet. This multi-layered framework used to understand literacies can be reflected upon while developing health promotion programs by utilizing the teachings of the rainbow/holistic approach.

Recently, a discussion of multiple literacies led researchers to understand the pathways of health information dissemination and use by Indigenous community members in Ottawa, Ontario (Smylie et al., 2009). In this study, the community members were divided into the three constitutionally recognized groups: Inuit, Métis, and First Nations. Each group had its own preferences and unique values, practices, and social structures that influence the pathways of health information. The findings from this study suggest that each participant community has unique and context-specific values, practices, and social structures that influence the pathways of health information (Smylie et al., 2009), and are congruent with the author's examinations of the diversity of Indigenous peoples in Canada. These teachings have influenced this research project to study dementia fact sheets within a diverse Indigenous urban community, similar to the study by Smylie et al. (2009). The next section discusses the importance of considering health promotion relative to cultural care and health literacy.

Health Promotion

The World Health Organization states, "health promotion is the process of enabling people to increase control over, and to improve, their health" (World Health Organization, 1986, n.p.). Moreover, health promotion provides an alternative discourse to health separate from biomedicine, responding to sociological determinants of health (Mundel & Chapman, 2010). The

Ottawa Charter for Health Promotion categorizes health promotion interventions into developing personal skills, strengthening community action, creating supportive environments, building healthy public policy, and reorienting health services (Macaulay et al., 1997).

Health promotion in a cultural sense is appropriate when researching community culture and values (Macaulay et al., 1997). The three themes consistent with Indigenous frameworks and approaches to health promotion are participatory research, understanding local contexts, and ecological models (Smylie et al., 2009). From this, Indigenous-specific models have been developed at different levels of the health care system. One example is the Integrated Life Course and Social Determinants Model of Aboriginal Health, a conceptual framework developed to understand the relationship between social determinants and various health dimensions at the proximal, intermediate, and distal levels of the environment, structures, systems, and institutions (Loppie Reading & Wien, 2009).

Other Indigenous frameworks, based on wellbeing and holistic health, have been consistent in that they respond to the physical, emotional, mental, and spiritual dimensions of holistic health (Loppie Reading & Wien, 2009; Macaulay et al., 1997; Mundel & Chapman, 2010; Smylie et al., 2009). The medicine wheel model, a widely accepted and recognized symbol of Indigenous holism (Mundel & Chapman, 2010), is a framework used by many individuals, Indigenous researchers, health promoters, and organizations to develop programs and services aimed at improving health (George, 2003; Marsh, Cote-Meek, Toulouse, Najavits, & Young, 2015; NCCAH, 2013; Young et al., 2013). A culturally and community-appropriate model, it serves a foundation for local Indigenous people to live a good life, in other words, *Mnaamaadziwin*. This

review of the literature has provided the context for understanding the complexity of developing dementia health promotion materials.

Overview of Subsequent Chapters

The first chapter of this thesis has highlighted the significance, relevance, and background to this research study. It has also provided a foundation to understand the impacts of cultural safety, health literacy, and health promotion as it relates to the research question. The second chapter provides an overview of the theory and method used to implement this project. The theoretical framework of two-eyed seeing and tribal epistemology, both decolonizing approaches, is embraced throughout the research process. In addition, local understandings of health are referenced in the design of the theoretical framework.

The third chapter is written for peer-reviewed publication. Drawing on data from a study led by Dr. Jacklin and Warry, it describes the process and outcomes of the knowledge translation and exchange phase resulting in Indigenous dementia fact sheets used to inform this thesis research.

The fourth chapter is also written for publication as a qualitative article. This chapter contains the findings of this research in which the fact sheets are examined for their applicability to Indigenous caregivers and older adults in an urban Northern Ontario community. The appropriateness of nationally developed materials was explored at a local level, with an aim to understand the implications of Indigenous cultural diversity.

The fifth chapter is the conclusion that summarizes the key findings from the study, thereby providing a discussion of the challenges faced, the importance of Indigenous knowledge, knowledge translation and exchange, decolonizing methodologies in qualitative research, and

clinical and practical implications. Finally, concluding thoughts related to the direction of Indigenous health promotion, cultural safety, and health literacy are shared with respect to improving the health of Indigenous people through culturally safe fact sheets.

Conclusion

Placing equal focus on both Indigenous knowledge and Western biomedicine enforces cultural safety in that it responds to the inequities experienced by Indigenous people. If cultural safety is based on understanding the inequities in health service delivery (Health Council of Canada, 2012), then understanding Indigenous approaches to health literacy can benefit those who are developing culturally appropriate health material. To reinforce several of Korhonen's (2006) recommendations of Indigenous approaches to health literacy, the current research addresses cultural safety by considering the languages, reading skills, language-comprehension skills, background knowledge, concepts of health-related topics, and the individual's level of comfort in the health setting. This research also reinforces several of Smylie et al.'s recommendations for health literacy and cultural safety that respond to the needs of diverse Indigenous communities (Smylie et al., 2009, 2006).

Chapter 2: Theoretical and Methodological Approach

This research was guided by a community-based participatory action research (CBPAR) approach (Israel, Schulz, Parker, & Becker, 1998) and Indigenous health research ethical guidelines (Canadian Institutes of Health Research Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada [CIH], 2014; LaVeaux & Christopher, 2009). To foster a decolonizing lens to the methodology, two-eyed seeing (Marsh et al., 2015; Martin, 2012) and tribal epistemological (Kovach, 2009) approaches were integrated with the principles of CBPAR to inform the research process.

Community-Based Participatory Action Research Approach

This study includes a CBPAR approach to developing health promotion materials. CBPAR approaches have eight key principles that guide research affecting community health: (a) recognizing the community as a unit of identity; (b) building on the strengths and resources of the community; (c) facilitating a collaborative, equitable partnership in all phases of research; (d) integrating knowledge and action for mutual benefit of all partners; (e) promoting a co-learning and empowering process that attends to social inequalities; (f) involving a cyclical and iterative process; (g) addressing health from both positive and ecological perspectives; and (h) disseminating findings and knowledge gained to all partners (Israel et al., 1998).

In parallel with the CBPAR approach, article 9.12 of the Tri-Council Policy Statement explains that researchers and communities should consider applying a collaborative and participatory approach as appropriate to the nature of the research (CIH, 2014). Utilizing these principles as the guiding framework, this research sought to include the participants' recommendations, ideas, and suggestions for the adaptation of the fact sheets. This collaborative effort promoted

participant co-learning and empowerment. In addition to including participants' voices, an Indigenous advisory group was established to facilitate a collaborative, equal, and ongoing process in the research study. This group consisted of community stakeholders from different sectors of the community (i.e. formal caregiver, informal caregiver, elders, and support care workers). Discussions occurred on a bi-monthly basis. All steps of the research were discussed and approved by the IAG and findings were disseminated with their approval. Two members of the advisory group were also involved in a previous research study concerning dementia (Jacklin et al., 2014c), which allowed for some continuity between projects.

Indigenous Health Research Guidelines

Where research is likely to affect the welfare of an Indigenous population, researchers shall seek engagement with members of the relevant community or communities (CIH, 2014). The N'Swakamok Native Friendship Centre Life Long Care Program was the community partner for the research. Two program workers identified as key stakeholders acted as organizational collaborators. They aided in the development of the advisory group and recruitment of participants, and helped direct the research path. A verbal collaboration agreement with the N'Swakamok Friendship Centre was obtained on June 15, 2015 based on trust and respect. Following the collaborative agreement and a discussion of the research proposal, approval from the N'Swakamok Native Friendship Centre's executive director was obtained.

In addition to CBPAR key principles, nine recommendations emerged from a literature review regarding CBPAR amongst Indigenous communities: (a) acknowledging historical experience with research and health issues and working to overcome the negative image of research; (b) recognizing tribal sovereignty; (c) differentiating between tribal and community membership; (d)

understanding tribal sovereignty and its implications; (e) planning for extended timelines; (f) recognizing key gatekeepers; (g) preparing for leadership turnover; (h) interpreting data within the cultural context; and (i) utilizing Indigenous ways of knowing (LaVeaux & Christopher, 2009).

Through adopting the key principles of CBPAR outlined by Israel et al. (1998) and principles of CBPAR specific to Indigenous communities outlined by Laveaux and Christopher (2009), key collaborative approaches with the Indigenous peoples in the City of Greater Sudbury, Ontario were established to conduct ethical research. The Royal Commission on Aboriginal Peoples, Vol. 3 states, “the gathering of information and its subsequent use are inherently political. In the past Indigenous people have not been consulted about what information should be collected, who should gather the information, who should maintain it, and who should have access to it” (Royal Commission on Aboriginal Peoples, 1996a, n.p.). As a result, more Indigenous and non-Indigenous researchers are moving toward the CBPAR approach to work in partnership with community members.

Decolonizing a CBPAR Approach to Indigenous Health Research

This research was granted ethical approval by the Laurentian University Research Ethics Board (See Appendix A) and reflected the Tri-Council Policy Statement (CIH, 2014). Many Indigenous and non-Indigenous researchers have employed decolonizing methodologies in their research (Jacklin & Warry, 2012; Kovach, 2009; Smith, 2012; Smylie et al., 2009). In addition to the usual required Laurentian University ethics approval process, this research also incorporated several ethical aspects that are considered decolonizing. The CBPAR guidelines that assist with the decolonizing methodologies included in this research study are: 1) an approach that adopts

the key principles of CBPAR and those that are specific to Indigenous communities, 2) utilizing advisory group members that are familiar with previous work in this area, 3) forming an IAG that consists of support workers, formal and informal caregivers, and an elder, 4) situating the research within the Indigenous community of the City of Greater Sudbury at the N'Swakamok Native Friendship Centre, and 5) utilizing Indigenous methods of gaining consent such as offering tobacco and smudging (explained later in this chapter).

Smith (2012) states that there is a need for Indigenous peoples to become the researchers because questions are formed differently, priorities are ranked differently, problems are defined differently, and people participate on different terms. In addition, the First Nations Centre (2007) also asserts that Indigenous researchers are often the best choice to research their own peoples, as they have a greater understanding of their communities and can contribute Indigenous knowledge, strength, and validity to the research. This approach is similar to “insider” research, where researchers conduct research in their home communities (Innes, 2009). Innes (2009) states that drawbacks from Indigenous researchers working in their own communities can include perceived bias in research findings, excluding other subgroups of the population, over-familiarity with the participants, and having difficulty distancing their intellectual and emotional selves from the research group. The author recognizes that there is an ongoing debate about the significance of insider research, and has taken precautions to reduce that impact on this study and the community. Any biases are explained below, as researcher preparation is a crucial step in creating the decolonizing framework.

Efforts to establish decolonizing research methodologies have been increasingly common amongst Indigenous and non-Indigenous researchers (Braun, Browne, Ka'Opua, Kim, &

Mokuau, 2014; Jacklin & Warry, 2012; Kovach, 2009; Smith, 2012; Smylie, Kaplan-Myrth, & McShane, 2009). Decolonizing methodologies aim to empower Indigenous elders and researchers (Braun et al., 2014). Empowerment can be a result of applying an Indigenous knowledge system that reflects the beliefs of the community the researchers are engaged in (Smith, 2012). Furthermore, Smylie, Kaplan-Myrth and McShane (2009) reviewed health promotion literature and policy and found three themes related to decolonizing frameworks: a) participatory research and health promotion, b) understanding local contexts and health promotion, and c) ecological models of health promotion.

There have been many Indigenous and non-Indigenous researchers discussing what it means to decolonize research (Kovach, 2009; Smith, 2012), meaning it is difficult to find an exact definition of this type of methodology, nevertheless, there are several reasons why this methodology is beneficial. These benefits include: embracing the history of colonization; using Indigenous research methodologies; reclaiming Indigeneity; and rediscovering ancestral traditions and cultural values (Marsh et al., 2015). In other words, decolonizing can be considered as a healing journey of the relationship between Indigenous people and the research realm.

Marsh, Cote-Meek, Toulouse, Najavits and Young (2015) explain that one goal of decolonizing research is “to break free from the Western paradigm of research that is often more focused on the discovery and interpretation of facts” (p. 3). As an Indigenous researcher, the author finds it extremely important if difficult to maintain her cultural identity throughout her research while preserving a cultural epistemic position within powerful institutions like universities (Kovach, 2009). It is extremely important to maintain academic regulations and protocols of research

within the institution and it is the researcher's responsibility to search for knowledge by looking at what other researchers have done. There are various studies that have used a decolonizing theoretical approach to their research.

Based on interviews with Indigenous researchers, Kovach (2009) conceptualized a tribal methodology by identifying a theoretical positioning as having its basis in "critical theory" with a decolonizing aim. In addition, Smylie et al. (2009) embedded their study on the pathways of health knowledge in a "critical" decolonizing Indigenous theoretical framework. Furthermore, a case study of the Garden Project and a study of Indigenous youth perceptions about community health were informed by "community-based participatory research" methodologies (Big-Canoe & Richmond, 2014; Mundel & Chapman, 2010). All studies have applied a decolonizing approach and can form a basis for the understanding of health promotion in the Indigenous context. In the next two sections the decolonizing methodology used in this research, specifically two-eyed seeing and Kovach's *Nêhiyaw Kiskêyihitamowin*, are described and outlined in relation to this research project.

Two-Eyed Seeing

Two-eyed seeing is an Indigenous decolonizing approach to research developed and proposed by Mi'kmaw elders Albert and Murdena Marshall (Marsh et al., 2015; Martin, 2012). Indigenous dementia fact sheets were developed using a decolonizing framework known as two-eyed seeing (Estey et al., 2008; Martin, 2012) and were guided by a cultural safety approach (Gerlach, 2012; Hart-Wasekeesikaw, 2009). Albert and Murdena Marshall suggest that two-eyed seeing is understanding, acknowledging, and respecting a diversity of perspectives of the world "without perpetuating the dominance of one over the other" (Martin, 2012, p. 24). The methodology

applied to research using this approach requires an innovative and unique understanding of both Indigenous cultural values and beliefs and Western biomedical knowledge.

The project data informing the knowledge translation phase reported on in this thesis resulted from a community-based research study led by Drs. Jacklin and Warry with six Indigenous research sites in Ontario. The authors' contributions began at the knowledge translation stage when she joined Dr. Jacklin's lab as a student and trainee. To ensure appropriate knowledge translation strategies at this stage, the process in the first phase of this project included: 1) an analysis of key Indigenous beliefs about dementia from a previous foundational research study, 2) an academic literature review, 3) an environmental scan of health promotion resources, and, significantly, 4) ongoing consultations with various Indigenous community health leaders, collaborators, and experts and ongoing consultation with an Indigenous knowledge keeper. Chapter 3 will outline how two-eyed seeing was used to combine data useful in the development of two culturally appropriate fact sheets.

Kovach's Nêhiyaw Kiskêyihitamowin

The research undertaken solely for the purposes of this Master of Arts thesis builds on the previous work led by Drs. Jacklin and Warry. It is here that the author fully embeds her approach as an Indigenous scholar. *Nêhiyaw Kiskêyihitamowin* originated from Plains Cree knowledge and was developed as a conceptual framework and methodology that is easily translatable to non-Indigenous researchers (Kovach, 2009). In the second phase of this project, *Nêhiyaw Kiskêyihitamowin* was used as a guiding tool to develop a theoretical framework. It is easily transferable to other tribal groups of the Indigenous population and includes the qualities of wholistic epistemology (i.e. *Anishinaabemowin*), story, purpose, the experiential, tribal ethics,

tribal ways of gaining knowledge, and an overall consideration of the colonial relationship (Kovach, 2009). Each of these qualities is also evident within the Anishinaabek culture. These key qualities are woven intricately throughout the research process of the second phase as if blanketing the data, themes, and research processes. This methodology is guided by Kovach's *Nêhiyaw Kiskêyihitamowin* as a decolonizing theoretical framework, which includes: (a) tribal epistemology, (b) decolonizing and ethical aims, (c) researcher preparations involving cultural protocols, (d) research preparation involving standard research design, (e) making meaning of knowledge gathered, and (f) giving back.

Tribal epistemology. To discuss Kovach's framework in a logical fashion while answering the original research question, the author returns to local tribal epistemologies as a foundation to discuss local Indigenous knowledge. Kovach's framework has been adapted into an *Anishinaabemowin* epistemology to reflect the beliefs of the Anishinaabek people of Greater Sudbury, Ontario. Stanley Peltier, a community member who is committed to rejuvenating the Anishinaabe language, described the philosophy of *Anishinaabemowin* eloquently at Laurentian University while participating as a learner for a presentation given by Dr. Margaret Kovach (October, 2015). His explanation (although not verbatim), with consent to share, is as follows:

When speaking of Indigenous knowledge... *Anishinaabemowin* is how the language is described by the Anishinaabek people of the City of Greater Sudbury and the region.

"*Anishinaabe*" is the word to describe the type of people, as in the communion of many tribal groups of the region. "*Mo*" is the part of that word that entails communication is expressed at a higher level through feelings and beliefs. "*Win*" makes it a philosophy. So

when we speak about the philosophy of the Anishinaabek people, it is highly linked to the language, also known as “*Anishinaabemowin*”.

This philosophy was used to reflect local Indigenous knowledge and epistemology and assisted in understanding the many facets of the diverse culture of Anishinaabek people. To use *Anishinaabemowin* as the philosophy, proper ethical conduct is deemed to reflect the Anishinaabek traditions of the Seven Grandfather Teachings (see Preface for a reflection of these teachings in this work). Kovach’s framework, specifically during research preparation, was adapted to include the medicine wheel, an Anishinaabek holistic model. The medicine wheel model, introduced in chapter 1 as a holistic health promotion model for Anishinaabek people, is a “widely accepted and recognized symbol of Indigenous holism” (Mundel & Chapman, 2010, p. 167), and is a framework used by many individuals, Indigenous researchers, health promoters, and organizations to develop programs and services aimed at improving health (George, 2003; Marsh et al., 2015; NCCAH, 2013; Young et al., 2013). Using this model ensured a decolonized lens, as local meaning of health was applied to answer the research question. In framing this research study within an Anishinaabek philosophy, it was anticipated that culturally appropriate health promotion materials could speak directly to the population it serves.

Decolonizing and ethical aim. Decolonizing and ethics are crucial components of Indigenous research and crucial in Kovach’s model (2009). Applying two-eyed seeing and adapting Kovach’s methodology in this research required ethical considerations important when working with Indigenous communities. See the summary above.

Researcher preparation. Researcher preparation is the situating of the self in the appropriate environment and is important when seeking knowledge and establishing connections with the research. Researcher preparation is the experiential aspect of the research process

(Kovach, 2009) and was completed by looking within through the journaling of significant dreams, challenges faced throughout the research, concerns regarding the data analysis, new perspectives developed by the data, visioning, affirmations from guides/community members, and offering tobacco. The author also situated herself in the appropriate environment, such as frequenting the friendship centre, nursing homes, and cultural gatherings, seeking Indigenous knowledge and establishing connections with the research.

Researcher preparation was a process and reflected the researcher's abilities to move forward with this exploration. Furthermore, special attention was given to intuition, conversations with community members, and the Anishinaabe teachings of humility, bravery, honesty, and respect. Affirmations from community members also guided this journey, and put focus on the process (See Epigraph). Additionally, the author viewed the exchanging of tobacco with her stakeholders as a respectful, necessary event that precipitated the belief that the information shared was trustworthy, honest, respectful, and greatly meaningful for all those involved.¹

Research preparation. Research preparation is the process of preparing the community for the research (Kovach, 2009). It is different from researcher preparation in that it is more than the personal journey of the process. Although both can be done simultaneously, research

¹ Tobacco teachings that have been given to the researcher throughout this process have assisted in gaining a clear vision of her role and responsibility as an Anishinaabe-kwe researcher. These teachings, although not fully transcribed here in order to protect the knowledge of her teachers, are diverse and varied; however, have a common belief that this sacred medicine is the connection between physical and spiritual beings. Tobacco leads and travels and helps with guidance (Personal communication with Perry McLeod-Shabogesic). Anyone who makes a commitment and then acts on that commitment will be aided by guiders, teachers, and spiritual protectors to watch over the traveler (Lane Jr., Bopp, Bopp, & Brown, 2003). When offering tobacco to the Creator and others, one holds it in their left hand, as it is closest to their heart. They pray for guidance, with gratitude, to be given the signs to walk the right path in their endeavors. As the researcher offered tobacco throughout the research process, she was also observant of her surroundings and sought direction based on intuition. This act of spirituality was the biggest impact in how she was to approach this research. This work was given the positive spirit it needed by offering tobacco to those who were interested in helping. Tobacco was offered to the participants, Indigenous advisory group members, and elders and ensured that proper conduct of sharing information was established. Not one participant refused the tobacco as an offering for the exchange of gifts by way of sharing stories.

preparation was done by developing an IAG and recruiting interested participants. Furthermore, in an inquiry into research methodologies conducted with Indigenous elders, Braun et al. (2014) found that qualitative methods are useful when examining the traditional roles of leaders, keepers of history and cultural knowledge, and mentors to the young. This finding is congruent with the current study as participants expressed that elders are to be consulted when developing culturally appropriate health promotion materials. Participants of the research study were approached ethically and culturally appropriately, through snowball sampling, offering tobacco, and smudging. The informed, voluntary decisions of the participants were respected, which minimized the risks and maximized the benefits to them (College of Nurses of Ontario, 2009). The procedures for consent for the caregiver and the older adult are found in Appendices B and C.

Community engagement. The Tri-Council Policy Statement (CIH, 2014) indicates that community engagement is a process of establishing a connection between the researcher and the Indigenous community relevant to the research project; other researchers have indicated the use of IAGs in their studies (Latycheva et al., 2013; Young et al., 2013). Local research advisory boards can help ensure that the research questions, methods, and dissemination are community driven and are composed of respected and knowledgeable community members (Jacklin & Kinoshameg, 2008; LaVeaux & Christopher, 2009).

Community engagement took many forms in this project, including research review, approval, and joint planning with the N'Swakamok Native Friendship Centre Life Long Care Program and monthly to bi-monthly dialogues with the IAG. The advisory group included two support care workers who are familiar with the population, an informal caregiver who has experience with a

family member with memory loss, a formal caregiver who provides services in a dementia/Alzheimer's section of a long-term care facility, and an esteemed Métis elder of the community. The benefits and appropriateness of the approach to the research (for example planning, data collection, analysis, interpretation, and dissemination) were discussed at bi-monthly meetings throughout the project.

Recruitment. Snowball sampling was deemed the appropriate recruitment strategy (Cueva, Dignan, & Kuhnley, 2012; Finkelstein et al., 2012). Members of the advisory group, and subsequently the participants, promoted the project by word of mouth. The project was also promoted through advertisements posted throughout the City of Greater Sudbury, Aboriginal organizations, the Société Alzheimer Society Sudbury-Manitoulin, and bulk e-mail at Laurentian University. The recruitment protocol involved discussion of the project, review of the information letter, and the signing of the consent form (Appendices B and C). In keeping with Anishinaabek protocol, cloth and tobacco were offered to honour the gifts the participants will be providing to the research project. The acceptance of the cloth and tobacco was an act of agreement to follow through with the request. The participants were encouraged to pray with the cloth and tobacco to ensure their insight about the topic is with good intention and is guided by spiritual vision. If participants did not wish to accept the offerings, they were encouraged to contact the researcher to discuss alternatives such as offering a small, hand-made item.

Incentive. Light snacks (reflecting the preferences/diets of participants) and refreshments were provided to focus group participants. This form of incentive is meant to encourage an open atmosphere amongst the participants and researchers as it provided an opportunity for discussion, relationship building, and trust. Additional incentives included \$10 gift cards for food through a

local company called The Good Food Box. This incentive was provided at the end of the focus groups and interviews to reflect ethical recruitment strategies by avoiding undue compensation or inducements to a potentially vulnerable population.

Sample and inclusion criteria. The snowball strategy resulted in a slow start and low interest from community members. Therefore, the process required flexibility in the research strategy. It was necessary to adjust the eligibility criteria for focus group members to include participants who fit the criteria for one-on-one interviews. As more interviews were conducted, momentum improved and additional participants for a focus group were identified. The research involved conversations with older Indigenous community members and with those caring for someone with dementia. These conversations were through focus groups and one-on-one interviews.

Focus group participants. Two focus groups brought together older Indigenous males [4] and females [4] (55 or older) who expressed an interest in the topic and included three participants who were caregivers. Indigenous older adults are defined as 55 years and older (Health Council of Canada, 2013), therefore adults under the age of 55 were initially excluded from the focus groups; however, given recruitment challenges younger Indigenous caregivers were not excluded. The participants were not asked to disclose their age, only to confirm that they were in the age range that enabled them to participate (See Appendix I). Anyone who self-reported as having dementia, as diagnosed by a health care practitioner, was excluded. This criterion was established to avoid triggering any negative responses about dementia.

One-on-one interview participants. Four female caregivers were interviewed. The caregivers were providing or had provided care for a family member/friend/neighbor with

dementia living in the City of Greater Sudbury. In addition, given the limited number of participants, one older adult male who was interested in speaking further about the topic (but who was not a caregiver) was interviewed. Caregiver age range is broad and therefore caregivers of any age were encouraged to participate in the interviews. Minors under 16 years of age were excluded from this study.

Gathering knowledge. Data collection occurred between November 2015 and January 2016 until saturation was met. Saturation is the term used when rereading the data reveals no further information or new topics and follow-up interviews reveal no new information (Lanting et al., 2011). Data collection involved using qualitative methods in the form of focus groups and interviews to explore the value, appropriateness, and relevance of the dementia fact sheets at the local level. The fact sheets were presented in a generic form, without graphics, color, images, or icons. See Appendices D and E for the fact sheets that accompanied the focus group and one-on-one interviews (Jacklin, Warry, Viau, Webkamigad, & Blind, 2015a, 2015b). The participants were given a conversation guide along with the fact sheets at the time they consented. This allowed them to review the material prior to the focus group or one-on-one session. The conversation guide for the focus groups and interviews included questions that were descriptive, broad, open-ended, and semi-structured. See Appendix H for the conversation guide. The focus groups and interviews were recorded via digital recorder and a journal.

Focus groups. Other studies have used focus groups with Indigenous peoples to obtain information regarding health materials (Lindeman et al., 2010; Schoen et al., 2010), pathways of health knowledge (Smylie et al., 2009), and care (Jacklin et al., 2014; Smith et al., 2011). Confidentiality was explained during the consent process and before each focus group. An oath

of confidentiality was gained through the presence of the N'Swakamok Native Friendship Centre's eagle staff and the author's sacred bundle in the room. The eagle staff and sacred bundle (which includes a smudge bowl, an eagle feather, and the four sacred medicines: sage, sweet grass, cedar, and tobacco) allowed for an open dialogue. The focus groups began with a smudge with all participants, except one participant who declined. This was respected, and the participant was still included in the focus group session. Participants were also given the option to participate in prayer prior to the discussion.

One-on-one interviews. Studies have utilized one-on-one interviews to obtain information about care, health materials, and pathways of health knowledge in Indigenous communities (Jacklin et al., 2014; Lindeman et al., 2010; Smylie et al., 2009). One-on-one interviews with the caregivers were preferred to accommodate for potentially problematic scheduling of a focus group and to provide flexibility of timing in relation to their caregiving responsibilities. Furthermore, the interviews were done at locations picked by the participants (for example, their homes, the university).

Making meaning.

Data analysis. A qualitative thematic analysis (Luborsky, 1994) was used in this study to categorize and analyze participant dialogues in relation to the conversation guide. This analysis involved entering, reviewing, and organizing the transcribed data in a qualitative software program, NVivo 10, and resulted in thematic identification. Each focus group and interview was imported into the software as the source of information. The conversation guide was then imported into the software and organized by question, which became the initial nodes. A word frequency cloud was developed to identify common words found throughout the transcripts, for

example: medicine wheel, language, and understand. The function of the software was to be able to access the information (such as a common word or phrase) and place the data into a node to restructure the data that resulted in the emerging themes. The data were reviewed and restructured several times before the final themes were identified.

Validation. As a researcher and an Anishnaabe-Kwe (Indigenous woman), it is a humbling experience to listen to the stories of the participants and be able to share them with the world. The stories are significant, and help to rewrite history (Smith, 2012). Member checking, or validation, is a test to identify if the researcher's account of the information shared is true to the participants' recollections (Jaffe & Miller, 1994). Therefore, it is imperative that their accounts are correct in all ways and the intent of their voice is heard. For that reason, member checking with the participants of all focus groups and one-on-one interviews was conducted within two months of data gathering through individual transcript reviews. Validation was also considered through discussion of the themes with the advisory group. This group discussion aimed to explore the meaning of the identified themes, as well as to guide the dissemination plan.

Giving back. Giving back to the community, as identified by Kovach's framework, is an important final step in this process. It ensures that the research project will encourage empowerment and self-determination of the community through involvement in the research.

Knowledge dissemination. Dissemination involved two strategies. At the local level, and in keeping with Anishinaabek protocol, knowledge dissemination occurred through a community feast and presentation on the research results. Academic dissemination included the thesis and the two articles prepared for publication included in this thesis. Furthermore, three academic presentations about the project were delivered at separate conferences organized by the

International Association of Gerontology and Geriatrics, the Alzheimer's Association International Conference, and the Canadian Institute of Health Research.

Conclusion

This research responds to the expressed need by Indigenous caregivers and older adults for dementia education that addresses their languages and cultures (Jacklin, Pace, & Warry, 2015). By addressing the research question: “How can we develop health promotion materials about dementia to meet the needs of Indigenous peoples living in an urban Northern Ontario community?”, the researcher relied upon the theoretical framework of the CBPAR approach, with additional considerations for research in Indigenous communities. Using a decolonizing lens in the design and methodology, as outlined in the following two papers, two CBPAR approaches were used to guide the development of culturally appropriate dementia fact sheets. The current study corresponds well with other CBPAR approaches and decolonizing researchers' beliefs of how to conduct research that responds to the needs of Indigenous communities in terms of two-eyed seeing and tribal epistemological approaches.

Benefits of this research include increased understanding of Indigenous caregivers and older adults about dementia through contributing to evidence-based research and knowledge translation in culturally safe care. Benefits of this research also include influencing policy and decision-makers' approaches to the development of health promotion material for Indigenous peoples. The Life Long Care Program support workers and any other organizations wishing to utilize the developed material will have access to it through a website (www.i-caare.com/factsheets). Furthermore, overall benefits of this research are that it addresses

knowledge translation, health promotion, health literacy and cultural safety in the Indigenous context.

Chapter 3: An Approach to Improve Dementia Health Literacy in Indigenous Communities

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Abstract

Purpose: This project aims to improve health literacy in Indigenous communities through the development of culturally relevant health promotion materials on dementia that bridge the gap between Indigenous and Western perspectives of the illness. **Design and Methods:** The research team worked in partnership with Health Canada's First Nations and Inuit Home and Community Care Program (FNIHCC) and consulted with Indigenous elders to utilize a two-eyed seeing framework that draws upon Indigenous knowledge and Western biomedicine. A consolidated review of materials and research involving Indigenous perspectives of Alzheimer's and age-related dementias led to the development of two culturally appropriate fact sheets. **Results:** This unique and innovative process resulted in two Indigenous-specific fact sheets on dementia care. The researchers discussed how the material incorporated clear and concise biomedical information with Indigenous knowledge for a population of older Indigenous adults, accounting for language usage, diverse Indigenous cultures, and literacy levels. **Implications:** This project provides a foundation for evidence-based knowledge translation in relation to cultural safety in dementia care. Specifically, the researchers outline how health care providers can develop culturally appropriate health promotion material, thus increasing Indigenous cultural understandings of dementia and health literacy.

Key Words: Cultural safety, knowledge translation, two-eyed seeing, Indigenous knowledge, health promotion, First Nations

Introduction

There are roughly 1.4 million Indigenous people in Canada (Statistics Canada, 2013a), which includes First Nations, Inuit, and Métis (Health Council of Canada, 2012). There are 618 First Nations in Canada, with distinct values, beliefs, and language/dialects (Aboriginal Affairs and Northern Development Canada, 2015). There have been reports that Indigenous people experience the poorest health of any group of people in Canada (Health Council of Canada, 2012; Royal College of Physicians and Surgeons of Canada, 2013); however, these reports are fragmented and do not account for the ways in which Indigenous people perceive health (Loppie Reading & Wien, 2009). Social determinants of health such as structural violence, racism, and discrimination are amongst the socio-economic health disparities (Allan & Smylie, 2015) and have led to chronic health conditions being experienced by Indigenous peoples at higher than then average rates, which also increases their risk of developing dementia (Walker & Jacklin, forthcoming 2017). Dementia is an umbrella term for a variety of brain disorders with symptoms such as memory loss, problems with judgement and reasoning, and changes in mood and behaviour, and these symptoms include issues with brain function that can affect a person's ability to function at work, in relationships, or in everyday activities (Alzheimer Society of Canada, 2010; Warren, Shi, Young, Borenstein, & Martiniuk, 2015).

Similar to the non-Indigenous population, the Indigenous older-adult age group (age 65 years and over) is projected to increase rapidly. There is a projected growth of the Indigenous population aged 65 years and over from 4.7% in 2006 to an expected 14.5–15.4% by 2031 (Malenfant & Morency, 2011). Increasing age is the most significant irreversible factor in the development of dementia. There have been very few studies that address the rates of dementia in Indigenous people (Warren et al., 2015); however a study suggests that the age-standardized

prevalence of dementia in First Nations in Alberta in 2009 was 7.5 per 1,000, compared to non-First Nations, which was 5.6 per 1,000 (Jacklin, Walker, & Shawande, 2013). Moreover, Walker and Jacklin suggest that there will be a fourfold increase in the number of First Nations people over age 60 with dementia in 2031, compared to non-First Nations population, who will have a 2.3-fold increase (Walker & Jacklin, forthcoming 2017).

Research shows a lack of basic dementia care resources in Canada, especially Indigenous-specific dementia care literature (Finkelstein et al., 2012). Caregivers, older adults, nurses, personal support workers, and researchers often request Alzheimer's and age-related dementias health promotion materials targeted to the Indigenous peoples in Canada but none exist (Jacklin et al., 2014; Pace, Jacklin, & Warry, 2013). The purpose of this article is to outline a unique and innovative process resulting in two Indigenous-specific fact sheets on dementia care for caregivers, older adults, people with dementia, and community health care providers.

Background

Canadian literacy scores are generally lower for Indigenous people and older adults, and 60% of adults and 88% of older adults are thought not to have adequate levels of health literacy (Chiarelli & Edwards, 2006; Public Health Agency of Canada, 2014). Health literacy is defined as an individual's ability to access, comprehend, evaluate, communicate, and use health information and services as a way to promote, maintain, and improve health and make good health-related decisions in a variety of settings across the life-course (Korhonen, 2006; Nielsen-Bohlman, Panzer, & Kindig, 2004; Public Health Agency of Canada, 2014; Rootman & Ronson, 2005; Vass, Mitchell, & Dhurrkay, 2011). Furthermore, literacy, one of the 12 determinants of

health (Public Health Agency of Canada, 2013), “is constructed and enacted within social, cultural, and political contexts” (Smylie et al., 2006, p. S22).

Increased understanding of health disparities has led to an ongoing priority among policy makers to improve health literacy for Indigenous peoples in Canada (Chiarelli & Edwards, 2006; Smylie et al., 2006), yet very few studies explain how Indigenous approaches to health literacy are utilized (Vass et al., 2011). Health care providers can address cultural safety and health literacy by considering the languages, cultural and social influences, education levels, reading skills, language-comprehension skills, listening skills, background knowledge and concepts of health-related topics, numeracy skills, emotional and physical factors, and the individual’s level of comfort in the health setting (Korhonen, 2006). The researchers of this paper anticipate that addressing access to health literacy for Indigenous people will improve health care and minimize the effects of structural barriers.

In addition to health literacy, addressing cultural safety in the development of health promotion materials can also reduce the structural barriers faced by Indigenous people. Cultural safety, a model originally developed by Dr. Irihapeti Ramsden, highlights how colonial, historical, and sociopolitical factors led to health disparities in Indigenous communities (Allan & Smylie, 2015). Placing equal focus on both Indigenous knowledge and Western biomedicine enforces cultural safety in that it responds to the inequities experienced by Indigenous people.

Decolonizing health information to improve health literacy requires an understanding that there are separate belief systems within different cultural groups that may contrast with Westernized biomedical beliefs (Nielsen-Bohlman et al., 2004), and requires the efforts of health professionals to understand the culture and everyday experiences of Indigenous peoples (Jacklin

& Warry, 2012). Indigenous people in North America are recognized as holding culturally specific understandings of dementia that influence health care seeking behaviour and caregiving (Henderson & Henderson, 2002; Jacklin & Warry, 2012; Lanting et al., 2011). In many cases, Indigenous peoples connect memory loss and confusion associated with aging as “normal”, “natural”, and “accepted” (Jacklin, Pace, & Warry, 2015), or “supernormal” (Henderson & Henderson 2002). Dementia knowledge associated with Western biomedical definitions may also be present (Hulko et al., 2010).

Culture, life experiences, and religious beliefs may affect Indigenous peoples’ understanding of aging, dementia, and perceptions of the caregiving role (Hayter et al., 2008; Luong et al., 2014). Pace (2013) argues that an appropriate understanding of personhood is important when developing culturally safe dementia care such as fact sheets. Furthermore, a discussion of the concepts of person-centred language and personhood is necessary to maintain the respect and recognition towards Indigenous people, older adults, and caregivers. There are variations in the form and function of personhood: egocentric (personal history, accomplishments), sociocentric (family, clan, lineage, community), ecocentric (environment, ecology), and cosmocentric (ancestors) cultural configurations of the self (Kirmayer, 2007). The Alzheimer Society (2012) puts forth personhood as the first principle in the support of person-centred language:

“A standing or status that is bestowed upon one human being by others in the context of relationship and social being. It implies recognition, respect and trust”
(Alzheimer Society of Canada, 2012, p. 2).

The concepts of person-centred care and personhood are questionable when applied to the Indigenous context. Person-centred care and personhood are egocentric, focus on the individual,

and may contradict with Indigenous ways of life. Care for older adults in the Indigenous context is ideally provided by the family and grounded in traditional values (Jacklin et al., 2015), thus supporting a dynamic, relational view (Morhardt & Spira, 2013) grounded in collectivism, love, reciprocity, and the understanding of the circle of life. Peoplehood, a concept developed in the 1980s by Robert K. Thomas, identifies four factors that imply how Indigenous people behave: language, sacred history, ceremonial style (formerly religion), and land (Holm et al., 2003). Understanding the applicability of concepts of peoplehood, personhood, and person-centred care can help to determine the information that is given in dementia health promotion fact sheets. In this paper, the context of peoplehood is preferred as it supports an ideology of relational, sociocentric care.

Methods

Indigenous dementia fact sheets were developed using a decolonizing framework known as two-eyed seeing (Estey et al., 2008; Martin, 2012) guided by a cultural safety approach (Gerlach, 2012; Hart-Wasekeesikaw, 2009). Two-eyed seeing is a framework proposed by Mi'Kmaq elders Albert and Murdena Marshall (Martin, 2012), who suggest that two-eyed seeing is understanding, acknowledging, and respecting a diversity of perspectives of the world “without perpetuating the dominance of one over the other” (Martin, 2012, p. 24). This approach offers a unique and innovative way of developing material that combines Indigenous and Western knowledge of dementia. To ensure appropriate knowledge translation strategies, the process included: 1) an analysis of Indigenous beliefs about dementia from a previous foundational research study, 2) an academic literature review, 3) an environmental scan of health promotion resources, and, significantly, 4) ongoing consultations with various Indigenous community health

leaders, collaborators, and experts and continuing consultation with an Indigenous knowledge keeper.

The research team began with an analysis of findings from a previous research study “Perceptions of Alzheimer’s Disease and Related Dementias among Aboriginal Peoples in Ontario” – in this paper referred to as the Perceptions Project. This study focused on the perspectives of dementia in six communities in Ontario, Canada (Jacklin, Warry, & Blind, 2014a, 2014b, 2014c, 2013; Jacklin, Warry, & Dietrich, 2013; Pace, Jacklin, & Warry, 2013): Sudbury, Thunder Bay, Ottawa, Six Nations, Moose Cree First Nation, and a combined group of Anishinaabek First Nations on Manitoulin Island (see Figure 1). The purpose of the Perceptions Project was to engage Indigenous people with dementia, their caregivers, health care providers, Indigenous knowledge keepers, and other key informants to gain diverse knowledge about the attitudes, beliefs, and behaviours related to dementia. The authors reanalyzed the data focusing on early warning signs/symptoms of dementia and cultural understandings of dementia with the intent of transitioning the findings into various health promotion materials. Drawing on the data specifically for the creation of the fact sheets, the location of the interviews, participant codes, key ideas, key quotes, and notes were captured in data tables for each community. In addition, the authors discussed the crucial themes from each location and then consolidated the data into two tables. One table focused on Fact Sheet #1: the cultural understandings of dementia, while the other covered Fact Sheet #2: the early warning signs and symptoms. Both tables included important points and examples and quotes from all six communities.

The next step involved reviewing published literature. In this step the authors were interested in ensuring that the findings from the Perceptions Project would have national relevance and be

applicable in other provinces and First Nations. The authors drew upon and updated an existing literature review prepared in 2012 by one of the authors for First Nations and Inuit Health (Jacklin & Walker, 2012). The literature review was updated to include references through 2016 and focused on: Indigenous-specific prevention and awareness campaigns; cultural understandings of dementia; dementia risk factors and co-morbidities; the detection, screening, and diagnosis of the illness; the incidence, prevalence, and rates of dementia amongst Indigenous Canadians; and the cultural considerations in diagnosis and care. Academic literature falling under the “cultural considerations in diagnosis and care” and “cultural understandings of dementia” were further analyzed and placed into tables that included the reference, key points, key quotes, and country of origin.

The third step involved an environmental scan of relevant unpublished web-based documents and paper-based resources. The authors extracted findings that were relevant to the health promotion materials related to dementia in Indigenous peoples in Canada, the United States, New Zealand, and Australia. The environmental scan also allowed a review of specific health promotion material on various topics (e.g., diabetes, cancer) developed for Indigenous people in Canada to assess for readability, design, visuals, color, and the overall presentation of the information.

Finally, collaborations were a key mechanism to ensure appropriateness and cultural safety. Ongoing collaboration between the principal investigators (KJ, WW) with Health Canada’s First Nations and Inuit Home and Community Care program (FNIHCC) occurred throughout the project. Stakeholders included First Nations FNIHCC program managers from across Canada. The principal investigators and FNIHCC program staff shared the common goal of improving

the cultural relevance of materials and programming in the area of Indigenous dementia care. The collaboration involved shared financial contributions, an ongoing dialogue on the research process and outcomes as well as dissemination strategies. The collaborative approach included two methods: (1) to facilitate the inclusion of a policy and programming perspective the PIs met bi-monthly with program staff from the FNIHCC office, and (2) during the final month of the project the principal investigators were invited to the FNIHCC program community stakeholders meeting where the two fact sheets were presented and discussed in relation to their applicability at a national level. Significantly, the two-eyed approach fostered a close collaboration with a project elder, Jerry Otowadjiwan, to develop and refine the resources. Elder Otowadjiwan is a life-long resident of Manitoulin Island, Anishinaabemowin language specialist, Fourth Degree Midewin, and Mishomis, and he provided guidance regarding the medicine wheel and life cycle models (Jacklin, Warry, Blind, Jones, & Webkamigad, 2016).

This project is unique in that two-eyed seeing helped to combine Indigenous with biomedical knowledge to develop the content in the fact sheets. This is accomplished by using the findings from the community reports to populate the fact sheets, followed by integrating published literature as appropriate. The environmental scan identified best practices in health promotion, as well as gaps in dementia materials aimed at Indigenous people in Canada. The authors relied on consultations with FNIHCC partners and Elder Otowadjiwan to strengthen and verify that the content and language used was culturally appropriate and relevant. Lastly, the project team reviewed drafts of the fact sheets with consideration for recommendations from an Alzheimer Society of Canada document titled “Person-Centred Language” (Alzheimer Society of Canada, 2012) and sought a literacy level of five using the Flesch-Kincaid Index feature on Microsoft

Word (described in results). Special attention was given to word selection, complex sentences, and sentence structure.

Results

This multi-stage knowledge translation process resulted in two polished fact sheets titled “What is dementia? First Nations Perspectives and Cultural Understandings”, and “Signs and Symptoms of Dementia: A First Nations Guide” (See Appendices F and G). The material incorporated biomedical information with Indigenous knowledge for a population of older Indigenous adults in Canada.

Fact Sheet 1: What is dementia? First Nations perspectives and cultural understandings.

The findings from the Perceptions Project and the literature review found that Indigenous cultural and Western understandings of dementia differ. Most Indigenous people accept memory loss and confusion as a normal part of the aging process and these understandings are intimately connected to Indigenous values and worldviews (Hulko et al., 2010; Jacklin et al., 2014a, 2014b, 2014c; Jacklin, Warry, & Blind, 2013; Jacklin, Warry, & Dietrich, 2013; Lanting et al., 2011; Pace et al., 2013). In the environmental scan, the authors found that 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, and is also described as causing behavioral and emotional changes that interfere with the person’s social and work life (Alzheimer Society of Canada, 2010). Both Indigenous and Western perspectives were respected by developing a description of the meaning of dementia while highlighting the Indigenous perspective. This excerpt is taken from the fact sheet:

There is some evidence that suggests age-related dementias have only recently become more common in Indigenous populations. As people live longer, they are more likely to experience dementia. Just as First Nations communities in Canada are different, First Nations peoples, communities and cultures hold different understandings of dementia, memory loss, forgetfulness and confusion related to aging. These understandings may be very different from those held by doctors, nurses and support workers. Some descriptions of dementia that are common are that: “it’s normal”, “it’s natural”, “it’s part of the circle of life” or “coming full circle”. Dementia may also be described as a “second childhood” and a time when one is “closer to the Creator.” A person’s spiritual beliefs often influence how dementia is viewed (Jacklin, Warry, Blind, & Webkamigad, 2015b).

The results suggested that the term dementia may or may not be an accepted or conceptually understood term for all Indigenous people (Hulko et al., 2010; Sutherland, 2007), and that there may be some underlying shame or stigma associated with the disease (Pace et al., 2013). Furthermore, there is an absence of the word “dementia” in Indigenous languages. There are, however, Indigenous words that describe the symptoms or state of mind associated with memory loss. For example, the Tahltan First Nations people in British Columbia say, “Kadousah”, which means “not knowing if you’re coming or going”; or “Edu M’Diid Sugo ta a”, which means “not brain well” (Stevenson, 2014). Similarly, participants from the Perceptions Project shared translated Indigenous phrases such as “my mind goes on me”, “breakdown of thoughts”, “sickness of the mind”, “brain not working right”, and “losing one’s mind”, which were used to describe the loss of balance between the mind, the body, and spirit (Jacklin et al., 2014a; Jacklin, Warry, & Blind, 2013). In the two fact sheets, an incorporation of words and phrases that came

from the Perceptions Project appeared to be harmonious across the provinces according to the literature on the topic. Language issues in the fact sheets were addressed as follows:

Dementia may or may not be an accepted term for all people. It may be more appropriate to speak of forgetfulness or thoughts being mixed up. There is no word that has been identified to mean dementia in Indigenous languages in Canada. Instead, First Nations languages have words that describe the symptoms or state of mind. For example, words and phrases such as: “forgetful”, “confused”, “thoughts mixed up”, “something wrong with my head”, “mind changes”, “going back to childhood” (Jacklin et al., 2015b).

Both the Perceptions Project and literature review found that colonialism and racism remain pervasive issues in the lives of Indigenous people in Canada, often resulting in some individuals being “out of balance” physically, emotionally, mentally, or spiritually. It has been documented that changes to Indigenous lifeways and culture have changed conceptions of dementia and aging over time (Hulko et al., 2010; Lanting et al., 2011; Pace, 2013; Wilson, Rosenberg, & Abonyi, 2011). These changes include collective suffering and historical trauma from the consequences of colonization and loss of connection to the land (Arkles et al., 2010; Mundel & Chapman, 2010; Wilson et al., 2011). The resulting shift from a traditional way of life is expressed as a significant risk factor for those elders who experience these challenges. The following is the excerpt from the fact sheet that responds to this finding:

Historical changes in diet, changes to the land or environment, disconnection from culture, as well as trauma, intergenerational trauma, stress, and unresolved grief are significant factors that cause people and communities to sometimes be out of balance and may partially explain a rise in the number of elderly with dementia (Jacklin et al., 2015b).

Fact Sheet 2: Signs and symptoms of dementia: A First Nations guide.

The review of materials suggests that Indigenous people are reluctant to discuss common signs and symptoms with their health care providers (Durey et al., 2012; Stevenson, 2014). With the goal of acknowledging the main factors contributing to this reluctance and in an effort to encourage more active involvement with health systems at earlier stages, the authors included this explanation in the fact sheet:

Some First Nations people may be reluctant to discuss forgetfulness or memory loss with health care providers for many reasons, for example: they consider it to be a normal part of aging and not problematic, they have not had good experiences with health care providers in the past, they do not think a diagnosis would make any difference, they are embarrassed and do not want others to know about their symptoms, they do not want to take the memory tests, or they have difficulty accessing health care services (Jacklin, Warry, Blind, & Webkamigad, 2015a).

Many Indigenous people perceive memory loss to be a normal part of the life cycle (Henderson & Henderson, 2002; Hulko et al., 2010; Lanting et al., 2011), and the analysis of the literature suggested that as in other populations, Indigenous people often asked or wondered where the line is between normal forgetting and illness-based forgetting (Pace et al., 2013). The authors examined how other health promotion materials dealt with this issue and adapted the language to reflect the differences. Meaningful differences of when memory loss is normal and when it is a symptom of illness using Indigenous specific experiences are included in the fact sheet and described in Table 1.

Table 1. When forgetfulness is part of normal aging versus a symptom of illness

Normal Aging	Symptom of Illness
<p>Forgetting can be a normal part of getting older. We may forget to pay a bill, lose things, and find it hard to remember the words we want to use every once and a while. It can be normal for our memories of events to be less detailed than they once were, we may take a little bit longer to remember. Sometimes we may have words on the tips of our tongues that we cannot find in the moment.</p>	<p>When these types of forgetting become worse over time or begin to happen more often, it may be a sign that something is wrong. For example, missing one bill payment once and a while may be normal, but missing many payments and not being able to manage money may not be normal. Losing track of the day may be normal, but losing track of the month or season is not. Difficulty finding the words we want may sometimes be normal, but not being able to carry on a conversation is not.</p>

Note: Reproduced from Jacklin et al., 2015a.

The contrasts between mainstream messages and Indigenous messages about common elements of signs and symptoms of dementia are listed in Table 2 (Alzheimer's Association, 2015; Alzheimer's New Zealand, 2012; Australia Alzheimer's, 2010; Canadian Alzheimer's Society, 2015).

An analysis of the Perceptions Project data showed that Indigenous perspectives of signs and symptoms of dementia shared some common elements with what was found in the environmental scan and literature review (Henderson & Henderson, 2002; Lampton, 1998; Smith et al., 2011). For example, through the Perceptions Project, it was found that some Indigenous people perceive seeing or hearing things that nobody else can, including deceased family members, as a normal part of growing older (Jacklin et al., 2014c). Hallucinations may not be

Table 2. Examples contrasting the language of early warning signs and symptoms of dementia

Mainstream messaging	Indigenous messaging
Problems with language, words, speaking, writing, and understanding what is said to them	Forgetfulness, including not being able to recognize people, places, or objects; repeating stories
Difficulty performing/completing/managing familiar complex or new tasks and taking longer to do so	Impaired judgement, including not understanding instructions; not understanding cause and effect
Withdrawal from usual/social/work activities due to lack of initiative or loss of social skills	Withdrawn from family, friends, or favourite activities
Changes in mood, behavior and personality with unpredictable behavior and ‘mood swings’	Changes in mood and personality, including emotional outbursts; changes in hygiene, including forgetting to brush hair, teeth; not interested in washing or getting cleaned up
Challenges in planning or solving problems, with impaired/decreased/poor judgement	Easily upset or frustrated; increased fear, paranoia or distrust of others; compulsive behaviour
Confusion with time or place/disorientation in time and space	Getting lost, this may include wandering or pacing; seeing or hearing things that nobody else can, including connections with people who have passed; hallucinations; delusions; sense of time is off
Misplacing things	Misplacing objects

Note: Reproduced from Jacklin, Warry, Blind et al., 2015a.

problematized by Indigenous people as they can be perceived as actual communications with the supernatural, or spiritual, world (Henderson & Henderson, 2002). However, recognizing the need to respect the Indigenous interpretations of these events with the potential of serious medical complications, the fact sheet identifies that there may be hallucinations that are not natural:

Hearing or seeing things that other people cannot may be a symptom of a more serious acute condition related to severe infection or the effects of prescription medications. If you think you may be experiencing unnatural hallucinations, you should seek care immediately (Jacklin et al., 2015a).

The Alzheimer Society of Canada's document "Person-Centred Language" was determined to conflict with core Indigenous values. The document suggested avoiding the term "loved one(s)" when referring to the person with dementia. It is suggested this term is challenging because relationships between family members may be difficult, some may be uncomfortable with the expression, and that it is funereal in tone (Alzheimer Society of Canada, 2012). The guideline recommends using "person/people with dementia", "family member", or "friend" instead.

To reflect the language of Indigenous peoples, Indigenous knowledge was pursued. Love, one of the Seven Grandfather Teachings, is an essential component of care provided to a person with dementia. The action of love is giving part of yourself to another. Following discussions with Elder Otowadjiwan, the authors identified that the term "loved one" is commonly accepted and welcomed in the Indigenous context as caring for a person with dementia requires a lot of love, understanding, and patience (Jacklin, Warry, Viau, Webkamigad, & Blind, 2015). As a result, the term "loved one" was used in the fact sheet.

Discussion

The researchers in this study supported Indigenous and Western understandings of dementia in the development of the fact sheets by utilizing a two-eyed seeing approach to decolonize health information. By embracing a broad knowledge translation approach in gathering information

regarding dementia, the researchers have strengthened the pathway to decolonizing health information by combining knowledge that leads to a new perspective gained by seeing through two eyes. Two-eyed seeing reflects an ability to view strengths of both Indigenous and Western biomedical knowledge and ways of knowing (Estey et al., 2008). This framework has offered a unique and innovative way of uniting key ideas gained from consulting with Indigenous elders and scholars, evidence-based findings from the Perceptions Project, and scholarly literature, as well as the contribution of both Indigenous and biomedical perspectives.

Part of the knowledge translation process included focusing on common health promotion considerations such as literacy level and language choice. The authors found throughout the knowledge translation process that high-syllable words greatly affected the readability level of the contents of the fact sheets. Special attention was therefore given to word selection, complex sentences, and sentence structure. The literacy level was assessed using the Flesch-Kincaid Index feature on Microsoft Word. The Flesch-Kincaid grade level of the “What is dementia? First Nations Perspectives and Cultural Understandings” and “Signs and Symptoms of Dementia: A First Nations Guide” fact sheets were 12.6 and 11.3, respectively. A Flesch-Kincaid grade level of 5 was sought throughout the materials, however the inclusion of terms such as Alzheimer’s, dementia, and Indigenous greatly affected the readability level. Even when adjusting the fact sheets to exclude high-syllable words such as dementia(s), Alzheimer’s, Indigenous, understanding(s), and community, the Flesch-Kincaid grade level was reduced to 11.2 and 10.5. The literature suggests different strategies to ensure the material is presented to counter low literacy levels when delivering health information (Jones, Berard, MacNeill, Whitham, & Yu, 2013) and special attention should be paid to future health promotion material that includes high-syllable words.

Throughout the development of the fact sheets, the authors identified differences between acceptable and unacceptable words used in the fact sheets (e.g. loved one). As a result, language choice became an important dialogue. As we utilized a person-centred care resource during the development of the fact sheets (Alzheimer Society of Canada, 2012), it was also necessary to consult with the project elder regarding terms that are egocentric in tone and which may not be acceptable in an Indigenous context. It was determined that elements from personhood and person-centred care can be used to identify how to deliver care to the individual (Kirmayer, 2007; Morhardt & Spira, 2013); however, this approach should be adapted further to include other aspects of the support system (e.g. loved ones, elders, community members). Language supportive of peoplehood and an understanding of relational care provided by the family can be used to ensure the unique values of Indigenous peoples are encouraged (Holm et al., 2003; Jacklin et al., 2015). Therefore, it is applicable to utilize terms that are congruent with an understanding of peoplehood as this resembles Indigenous values of caregiving.

It is important that health professionals in the field of health literacy, health promotion, and Indigenous knowledge translation understand local socio-cultural realities to truly reflect culturally safe material. These recommendations are congruent with other researchers' findings (Lindeman et al., 2010; Smylie et al., 2006, 2009). When working within a culturally diverse population, health care professionals must understand that there are differences in intercultural communication amongst Indigenous peoples (Smylie et al., 2009; Taylor et al., 2012). As a result, the collaborative approach with FNIHCC led to a few key decisions concerning the formatting of the fact sheets, with less discussion concerning the content. As an organization, the FNIHCC program had an interest in materials that were generic enough in design that they could be easily adapted for various First Nations based on their own culture. This resulted in the

decision to provide the fact sheet content in two formats: (1) a version that could be modified to include locally appropriate and relevant content, which was used for the second phase of this research (See Appendices D & E); and (2) a second, polished version suitable for a national audience (See Appendices F & G). When the generic fact sheets were presented at the FNIHCC national stakeholder meeting there was widespread agreement with the content, the interpretation of the information sources, and that these perspectives were national in scope. The stakeholders then discussed the visual portrayal of the information. Some members commented that the information could be better portrayed in formats more accessible to them (e.g., a circle or medicine wheel), while others expressed concern for recognizing the diversity of Indigenous cultures and the need to consult the First Nation communities individually on the best visual representation. The stakeholder discussion reinforced the need for a generic approach to the content as well as the need to support diverse Indigenous communities in their uptake and modification of the materials based on local understandings of Indigenous systems of health knowledge.

Cultural safety is based on understanding inequities in health service delivery (Health Council of Canada, 2012) and Indigenous approaches to health literacy (Smylie et al., 2006). To respond to the need for cultural safety in Indigenous health, this paper has enriched health care provider education. The authors are optimistic that sharing this approach will lead to systemic changes in delivering culturally safe care. The authors have also reinforced several of Korhonen's recommendations of Indigenous approaches to health literacy by addressing cultural safety through considering the languages, reading skills, language-comprehension skills, background knowledge and concepts of health-related topics, and the individual's level of comfort in the health setting (Korhonen, 2006).

Health literacy improves the accessibility to information that has evidence-based Indigenous knowledge regarding memory loss and forgetfulness. Improving health literacy is thought to benefit both the individual and health system, in that it can improve self-management, allowing Indigenous people to make sound health decisions and reduce the use of health services (Mitic & Rootman, 2012). Research suggests that older Indigenous people may be accessing services quite late in their dementia journey and are not benefiting from early detection and intervention (Buchignani & Armstrong-Esther, 1999; Finkelstein et al., 2012; Henderson & Henderson, 2002). The resultant fact sheets can serve to support those initial conversations between health care providers and Indigenous older adults and families concerned about memory loss and confusion; or, as a tool for individuals and families outside of the health system. In either case, the facts sheets hold the potential to raise awareness and lead to earlier engagement with health systems for memory loss and dementia.

Conclusion

The lack of culturally grounded health promotion material focused on dementia prompts the need for more attention in this area. Further action is needed within the health care sector to develop culturally based health knowledge and to raise awareness of health concerns, and also to build capacity, infrastructure, and partnerships to improve health literacy and cultural safety for Indigenous peoples (Mitic & Rootman, 2012). This project provides a foundation for evidence-based knowledge translation in relation to cultural safety in dementia care that draws heavily on a study that used a community-based participatory action research approach and responds to community partners' desire for action.

The approach outlined is one example of how knowledge translation in the Indigenous context must be deliberate in combining Western and Indigenous knowledge. The fact sheets use essential biomedical knowledge deemed important to convey Indigenous understandings and explanatory models of dementia. Two-eyed seeing paves the way for future Indigenous and non-Indigenous researchers, resource developers, and policy makers to provide culturally appropriate health promotion education and health literacy. The development of culturally appropriate health promotion materials for Indigenous communities requires a process to collect and analyze Indigenous knowledge on health-related topics; it is not simply a cut and paste process where mainstream materials are adapted through changes to imagery but not meaning. Improving the ability of Indigenous people to access, comprehend, evaluate, communicate, and use health information is essential to improving Indigenous peoples' health.

**Chapter 4: Exploring the Appropriateness of Culturally Safe Dementia Information for
Indigenous People in an Urban Northern Ontario Community**

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Abstract

Purpose: The goal of this knowledge translation project is to understand the effectiveness of culturally safe health promotion material related to dementia for Indigenous people in an urban setting in Northern Ontario. The process explored the appropriateness of utilizing materials that were developed for a national Indigenous population with Indigenous people living in a northern Ontario urban community. **Design and Methods:** A decolonized, community-based participatory action research approach using tribal epistemology was used. This included the establishment of a local Indigenous advisory group and a partnership with the N'Swakamok Native Friendship Centre in the City of Greater Sudbury. Data collection included two focus groups (n=8) with Indigenous adults and five one-on-one interviews with Indigenous caregivers of a person with dementia. A qualitative thematic analysis was used to categorize and analyze participant responses. This analysis involved coding interview transcripts using the qualitative software program, NVivo 10. **Results:** Four themes emerged from the data: 1) the need for shared understandings of Indigenous and Western cultures in health care; 2) improving cross-cultural communication; 3) grounding health promotion materials in culture; and 4) Indigenous health literacy strategies for dementia awareness. **Implications:** As health care providers search for effective ways to communicate with Indigenous people, it is important to deliver information with clear messages that are locally and culturally relevant. While it is desirable to have tools and resources that are shared nationally, it is important that those tools leave room for local adaptation to improve uptake and effectiveness by Indigenous people.

Keywords: Health Literacy, Cultural Safety, Indigenous, Dementia

Introduction

Indigenous caregivers of people with dementia face a lack of support or marginal support services from their community and health care system (Jacklin, Pace, & Warry, 2015; Pace, 2013). Dementia health promotion materials specific to Indigenous people in Canada are often requested by caregivers, older adults, nurses, personal support workers, and researchers but are absent (Jacklin et al., 2015). To address this deficiency, this project aimed to explore the appropriateness of health promotion materials concerning dementia in meeting the needs of Indigenous people living in the City of Greater Sudbury, Ontario.

This research approach sought to apply the principles of community-based participatory action research (Israel et al., 1998; LaVeaux & Christopher, 2009) grounded in tribal epistemology (Kovach, 2009) to examine the appropriateness of culturally safe health promotion materials and to improve their relevance in an urban context. The significance of addressing this topic is to improve the quality of life for Indigenous people by improving access to appropriate information regarding cultural understandings of dementia and its signs and symptoms, thereby reducing health inequities faced by Indigenous people.

A recent and Indigenous model of health care, cultural safety, is being applied by health care professionals as a result of health inequities faced by Indigenous people (Allan & Smylie, 2015). Cultural safety, a model originally developed by Dr. Irihapeti Ramsden, highlights how colonial, historical, and sociopolitical factors led to health disparities in Indigenous communities (Allan & Smylie, 2015). In addition, the Health Council of Canada (2012) states that cultural safety “is based on understanding the power differentials inherent in health service delivery, the institutional discrimination, and the need to fix these inequities through education and system

change” (p. 5). To respond to the increased need for cultural safety in dementia health promotion materials in Canada, the authors take a closer look at the need to address knowledge translation and exchange (KTE) at the local level. This research was carried out just as a project concerning the creation of dementia health promotion fact sheets for a national Indigenous audience was being completed (Chapter 3). Designed to complement and build on that process, this project sought to understand how applying the KTE process to a specific Indigenous population could further refine the fact sheets and improve their significance locally.

KTE is a reciprocal process used between researchers, people with lived experience, health care providers, policy makers, and partner organizations that assists in determining priority areas for the health needs of people living with dementia (CCNA-CCNV, 2015). This process takes evidence-based findings and develops them for strategic action. As a result, culturally appropriate health promotion material is developed with Indigenous people that reflects local preferences of sharing information; this strengthens the relationship between the health care provider and Indigenous community members. In addition to KTE, it is important to explore Indigenous conceptualizations of health literacy, as it builds on Indigenous understandings and perspectives (Smylie et al., 2006). Health literacy, as a determinant of health, can be established in the dementia field through proper health communication and culturally appropriate care by way of knowledge translation.

Purpose

In an attempt to understand the implications of Indigenous cultural diversity on the appropriateness of culturally safe health promotion material at a local level, for her master’s thesis, the primary author (SW) worked with a research team led by the senior author (KJ) to

develop a knowledge translation project with members of the Indigenous community of the City of Greater Sudbury. The aim of this study is to explore the research question: “How can we develop health promotion materials about dementia to meet the needs of Indigenous peoples living in an urban Northern Ontario community?”

Design and Methods

Approval for this research project was obtained from the Laurentian University Research Ethics Board and reflect the Tri-Council Policy Statement, Chapter 9 (CIH, 2014). In addition, the N’Swakamok Native Friendship Centre also granted approval and was the community partner.

Using a decolonizing approach is deemed highly important for any research carried out within Indigenous communities. *Nêhiyaw Kiskêyîhtamowin* (Kovach, 2009), originating from Plains Cree knowledge, is easily translatable and provides an inclusive integration of Indigenous ethical considerations. This framework was deemed appropriate as a guiding tool in developing a theoretical framework because it is easily transferable to other tribal groups of the Indigenous population. It includes key qualities of holistic epistemology (i.e. *Anishinaabemowin*), story, purpose, the experiential, tribal ethics, tribal ways of gaining knowledge, and an overall consideration of the colonial relationship (Kovach, 2009). Each of these qualities is also evident within the Anishinaabek culture and was adapted to incorporate the local epistemology of the Indigenous people of the City of Greater Sudbury. By using this decolonizing theoretical framework, the methodology of this project contains: (a) tribal epistemology, (b) decolonizing and ethical aim, (c) researcher preparations involving cultural protocols, (d) research preparation involving standard research design, (e) making meaning of knowledge gathered, and (f) giving back. The primary author was engaged in each of these methodological stages.

Tribal Epistemology

Stanley Peltier, a community member who is committed to rejuvenating the Anishinaabe language, described the philosophy of *Anishinaabemowin* eloquently at Laurentian University while participating as a learner for a presentation given by Dr. Margaret Kovach (October, 2015). His explanation (although not word for word), with consent to share, is as follows:

When speaking of Indigenous knowledge... *Anishinaabemowin* is how the language is described by the Anishinaabek people of the City of Greater Sudbury and the region.

“*Anishinaabe*” is the word used to describe the type of people, as in the communion of many tribal groups of the region. “*Mo*” is the part of that word that entails communication is expressed at a higher level through feelings and beliefs. “*Win*” makes it a philosophy.

So, when we speak about the philosophy of the Anishinaabek people, it is highly linked to the language, also known as “*Anishinaabemowin*”.

This philosophy was used to reflect local Indigenous knowledge and assisted in understanding the many facets of the diverse culture of Anishinaabek people. In order to practice *Anishinaabemowin* as a philosophy, proper ethical conduct reflected the Anishinaabek traditions of *wewena ji bmaadziwin*, also known as the Seven Grandfather Teachings: *mnaadendiwin* (respect), *nbwaakawin* (wisdom), *zaagidiwin* (love), *gwekwaadziwin* (honesty), *bbasendiziwin* (humility), *aakdewin* (bravery), and *debwewin* (truth). It was also crucial to include an understanding of the medicine wheel, an Anishinaabek holistic model, in the development of the interview guide. The medicine wheel model, a “widely accepted and recognized symbol of Indigenous holism” (Mundel & Chapman, 2010, p. 167), is a framework used by many

individuals, Indigenous researchers, health promoters, and organizations to develop programs and services aimed at improving health (George, 2003; Marsh et al., 2015; NCCAH, 2013; Young et al., 2013). The specific teaching from the medicine wheel model applied to this research is an understanding of holistic health, which is the balance of the physical, mental, spiritual, and emotional aspects that unify every individual. Using both *Anishinaabemowin* and the medicine wheel model during the development of the research methods supported a decolonized lens.

Researcher preparation (Reflexivity)

Researcher preparation is the experiential aspect of the research process and is established as the researcher's role, thoughts, possible bias, and interpretation of the data as reflected upon simultaneously throughout the research process (Kovach, 2009). SW engaged in researcher preparation by looking within and identifying certain dreams, conversations, and intuitions that directed her research path. Most importantly, researcher preparation provided an effective means of direction through awareness of cosmocentric guidance, which is a connection to spirits and ancestors (Kirmayer, 2007); this resulted in following a path that felt right.

Research preparation (Community engagement and recruitment)

Research preparation is the process of preparing the community for the research (Kovach, 2009). It is different from researcher preparation in that it is more than the personal journey of the process. In this paper, it includes community engagement, recruitment, incentives, sample, and inclusion criteria.

Community Engagement. Community engagement was completed through many forms in this project, which included review, approval, and joint planning with the N'Swakamok Native Friendship Centre Life Long Care Program and monthly or bi-monthly dialogue with an Indigenous advisory group (IAG) that was composed of knowledgeable community members in the areas of dementia and/or caregiving. The IAG consisted of two Life Long Care Program support workers, an informal and a formal caregiver of a person/people with dementia, and an esteemed Métis elder of the community. This group ensured that the approach to the research was appropriate and beneficial for the community at all stages. The IAG met bi-monthly throughout the research project to discuss the benefits and appropriateness of the approach to the research (for example, planning, data collection, analysis, interpretation, and dissemination).

Recruitment. Snowball sampling was deemed the appropriate recruitment strategy (Cueva et al., 2012; Finkelstein et al., 2012). The project was also promoted through advertisements posted throughout the City of Greater Sudbury, Aboriginal organizations, the Société Alzheimer Society Sudbury-Manitoulin, and bulk e-mail at Laurentian University. The recruitment protocol involved discussion of the project and review of the letter of information and signing of the consent form (Appendices B and C). In keeping with Anishinaabek protocol, cloth and tobacco were offered to honour the gifts the participants will be providing to the research project. The acceptance of the cloth and tobacco was an act of agreement to follow through with the request. The participants were encouraged to pray with the cloth and tobacco to ensure their insight about the topic is with good intention and is guided by spiritual vision. If the participants did not wish to accept an offering of cloth and tobacco they were encouraged to contact the lead author to discuss alternatives, such as offering a small, hand-made item.

Incentive. Light snacks and refreshments were provided during focus group sessions. This form of incentive is meant to encourage an open atmosphere amongst the participants and researchers as it provided an opportunity for discussion, relationship building, and trust. Additional incentives included \$10 gift cards for food through a local company called The Good Food Box.

Sample and Inclusion Criteria. Two focus groups brought together older Indigenous males [4] and females [4] (55 or older) who expressed an interest in the topic and included three caregivers. Anyone who self-reported as having dementia, as diagnosed by a health care practitioner, was excluded. In addition to the focus groups, five one-on-one interviews were conducted. Four female caregivers who are providing or have provided care for a family member/friend/neighbor with dementia who is living in the City of Greater Sudbury were interviewed one-on-one. In addition, one older male who was interested in speaking further about the topic but is not a caregiver was included. Caregiver age range is broad and therefore caregivers of any age were encouraged to participate. Minors under 16 years of age were excluded from this study. All participants were not asked to disclose their age. Participants were not asked to disclose their Indigenous ancestry, however, one participant openly identified as Métis and another as Inuit.

Gathering knowledge (Data collection)

Two fact sheets developed for Indigenous people at a national level were used as prompts and to facilitate discussion (See Appendices D and E). A semi-structured interview conversation guide was developed with the IAG and the master's supervisory committee (See Appendix H).

Questions in the conversation guide were organized into the four aspects of the medicine wheel to discuss physical, mental, emotional, and spiritual aspects of holistic health. Direct questions

regarding the fact sheets included insights into thoughts, usefulness, and new information gained by reviewing the fact sheets prior to the discussion. Data collection occurred during the months of November 2015 to January 2016, and ended when rereading the data revealed no further information or new topics. This data gathering technique sought to determine (1) the preference for the communication of dementia-related information for Indigenous people in the City of Greater Sudbury, Ontario, (2) the role of Indigenous language in creating appropriate materials; and (3) the role of Indigenous oral/visual traditions of knowledge sharing in developing culturally appropriate dementia health promotion tools.

Making meaning (Data analysis and validation)

Data analysis. A qualitative thematic analysis (Luborsky, 1994) was used in this study to categorize and analyze participant dialogues in relation to the conversation guide. This analysis involved entering, reviewing, and organizing the transcribed data in a qualitative software program, NVivo 10, and resulted in thematic identification. Each focus group and interview was imported into the software as the source of information. The conversation guide was then imported into the software and organized by question, which became the initial nodes. A word frequency cloud was developed to identify common words found throughout the transcripts, for example: medicine wheel, language, and understand. The function of the software was to access the information (such as a common word or phrase) and place the data into a node; restructuring the data resulted in the emerging themes. The data were reviewed and restructured several times before the final themes were identified.

Validation. Member checking with the participants was conducted within two months of data gathering through individual transcript reviews. Validation was also considered through

discussion of the themes with the IAG. This group discussion aimed to explore the meaning of the identified themes, as well as to guide the dissemination plan.

Giving back

Giving back to the community, as identified by Kovach's framework, is an important final step in this process. It ensures that the research project will encourage empowerment and self-determination through involvement in the research. Dissemination involved two strategies. At the local level and in keeping with local Anishinaabek protocol, knowledge dissemination occurred through a community feast and presentation on the research results. Academic dissemination included the thesis, two articles prepared for publication, and several oral presentations to the academic community and during international aging conferences (See Chapter 2).

Results

Four themes emerged from the data analysis: 1) the need for shared understandings of Indigenous and Western cultures in health care; 2) improving cross-cultural communication; 3) grounding health promotion materials in culture; and 4) Indigenous health literacy strategies for dementia awareness. This study also produced data relevant to the creation of culturally appropriate dementia-related health information. Specifically, the inquiry considered how the two fact sheets were useful, what thoughts they provoked, and if the participants learned anything new about dementia.

Theme 1: The need for shared understandings of Indigenous and Western cultures in health care.

For health care providers to engage in culturally safe discussions concerning dementia with Indigenous people, they first need to know about Indigenous people and vice versa. This includes a shared understanding of Indigenous history within Canada, as well as cultural values and beliefs of Indigenous and Western ways of life.

Indigenous history. A discussion about dementia generated conversations about changes to Indigenous ways of life. Participants reported that past socioeconomic factors such as colonization influenced how Indigenous people have come to have increased rates of dementia. They expressed how elders have said dementia happened a long time ago; however, people never viewed it as an illness and accepted the condition amongst family members.

And you never know, what if those elderly people have said that used to happen a long time ago. But we never thought anything of it. That's always what they say, you know.

CG301

Participants also expressed that changes have occurred in Indigenous communities, including a change in the role of the chief in First Nations communities, an increase in Roman Catholicism, and a reduction in Indigenous ceremonies. These changes have contributed to the changing views of society, memory loss, and spirituality.

Whereas my parents weren't really introduced to ceremonies and all these other things. But they knew it was us, it's who we are. But because they were both raised Roman Catholic, I believe enriched their spirituality. CG401

Cultural values and beliefs of Indigenous and Western ways of life. When discussing language use in the fact sheets, a participant expressed how Anishinaabek people have their own philosophy of life, the medicine wheel, also known as teachings.

Everyone has ... different teachings, different ways of looking at things ... I started to learn who we are as Anishinaabek and what our teachings are ... but, we're forgetting all of those things ... We're still Anishinaabe ... we have to talk about our own philosophies of life to understand what we need to do today. CG401

The participants spoke frequently about the Anishinaabe medicine wheel teachings, which are common to this region. The discussions of the medicine wheel included balancing the aspects of holistic wellness, the stages of life teachings, the four races, and the four sacred medicines. Other Anishinaabek teachings discussed by participants include the Seven Grandfather Teachings, the importance of certain animals, and the importance of the circle. There was no discussion of teachings that would be specific to First Nations, urban Indigenous people, Metis, or Inuit separately.

The most appropriate icon is the medicine wheel and the four colors ... from an Anishinaabe point of view, we know what the four colors are ... it doesn't matter because dementia can affect anyone ... doesn't matter what color you are. So, I just thought like if you're going to do a teaching or something for Anishinaabe, or First Nations, to me that would be the most appropriate one ... And not only that because the medicine wheel is in a circle, and you know, how it affects all colors, all races, and we, as a people, we always say the circle of life. Well it's a circle of the people. And it doesn't matter who we are, it can affect you. CG201

Theme 2: Improving cross-cultural communication

Participants emphasized the importance of communication strategies to reduce barriers caused by differences in belief systems and to develop meaningful, relational interactions. There is an overarching belief that a relationship developed between an Indigenous and a non-Indigenous person can be fostered by careful attention to appropriate verbal and non-verbal communication.

Barriers. Participants expressed that there are different values between the Western and Anishinaabek perspectives to communication. These differences can cause barriers to communication.

For us, you know, we would, we wouldn't so much rationalize it verbally. We would rationalize it, you know, at a different level. Without saying too much about it in words.

OA302

And then talking about, umm, the connections for like communication and all that. And you're talking to someone but something interferes with that. Well, you don't get that message across. They call it synapses in the communication. CG101

There was consensus amongst participants that when Western belief systems are adopted by Indigenous people, it can lead to a disconnection from Indigenous belief systems. It was believed by one participant that this disconnection leads to mistrust between community members who have different values.

We have a different approach to healing and wellness. It's not like the Western medical model ... when you bring white middle-class values to Anishinaabek, you know it sort of disconnects them from their own community ... So, you know, they become confused ...

you know it still causes a problem. You know, like about your own identity ... When I look at it, I see a lot of disconnect there. You see, when our elders, our ancestor told us to get an education, they didn't mean get assimilated. So that's changing our thinking about who we are. You know, that's what education does. It changes our thinking. But what the elders really meant though was, all right, get educated. Get as much education as you can, you know get a university degree. And, but don't forget who you are. OA302

Cross-cultural considerations. To overcome barriers and communicate cross-culturally, participants talked about the need for a level of connection that uses verbal communication such as humor, listening, and Indigenous language, as well as non-verbal communication, such as offerings.

An elder participant expressed that humor is needed to communicate.

Yeah. Humor needs to be there ... all our elders are all good-humored. They need to laugh in order to communicate. OA702

Participants also emphasized the importance of listening to Indigenous peoples.

It's always the best part, is listening to their stories. OA802

You guys, if you want to do Native ways, LISTEN! (laughs). OA702

A participant explained how language is an important aspect of Indigenous knowledge and is essential for communicating with elders.

Culturally appropriate workers must know traditional knowledge. Workers have to know compassion. If they can, maybe the ordinary words, like *aanii* [hello, welcome], *baamaapii*

[see you later]. All those things that you know you can talk to, and they're mostly elderly people. Elder people. And they know the language. A lot of them know the language. So for a culturally appropriate organization, language is so important. OA702

In addition, participants indicated that the connections to language are so intimately tied to self and community that even those who do not speak it feel it and live it.

So, you know that's a part of language that a lot of the younger generation don't really understand but they still have it ... So that's part of who we are, and when we take a look at some of the things that people understand about us, that's one of the things that's going to be really difficult for them to understand. OA302

Furthermore, participants expressed that there are differences when explaining topics in English versus an Indigenous language. The language spoken provides Indigenous knowledge through culturally grounded and detailed meaning of words, as it describes what you are seeing or doing. Fact sheets would be exceptional if they are presented in the language for those who know how to speak it; however, some participants who are not fluent in their Indigenous language felt that they would not be able to understand.

No ... I'm not very fluent but I understand the language because I heard it, but again I never really experienced conversational language as I was growing up. CG401

Participants noted that translators for the elders who are fluent in their language would help them to understand dementia. For those participants who are not fluent in their language, having the cultural component of the medicine wheel is important.

If you are talking to an elder, and they are more fluent in the language, it would be better for them, instead of reading it, it would be better to talk with them. OA802

I totally agree in regards to that because they would rather it explained to them in Anishinaabe, its better understanding for them. Especially if they speak their language ... Because even when they come to the city they shy away from the English language, because they don't understand. CG301

In addition to verbal communication, participants voiced that non-verbal communication such as offerings of tobacco, food, and drinks can help people connect in a spiritual way, as it will help them be more receptive. Participants articulated that it also helps people connect with the Creator through prayer.

If you are going to have a seminar or workshop, you should make sure that the first thing that you would say is, you know, okay, we are going to provide you with food. There will be food and drinks available. And so that really sets things off, people will want to come. And it's the same way we're meeting right here, at the table. This is when people can sit down and make themselves more receptive to – and it seems almost as if your cause, you don't put it forefront. You sort of bring it as something that's going to happen. OA302

This participant also explained that verbal and non-verbal communication can foster *Anishinaabe-mo*, which is the connection developed between people associating with each other.

In our language when we associate, you know, with one another, you know, we've been associating like that for thousands of years ... So in our language we say, "*mo*". Just like in the word, *Anishinaabe-mo*. That signifies a level of social interaction ... Sometimes we

even, we believe that all humans have that, you know, that type of connection. ...But not everybody connects in that way ... But we would take it to that level, *mo* ... When you take it to that level it's like a higher level of understanding. OA302

Theme 3: Grounding health promotion materials in culture

To improve awareness regarding dementia amongst Indigenous people, health care providers can ground the fact sheets in Anishinaabe culture to overcome cross-cultural barriers presented in theme 2. Participants expressed that oral and visual resources are culturally effective styles of education.

Oral teachings through storytelling, sharing circles, health care providers, and community support services. Oral teachings are highly regarded by the participants in this study and are defined as visiting, sharing, teachings, and storytelling.

Participants identified that visiting is an important part of transferring knowledge.

I think it's really important in my own experience ... is really taking the time to visit people ... Yeah, and we have always been storytellers and our parents and grandparents taught us lessons through storytelling too. CG401

A participant expressed how early education with the family is important and can be done through having a sharing circle. Participants voiced that sharing circles are small-scale talking circles where the person talking holds talking sticks or an eagle feather fan. This informal approach helps members of the circle respect what each person has to say.

But say the more the family can get in there for that circle, the better it would be so everybody has the same perspective on what dementia is ... So early type of information giving is probably the best, you know, and starting off with the family. OA302

Participants voiced that culturally appropriate dementia information can best be shared through teachings at sharing circles for family members and persons with dementia, workshops for the community at large, and training for community members, family, and health care workers.

Every one that was there, in that panel, they got to voice their opinion, share their story, share their thoughts, share their knowledge. And us, as a people, sitting back, we were the little leaves. Like, they were the seeds. They are the seeds of the community. Spreading out ... So, it's a way of learning ... then you're going to take that knowledge that you learn and you'll share it with someone else and it just goes on. CG201

And other times we can refer back to the training. Then let's train our people that are on our First Nations to prepare for this. CG301

Acceptable forms of visual resources. Participants voiced that visual learning with pictures is an important part of the culture. DVDs are appropriate for the participants and are most helpful if they are translated into the Ojibway and Cree languages. Participants of the first focus group believed a website to accompany the fact sheets would be helpful. Some participants had searched online for information about dementia. The elderly use social media more often now, and billboards and bulletins were also identified as an important source of sharing health information.

I'd think it would be more helpful with pictures and stuff ... I can't read something and remember what I read after I read it and stuff ... Because I got to read and read and read and I'll get it ... So sometimes I don't even read stuff like that [fact sheets]. CG502

Participants suggest educating people with pamphlets, PowerPoint presentations, posters, and a binder with all of the information in it would be helpful.

What would be helpful is if a binder was created with all of the information about Alzheimer's, dementia. And then the individual that is caring for them, information to help that person ... and binders for the different programs that are made available for them, like I was saying for the health care centres on our First Nations and stuff ... For the families, caregivers of that person or individual. CG301

Theme 4: Indigenous health literacy strategies for dementia awareness

Participants discussed data relevant to the creation of culturally appropriate dementia-related health information, which includes: who to involve in developing health promotion material and workshops; how to develop dementia-related material; and where to share the information. The subtheme, how to develop dementia-related material, also captures how the two fact sheets used as prompts are a source of visual teaching.

Who to involve. Participants prefer to learn from Indigenous elders, health care providers, and teachers who are experienced; however, they noted that anyone who is well educated in the topic and is culturally aware is also welcome. Participants also voiced that the process needs to involve community members who have experience with providing care in the planning and presentation

of information. They also recommend involving other key members of the community such as the priest and traditional knowledge keepers.

We should have our own people. You know, like involved in anything, even education. ... we should get our own people to teach our own kids. That's why we like to see you guys, you know come in there to do the health. Our own teachers teaching our own children.

OA302

A recommendation by the focus group participants is for people who are dealing with health issues to join groups and speak to a physician or pharmacist for information. Focus group participants felt that talking with a physician is an important source of health information. The participants also expressed that people with experience and education in dementia will help them understand the disease.

But if they're educated and trained in this field in regards to Alzheimer's and dementia that would probably help them a long way also. CG301

Participants expressed that the support system is different in the city versus on-reserve. Participants go to places like the Friendship Centre and the Alzheimer Society of Canada to get support. Most participants felt that sharing circles that accompany community programming by nurses, physicians, support workers, and experienced community members could help them understand health issues and new information.

And getting them there to participate in that caregiver support group at the Alzheimer's Society as well as myself, was a good learning experience ... I think for me, if it was spoken to me, it depends again on the, umm, on the person. The knowledge that they're

carrying. A good example I could give you is like, a presenter from the Alzheimer Society, right. Because that person works in that field. That person is very knowledgeable. So, if you took someone from there that has the skills and the background, and they know what they're talking about. Well then you're going to get something out of it. CG201

How to develop dementia-related material. Participants agreed that it is important for the caregiver to learn about the differences between the types of dementia and how to prepare for different stages of the disease. Participants felt that the fact sheets used as prompts were very helpful for them as they contain a direct, brief overview of dementia. Overall, participants believed that the fact sheets were meaningful and provided them with information they needed to seek further health advice.

Yeah, again to when it comes to my own health, ensuring that I should make an appointment with my doctor very soon to address some of these symptoms that are outlined in your handout here. CG401

Participants also felt that other information should be included: risk factors, causes, and support; differences of mainstream points of views on dementia; how to maintain quality of life; how dementia will impact people mentally, emotionally, physically, and spiritually; and how to cope using the Seven Grandfather Teachings. Participants also felt that additional information could be helpful if included in the fact sheets: responsive behaviours; emotional changes; caregiver coping; and strategies for family members.

The signs are there, and the facts. But like, there could be more to it, I feel in regards to that person, and that individual themselves caring for that person on what they could do.

CG301

Those teachings, our Seven Grandfather Teachings are very important to us as Anishinaabe people. CG201

Where to share the information. Participants felt that it was important for the fact sheets to be available at the community level, including doctors' offices, Société Alzheimer Society Sudbury-Manitoulin, the Health Unit, and Indigenous organizations (such as Aboriginal Peoples' Alliance of Northern Ontario and Aboriginal health centres).

And a lot of our First Nations, they always have to come out to the urban setting to find medical help and resources ... If there was somebody that could go to them sometimes, that would be all the better for them. They would be in their own surrounding, comfortable surrounding at that ... and because, a lot of times if they got to leave their reserve and come to the city it's a big step for them. CG301

Discussion

This research sought to determine the appropriateness of nationally developed dementia health promotion materials for use with a group of Indigenous people in an urban community. Our findings suggest that there is a need for all-embracing education to share a common knowledge of Indigenous culture, ways of life, and Indigenous knowledge in relation to communicating health information. Findings suggest that conveying health information geared to Indigenous peoples requires a shared understanding by Indigenous people and health care professionals about past and present Indigenous history, culture (values, beliefs, and ways of life), and language usage. Although the research findings display differences between Western and

Indigenous beliefs and values, other research evidence suggests that “focusing on the similarities between the two systems of knowledge rather than on their differences may be a more useful place to start when considering how to best introduce educational reform” (Battiste, 2005, p. 6). In many ways, the findings are also similar to Dr. Marie Battiste’s findings in her literature review of Indigenous knowledge:

“Such rethinking of education from the perspective of Indigenous knowledge and learning styles is of crucial value to both Indigenous and non-Indigenous educators who seek to understand the failures, dilemmas, and contradictions inherent in past and current educational policy and practice for First Nations students” (Battiste, 2005, p. 3).

Drawing from Battiste’s standpoint (2005), the application of Indigenous knowledge is also useful in the health care context to prepare for effective knowledge translation with this diverse population. In addition, as also identified by Arkles et al. (2010), “developing resources that complement rather than conflict with existing health beliefs and world views is therefore a necessary factor for the uptake of information” (Lindeman, Taylor, Kuipers, Stothers, & Piper, 2010, p. 35). As we have found, modifying the existing fact sheets to include important models, values, and beliefs such as the medicine wheel and the Seven Grandfather Teachings will make them meaningful for this particular group of urban Indigenous people.

Anishinaabe-mo in the context of dementia knowledge includes improving cross-cultural communication through connecting at a deeper cultural level. The levels of connection participants discussed included relationship building, trust, respect, listening, humor, storytelling, and offerings. In highlighting the importance of elders being involved in the planning stages of development, the authors were reassured by the Report of the Royal Commission on Aboriginal

People, which states: “elders are being restored to their former place of respect in communities, and Aboriginal people are turning to them for guidance as they search in increasing numbers for a meaningful identity” (Royal Commission on Aboriginal Peoples, 1996b). This is especially important for urban Indigenous people, as the regeneration of the culture will be accomplished by maintaining connections with elders who carry that knowledge. Furthermore, *Anishinaabe-mo* is a concept that health care providers can be aware of to develop and foster relationships with Indigenous peoples, thereby embracing a level of connection through culturally effective strategies in communication. By embracing *Anishinaabe-mo* in the development of materials and programs it may be possible to communicate culturally grounded health information in English.

Findings suggest a mixture of both human and material resources are required for effective health promotion. While visual materials such as fact sheets are significant in conveying health information, it is equally important to include oral aspects such as sharing circles and community workshops. Bridging essential Western-based strategies such as billboards, binders, expert knowledge, and media with Indigenous modalities such as sharing circles and community and cultural events demonstrates cross-cultural considerations. For example, in this study, two younger participants agreed that using several forms of media such as billboards, internet, and Facebook will help to bring awareness about dementia. In addition, participants noted that elders were also in agreement with these modalities as more people are accepting the mode of information sharing. This finding supported other researchers’ work, as “information presented in an engaging and accessible format can make a profound difference to people’s awareness and understanding of an issue such as dementia” (Taylor, Lindeman, Stothers, Piper, & Kuipers, 2012, p. 215). The findings suggest that fact sheets should be part of a larger strategy utilizing an extensive list of resources that are culturally safe and factual.

When developing tools for urban Indigenous groups, health care providers can include various organizations like the Alzheimer Society and local Indigenous community centres to deliver culturally safe health promotion strategies. In 1996, roughly half of Indigenous Canadians lived in cities (Canadian Policy Research Networks, 2002), and as Newhouse notes, “Aboriginal people are reformulating Western institutions and practices to support Aboriginal cultures and identities, so that Aboriginal people can survive as distinct people in contemporary societies” (as cited in Graham & Peters, 2002, p. 21). Revitalization of culture within urban Indigenous communities is engaged through selecting aspects of the old ways and blending them with the new, and Indigenous organizations such as friendship centres can provide effective cultural programming in the urban setting (Royal Commission on Aboriginal Peoples, 1996b).

Limitations

The use of tribal epistemology of *Anishinaabemowin* in this study meant that the Anishinaabek approach (a First Nations view) is more prominent than the other two (Inuit, Métis). Although the project aimed to include Inuit and Métis values and beliefs, the medicine wheel model was used as it particularly responds to the Anishinaabek in this region; specifically, the Ojibway, Odawa, Cree, and Algonquin. However, the Inuit and Métis participants did not suggest that these values or teachings are inappropriate. Diverse Indigenous ways of knowing by means of the medicine wheel or Seven Grandfather Teachings may not be suitable for all Indigenous people and further analysis would suggest different models and beliefs within the diverse Indigenous communities across Canada. To reduce this limitation, it is suggested that an exploration of this topic specifically with Inuit and Métis individuals will enhance understanding. A Métis elder of the community was part of this project’s IAG. The involvement of this elder encouraged the contribution of the Métis culture, values, and beliefs.

The results suggest that even within an Indigenous community there can be diversity that challenges the creation of locally culturally appropriate materials. Diversity in language is one such challenge. The participants' comments suggest that there are different needs for those who do and do not speak *Anishinaabemowin*. Many of the participants who speak the language believe that Indigenous knowledge is shared through language and is beneficial for those who understand it. However, other participants who did not speak the language would be challenged by materials or sessions provided in *Anishinaabemowin*.

Conclusion

Guided by other researchers (Lindeman et al., 2010; Schoen et al., 2010; Smylie et al., 2006; Taylor et al., 2012), this study increases the understanding of the interrelationships among literacy, language, culture, and health in a local urban Indigenous community. This research responds to the need for a better understanding of cultural safety in health promotion material related to dementia. Urban Indigenous conceptualizations of literacy are demonstrated as oral and visual avenues of sharing information, whether through storytelling by an esteemed elder or a health care worker from the community who understands the health information contained in the material. When developing culturally safe health promotion material, it is important to consider how to deliver a comprehensive approach that includes materials such as fact sheets in conjunction with an overall strategy to address relationships with health care providers and systems, cross-cultural communication, and local culture. The study demonstrated that while many aspects of the national Indigenous dementia materials were appropriate and accepted, it is important that there is room for local adaptation to improve uptake and effectiveness by Indigenous people. We encourage Indigenous and non-Indigenous organizations to collaborate

with local community members, caregivers, elders, support care workers, and researchers to continue to decolonize the approaches to health promotion to reflect the ways of Indigenous people.

Chapter 5: Conclusion

This thesis aimed to understand the effectiveness of nationally developed culturally safe dementia-related health promotion material for Indigenous people in a local urban Indigenous community. Applying two decolonizing methodologies (Kovach, 2009; Martin, 2012) and a community-based participatory action research approach (Israel et al., 1998; LaVeaux & Christopher, 2009) to the research, the author participated in and reported on the development of Indigenous dementia fact sheets for a national audience. This process included developing and exploring the appropriateness of these fact sheets within an urban Indigenous community through qualitative interviewing. In this chapter, findings from the two studies discussed are summarized and framed within a larger knowledge translation and exchange project along with key findings and suggestions for future research as well as clinical and practical implications. The chapter ends with concluding thoughts.

Chapter three of this thesis presented an article prepared for publication titled “A Strategy to Improve Dementia Health Literacy in Indigenous Communities.” Two-eyed seeing facilitated combining Indigenous knowledge with Western biomedical knowledge to develop two culturally appropriate fact sheets on dementia (See Appendices D to G). The two fact sheets were developed as part of the CCNA Team 20 Project in collaboration with Health Canada’s First Nations and Inuit Home and Community Care (FNIHCC) program. This project provides a foundation for evidence-based knowledge translation in relation to cultural safety in dementia care. The development of health promotion materials for Indigenous people includes a process of incorporating biomedical information with Indigenous knowledge, accounting for language usage and diverse Indigenous cultures, and striving for literacy levels that are clear and concise.

Chapter four of this thesis presents a second article prepared for publication titled “Exploring the appropriateness of culturally grounded dementia information for Indigenous people in an urban Northern Ontario community.” This research was grounded in an adapted version of a tribal epistemological perspective from Plains Cree knowledge, *Nêhiyaw Kiskêyihitamowin* (Kovach, 2009) to Anishinaabek understandings of *Anishinaabemowin*, to explore the appropriateness of culturally safe dementia health promotion materials. The overall aim of this qualitative research project was to understand the implications of Indigenous cultural diversity on the appropriateness of two fact sheets developed in a local urban Indigenous context. Findings from this study include a process of understanding Indigenous history, developing connections with Indigenous people using an understanding of *Anishinaabe-mo*, utilizing material and human resources to share information, and developing dementia awareness by collaborating with various services in the community.

Challenge of Diverse Indigenous Cultures

In the City of Greater Sudbury, there are many tribal groups represented; however, this study chose a regional epistemology of the *Anishinaabek* people. Although the researcher aimed to include Inuit and Métis values and beliefs, the medicine wheel model particularly corresponds to a group of *Anishinaabek*, specifically the Ojibway, Odawa, Cree, and Algonquin in this region. This challenge biased the results by utilizing local Indigenous knowledge, *Anishinaabemowin*, as a tribal epistemology. Using this epistemology prioritized First Nations epistemology, resulting in a knowledge gap of Inuit and Métis values and beliefs. The author responded to this bias by including a Métis elder in the project through involvement in the Indigenous advisory group. The presence of this elder encouraged the contribution of the Métis culture, values, and beliefs. Métis

teachings of building respect and trust are parallel to the Anishinaabek teachings, such as giving offerings when asking for help. The elder's input was also valuable in identifying common terms and phrases that are acceptable to the Métis culture. There was no evidence to suggest that the Inuit and Métis participants were uncomfortable with utilizing local Indigenous knowledge, and in fact embraced it. It is important to understand there are diverse Indigenous ways of knowing e.g. the medicine wheel or Seven Grandfather Teachings. One tribal group's epistemology may not be suitable for all Indigenous people, and further analysis would suggest different models and beliefs exist within the diverse Indigenous communities across Canada. This challenge adds to research recommendations that an understanding of diverse Indigenous cultures is warranted prior to developing a research study. To overcome this challenge in further decolonizing methodologies, exploration of topics with Inuit and Métis involvement is encouraged.

Limitation

A limitation to conducting a CBPAR study for a master's level thesis is that data collection and analysis can be a lengthy process. The approach to data collection included a cyclical, iterative process through repeated interviews (Abbott, Davison, Moore, & Rubinstein, 2010; LaVeaux & Christopher, 2009) to directly represent the descriptions, experiences, beliefs, and perceptions of the participants. Because of data collection and analysis, the research timelines were extended. A lengthy data collection process has been identified by others who also used qualitative interviews in their methods (Goins, Garroutte, Fox, Geiger, & Manson, 2011). Although these processes are time-consuming, it is a required step to develop trusting relationships with the community, validate the integrity of the information, and reflect community needs (LaVeaux & Christopher, 2009). Further research utilizing a cyclical, iterative process should consider ways in which data

collection and analysis can be accelerated through having additional interviewers and planned extended timelines.

Discussion of Findings

Health Literacy and the Importance of Indigenous Knowledge

A major aim of this research was to explore the concepts of health literacy and cultural care in developing educational materials for a particular group of Indigenous people. Health literacy, a concept less defined in an Indigenous context, is an emerging process that, given the attention it warrants, will evolve into approaches rooted in Indigenous perspectives and understandings (Smylie et al., 2006). Recent research shows that there are limited resources regarding Indigenous health literacy in Canada, however there are international efforts that are succeeding in establishing this concept, thereby developing separate domains of health literacy. These domains include: fundamental literacy and numeracy; science and technology literacy; community and civic literacy; and cultural literacy (Zarcadoolas, Pleasant, & Greer, 2003).

Understanding Indigenous approaches to health literacy can benefit those who are developing culturally appropriate health material. In this project, we have reinforced several of Korhonen's recommendations of Indigenous approaches to health literacy by addressing cultural safety by considering the languages, education levels, reading skills, language-comprehension skills, background knowledge and concepts of health-related topics, and the individual's level of comfort in the health setting (Korhonen, 2006).

Further attention is required to assess whether improving health literacy will improve the health outcomes of Indigenous people (Vass et al., 2011). Indigenous health models with an extended focus on health education that explores language and worldviews (Vass et al., 2011) can be

beneficial to both the individual and the health system (Mitic & Rootman, 2012). A particular model, the Integrated Life Course and Social Determinants Model of Aboriginal Health (ILCSDAH), lists health behaviors and education as proximal determinants of health (Loppie Reading & Wien, 2009). These determinants have direct impacts on the holistic health of the Indigenous population.

It is crucially important that health professionals in the field of health literacy, health promotion, and Indigenous knowledge translation and exchange understand local socio-cultural realities (Smylie et al., 2006) to truly reflect culturally safe material. Moreover, health behaviors and education must be considered within the socio-political context of Indigenous health (Loppie Reading & Wien, 2009); further action is needed by those who provide health services to develop knowledge, raise awareness, build capacity, and build infrastructure and partnerships to improve health literacy (Mitic & Rootman, 2012). Increased action ensures that power differentials in service delivery are uprooted, thereby reducing health inequities and discrimination.

This research reveals that there are marked differences in the knowledge of urban Indigenous people as determinants of health are more accessible in urban communities. Systemic changes within Indigenous communities have contributed to a modernized, urban Indigenous way of life, one that is positioning language at the core of cultural revitalization. Further attention to these differences is highly recommended.

Knowledge Translation and Exchange

This project provides the foundation to evidence-based knowledge translation in relation to cultural safety in dementia care. By embracing a broad knowledge translation approach in gathering information on dementia, this project has enriched the pathway in culturally safe health information. This knowledge translation project, guided by community-based participatory action research, focused on dementia and responds to community partners' desire for action. The approach included a combination of sources such as reports from a previous research study, an academic literature review, a non-academic environmental scan, and on-going consultations with various collaborators and experts. This knowledge translation framework is beneficial and ideal as Indigenous health knowledge and institutions are reclaiming and rebuilding in a decolonized setting (Ellison, 2014). Knowledge translation will not reflect Indigenous contexts if research findings are not acted upon, as knowledge is almost always linked to action practically and philosophically (Smylie, Olding, & Ziegler, 2014). Important efforts for knowledge translation focus on local languages, concepts, systems, and protocols (Smylie et al., 2014). This reinforces the need to support individual First Nations in their uptake and modification of the materials based on local understandings of Indigenous systems of health knowledge (Smylie et al., 2009).

Decolonizing Methodologies in Qualitative Research

Utilizing a two-eyed seeing framework has offered a unique and innovative way of uniting ideas from consulting with Indigenous elders and scholars, evidence-based findings from an Ontario-based research project, Canadian literature, and the contribution of a Western biomedical perspective. Considering the language, cultural influences, reading levels, background knowledge, and concepts of dementia of the Indigenous peoples will promote health literacy. The reason for this combined approach was to respond to the concern that there was a service

gap in the presentation of culturally relevant dementia-related information that is appropriate and reflective of the Indigenous culture (Jacklin, Warry, & Blind, 2014), and specifically, evidence that would help Indigenous people understand the illness, its progression, and how to access support services.

Improving the ability of Indigenous peoples to access, comprehend, evaluate, communicate, and use health information will contribute to the Indigenous determinants of health and improve the cognitive, mental, physical, emotional, and spiritual health of Indigenous people. Findings in this study reinforce Jacklin and Warry (2011) in that future health care professionals should be trained in Indigenous health. Participating in Indigenous cultural activities can broaden the scope of understanding Indigenous health issues. One participant, CG201, stated that researchers “taking part in cultural events ... like I saw you at one” is a way to spread health messages in the community and is appreciated by Indigenous people. For health care professionals to decolonize health services, they must understand that Indigenous people have different choices than mainstream Canadians (Jacklin & Warry, 2011). These cross-cultural considerations can lead to inclusion, trust, respect, collaboration, and acceptance of both Indigenous and non-Indigenous people.

Concluding Thoughts

This community-based participatory action research approach included Indigenous people in the planning and development process to reflect local Indigenous knowledge regarding sharing of health information. Reflecting local Indigenous languages, knowledge, values, and beliefs in the adapted material was an important but lengthy task that responded to participant recommendations. This research responds to the need that culturally appropriate health

promotion material be developed by and for Indigenous people to reflect local information sharing preferences. It strengthens the relationship between the researcher and the community to develop material that is community based.

The findings encourage Indigenous and non-Indigenous organizations to develop culturally appropriate material by collaborating with community members, caregivers, elders, support care workers, and researchers. It is crucial that both Indigenous and non-Indigenous people ensure cultural safety through understanding historical underpinnings of Indigenous health, establishing trust and reciprocal connections, communicating in ways that respond to local Indigenous knowledge, and envisioning a future that consists of the strengths of both Indigenous and Western biomedical perspectives. The findings suggest that there is a need for all-embracing education to share a common knowledge of Indigenous culture, ways of life, and Indigenous knowledge. In addition, these findings can be translated to inform policy and practice through recommendations regarding the development of health promotional materials. It is important that when working with Indigenous peoples, proper avenues of health communication and culturally appropriate care be encouraged to improve literacy, thus contributing to the determinants of health. This work holds the promise of improving the quality of life of caregivers of people with dementia and the ones they care for.

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Appendix A: Laurentian University Research Ethics Board Approval Letter



APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS
Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL	New <input checked="" type="checkbox"/>	Modifications to project	Time extension
Name of Principal Investigator and school/department	Sharlene Webkamigad, MA Interdisciplinary Health supervisor, Kristen Jacklin, NOSM		
Title of Project	Developing dementia health promotion materials to meet the needs of Aboriginal peoples in the City of Greater Sudbury, <u>Ont.</u>		
REB file number	2015-09-07		
Date of original approval of project	November 5 th , 2015		
Date of approval of project modifications or extension (if applicable)			
Final/Interim report due on: <i>(You may request an extension)</i>	November, 2016		
Conditions placed on project			

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate REB form.

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate LU REB form. In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best wishes in conducting your research.

Rosanna Langer, PHD, Chair, Laurentian University Research Ethics Board

Appendix B: Letter of Information for One-on-One Interviews



Letter of Information and Consent form for Caregivers in One-on-One Interviews

Project Title: **Developing dementia health promotion materials to meet the needs of Aboriginal peoples in the City of Greater Sudbury, Ontario**

Program: Master of Arts: Interdisciplinary Health

Sharlene C. M. Webkamigad, Investigator
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swebkamigad@laurentian.ca

Kristen Jacklin, PhD Supervisor,
Co-Investigator
Associate Professor, Human Sciences
Northern Ontario School of Medicine
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1-800-461-8777 ext. 7277

Sheila Cote-Meek, Co-Investigator
Associate Vice President,
Academic & Indigenous Programs
Laurentian University
scotemeek@laurentian.ca
(705) 675-1151 ext. 3429

Birgit Pianosi, Co-Investigator
Associate Professor, Gerontology
Huntington University
bpianosi@huntingtonu.ca
705-673-4126 ext. 206

Purpose of the Research:

The purpose of this research is to address the lack of Aboriginal specific Alzheimer's disease and related dementia health promotion material. The goal of my thesis project is to assess culturally-specific health promotional materials for people with dementia and their caregivers in the community setting. My research goal is driven by the project 'Perceptions of Alzheimer's disease and related dementia among Aboriginal peoples in Ontario'; and in speaking with my supervisor, Dr. Kristen Jacklin, we have identified that Alzheimer and age-related dementia resource material may benefit local Aboriginal caregivers and persons with Alzheimer's or age-related dementia.

What will happen during the study?

You are being invited to participate in a study entitled **Developing dementia health promotion materials to meet the needs of Aboriginal peoples in the City of Greater Sudbury, Ontario** that is being conducted by me, Sharlene Webkamigad. I am an Anishnaabe-Kwe from Wiikwemikoong Unceded Territory and am a Registered Nurse, as well as a student in the Master of Arts in Interdisciplinary Health program at Laurentian University.

The Aboriginal caregivers selected for one-on-one interviews will be providing care for a family member/friend/or neighbor with dementia who is living in the Greater City of Sudbury. The interviews will take place at a location convenient to you, for example in your home or at the N'Swakamok Native Friendship Centre. The interview may take up to two hours, with breaks if needed. If we cannot gather enough information in the first interview, we will arrange for a follow-up interview. The discussion will be guided through a holistic model, the medicine wheel, to include the four aspects of well-being (physical, mental, emotional, and spiritual). Two fact sheets will be provided to you for review and input: "What is Dementia? First Nations Perspectives and Cultural Understandings", and "Signs and Symptoms of Dementia: A First Nations Guide". You will be audio-recorded during the interview, which is very helpful in tracking common themes and ideas from the group of participants. The collected data will be used for my analysis while participants will be given the opportunity to review and make changes to their interview transcripts. If you wish not to be audio recorded you will still receive an incentive and will be included in the study. However, the session will be recorded through hand-written journaling by myself as an alternative to the audio-recording.

Participation

Participating in this study will cause no known or anticipated inconveniences or risks to you by participating in this research. Your participation in this research is completely voluntary. If you decide to participate, you may still decline to answer any questions and may withdraw at any time without any consequences or any explanation. If you do withdraw from the study before its conclusion in October 2016, your data will not be used in the final study or its subsequent dissemination.

In all cases, a unique code will represent you during data analysis. This code will be attached to your words. A separate password protected file with your code attached to your name will only be accessed by myself. I would like to acknowledge your insights and knowledge on the subject by citing you directly, and you may agree or disagree to have your name used in any future reports, presentations, or publications.

If you feel upset about the discussion, I or my supervisor can help make arrangements for you to access mental health services through the N'Swakamok Native Friendship Centre's Life Long

Care program. Our phone numbers are listed at the beginning of this fact sheet and you are encouraged to call either of us if you feel upset and need further assistance. The phone number for the Life Long Care program support workers, Sue Roque and Tony Tyson is 705-674-2128. An additional referral to the Société Alzheimer Society Sudbury-Manitoulin may be made if you feel additional supports are needed.

Potential Benefits: What good will this do?

The potential benefits of your participation in this research are to support you and others' perspectives of culturally-appropriate health promotional materials. Through this research, there is potential in developing existing community strengths and resources, increasing community control over the research process, and empowering the community. Any materials developed will be given to the N'Swakamok Native Friendship Centre for use in their programs.

Honorarium

In keeping with Anishinabek protocol, I will be offering cloth and tobacco to honour the gifts you will be providing me by agreeing to share your experience and wisdom. If you do not wish to accept an offering of cloth and tobacco please contact me to discuss alternatives. Prior to the one-on-one interview you will receive an incentive in the form of an \$8 gift card for food through a local company called the "Good Food Box".

Disclosure

As a Registered Nurse in the City of Greater Sudbury, I may know and have a relationship with potential participants. To help prevent this relationship from influencing your decision to participate, the following steps to prevent coercion have been taken: I will not conduct interviews with current clients of my nursing services. Also, this research will not influence future nurse-client relationships.

Confidentiality

All data will remain confidential and will be stored in a secure location at Laurentian University.

All audio recordings and transcriptions will be stored electronically on a password-protected computer housed at Laurentian University. Any paper files, such as the consent forms and notes, will be locked in a filing cabinet in a secure locked room at the Northern Ontario School of Medicine. Only the investigators/ researchers will have access to these materials. All names will be removed from the transcripts and will be given a numeric code. Only the investigators will have access to the audio recordings and transcripts.

Information obtained will be kept confidential to the full extent of the law and we will treat all information provided to us as subject to researcher-participant privilege. However, we may have to reveal certain personal information if the law requires it.

Information about the Study Results:

After completing the written transcription, I will immediately send you a copy for you to review. If you identify changes or corrections that need to be made, please notify me within two weeks of receiving the transcripts so that I can make the necessary corrections before I begin the analysis. It is anticipated that the results of this study will be shared with others in the following ways: directly to participants, presentations at scholarly meetings, published articles or books, internet, media, and directly to Anishinabek communities and Indigenous organizations.

If you have questions or require more information about the study itself, please contact me, Sharlene Webkamigad at (705) 662-7223, or by email at swebkamigad@laurentian.ca. Alternatively, you may contact my supervisor, Dr. Kristen Jacklin at (705) 662-7277, or by email at kjacklin@nosm.ca.

This research has been reviewed and approved by Laurentian University Research Ethics Board (**certificate #2015-09-07**). If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

Research Ethics Officer, Laurentian University Research Office
Telephone: 705-675-1151 ext 2436 or toll free at 1-800-461-4030
Email: ethics@laurentian.ca.

I have read the information presented in the information letter about a study being conducted by Sharlene Webkamigad. I have had the opportunity to ask questions about my involvement in this study, and to receive any additional details I wanted to know about the study. I understand that I may withdraw from the study at any time, if I choose to do so, and I agree to participate in this study. I give my permission to have the discussion audio recorded. I have been given a copy of this form and another copy will be kept in a confidential location by the researcher.

- I agree to have my name used in any future reports, presentations, or publications through either acknowledgements or through quotes with my name attached.
- I do not agree to have my name used in any future reports, presentations, or publications.

Name of Participant

Signature

Date

Appendix C: Letter of Information for Focus Groups



Letter of Information and Consent form for Older Adults in Focus Groups

Project Title: Developing dementia health promotion materials to meet the needs of Aboriginal peoples in the City of Greater Sudbury, Ontario

Program: Master of Arts: Interdisciplinary Health

Sharlene C. M. Webkamigad, Investigator
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Sheila Cote-Meek, Co-Investigator
 Associate Vice President,
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 (705) 675-1151 ext. 3429

Birgit Pianosi, Co-Investigator
 Associate Professor, Gerontology
 Huntington University
bpianosi@huntingtonu.ca
 705-673-4126 ext. 206

Purpose of the Research:

The purpose of this research is to address the lack of Aboriginal specific Alzheimer's disease and related dementia health promotion material. The goal of my thesis project is to assess culturally-specific health promotional materials for people with dementia and their caregivers in the community setting. My research goal is driven by the report 'Perceptions of Alzheimer's disease and related dementia among Aboriginal peoples in Ontario'; and in speaking with my supervisor, Dr. Kristen Jacklin, we have identified that Alzheimer and age-related dementia resource material may benefit local Aboriginal caregivers and persons with Alzheimer's or age-related dementia.

What will happen during the study?

You are being invited to participate in a study entitled **Developing dementia health promotion materials to meet the needs of Aboriginal peoples in the City of Greater Sudbury, Ontario** that is being conducted by myself, Sharlene Webkamigad for my Master's thesis project. I am an Anishnaabe-Kwe from Wiikwemikoong Unceded Territory and am a Registered Nurse, as well as a student in the Master of Arts in Interdisciplinary Health program at Laurentian University.

Two focus groups of four to five older Aboriginal adults (55 years of age or older) who express an interest in the topic will occur at the N'Swakamok Native Friendship Centre. It is anticipated that each focus group will take no longer than two hours. The discussion will be guided through a holistic model, the medicine wheel, to include the four aspects of well-being (physical, mental, emotional, and spiritual). Two fact sheets will be provided to you for review and input: "What is Dementia? First Nations Perspectives and Cultural Understandings", and "Signs and Symptoms of Dementia: A First Nations Guide". You will be audio-recorded during the focus group, which is very helpful in tracking common themes and ideas from the group of participants. The collected data will be used for my analysis. Participants will be given the opportunity to review the written versions of the recordings to make corrections or clarify their comments. If you wish not to be audio recorded you will still receive an incentive and will be included in the focus group. However, the session will be recorded through hand-written journaling by myself and other Advisory group members of this study as an alternative to the audio-recording.

Participation

Participating in this study will cause no known or anticipated inconveniences or risks to you by participating in this research. Your participation in this research is completely voluntary. If you decide to participate, you may still decline to answer any questions and may withdraw at any time without any consequences or any explanation. If you do withdraw from the study before its conclusion in October 2016, your data will not be used in the final study or its subsequent dissemination.

In all cases, a unique code will represent you during data analysis. This code will be attached to your words. A separate password protected file with your code attached to your name will only be accessed by myself. I would like to acknowledge your insights and knowledge on the subject by citing you directly, and you may agree or disagree to have your name used in any future reports, presentations, or publications.

If you feel upset about the discussion, I or my supervisor can help make arrangements for you to access mental health services through the N'Swakamok Native Friendship Centre's Life Long

Care program. Our phone numbers are listed at the beginning of this letter of information and you are encouraged to call either of us if you feel upset and need further assistance. The phone number for the Life Long Care program support workers, Sue Roque and Tony Tyson is 705-674-2128. An additional referral to the Société Alzheimer Society Sudbury-Manitoulin may be made if you feel additional supports are needed.

Potential Benefits: What good will this do?

The potential benefits of your participation in this research are to support you and others' perspectives of culturally-appropriate health promotional materials. Through this research, there is potential in developing existing community strengths and resources, increasing community control over the research process, and empowering the community. Any materials developed will be given to the N'Swakamok Native Friendship Centre for use in their programs.

Honorarium

In keeping with Anishinabek protocol, I will be offering cloth and tobacco to honour the gifts you will be providing me by agreeing to share your experience and wisdom. If you do not wish to accept an offering of cloth and tobacco please contact me to discuss alternatives. Light refreshments will be served during the focus group sessions. Prior to each focus group you will receive an incentive in the form of an \$8 gift card for food through a local company called the "Good Food Box".

Disclosure

As a Registered Nurse in the City of Greater Sudbury, I may know and have a relationship with potential participants. To help prevent this relationship from influencing your decision to participate, the following steps to prevent coercion have been taken: I will not conduct interviews with current clients of my nursing services. Also, this research will not influence future nurse-client relationships.

Confidentiality

All data will remain confidential and will be stored in a secure location at Laurentian University.

All audio recordings and transcriptions will be stored electronically on a password-protected computer housed at Laurentian University. Any paper files, such as the consent forms and notes, will be locked in a filing cabinet in a secure locked room at the Northern Ontario School of Medicine. Only the investigators / researchers will have access to these materials. All names will be removed from the transcripts and will be given a numeric code. Only the investigators will have access to the audio recordings and transcripts.

Information obtained will be kept confidential to the full extent of the law and we will treat all information provided to us as subject to researcher-participant privilege. However, we may have to reveal certain personal information if the law requires it. Everything that is discussed in the focus group will be kept confidential by the researchers; however this is an open discussion with other participants.

It is expected that all participants will respect each other and not share personal information disclosed in the focus group. Before each focus group begins there will be an oath of confidentiality expressed through the presence of the N'Swakamok Native Friendship Centre's Eagle Staff and my sacred bundle in the room. The Eagle Staff and a sacred bundle (which includes a smudge bowl, an eagle feather, and the four sacred medicines: sage, sweet grass, cedar and tobacco) will allow for an open dialogue. The focus group will begin with a smudge with all participants. If you choose not to smudge, this will be respected and you will be included in the focus group session otherwise. The participants will be asked if anyone wishes to say a prayer before we proceed. Tony Tyson is a support worker with the Life Long Care program and is on the Aboriginal Advisory group of this project. He or I will then proceed by explaining the oath of confidentiality, which is simply obtained by agreeing verbally or non-verbally through a head nod. Please keep in mind that the research team cannot guarantee that everything discussed will be kept confidential by the participants involved.

Information about the Study Results:

After completing the written transcription, I will immediately bring you a copy for you to review. If you identify changes or corrections that need to be made, please notify me within two weeks of receiving the transcripts so that I can make the necessary corrections before I begin the analysis. It is anticipated that the results of this study will be shared with others in the following ways: directly to participants, presentations at scholarly meetings, published articles or books, internet, media, and directly to Anishinabek communities and Indigenous organizations.

If you have questions or require more information about the study itself, please contact me, Sharlene Webkamigad at (705) 662-7223, or by email at swebkamigad@laurentian.ca. Alternatively, you may contact my supervisor, Dr. Kristen Jacklin at (705) 662-7277, or by email at kjacklin@nosm.ca.

This research has been reviewed and approved by Laurentian University Research Ethics Board (**certificate #2015-09-07**). If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

Research Ethics Officer, Laurentian University Research Office
Telephone: 705-675-1151 ext 2436 or toll free at 1-800-461-4030
Email: ethics@laurentian.ca.

I have read the information presented in the information letter about a study being conducted by Sharlene Webkamigad. I have had the opportunity to ask questions about my involvement in this study, and to receive any additional details I wanted to know about the study. I understand that I may withdraw from the study at any time, if I choose to do so, and I agree to participate in this study. I give my permission to have the discussion audio recorded. I have been given a copy of this form and another copy will be kept in a confidential location by the researcher

- I agree to have my name used in any future reports, presentations, or publications through either acknowledgements or through quotes with my name attached.
- I do not agree to have my name used in any future reports, presentations, or publications.

Name of Participant

Signature

Date

Appendix D: What is Dementia? Fact Sheet

What is Dementia? First Nations Perspectives and Cultural Understandings

Health Care Providers Understandings of Dementia

"Dementia is an umbrella term for a variety of brain disorders. Symptoms include loss of memory, judgement and reasoning, and changes in mood and behaviour. Brain function is affected enough to interfere with a person's ability to function at work, in relationships or in everyday activities." *The Alzheimer's Society of Canada*

First Nations Understandings of Age-Related Dementia

There is some evidence that suggests age-related dementias have only recently become more common in Indigenous populations. As people live longer they are more likely to experience dementia.

Just as First Nations communities in Canada are different, First Nations peoples, communities and cultures hold different understandings of dementia, memory loss, forgetfulness and confusion related to aging. These understandings may be very different from those held by doctors, nurses and support workers.

Some descriptions of dementia that are common are that:

- "It's normal"
- "It's natural"
- "It's part of the circle of life" or "coming full circle"

Dementia may also be described as a "second childhood" and a time when one is "closer to the Creator." A person's spiritual beliefs often influence how dementia is viewed.

Historical changes in diet, changes to the land or environment, disconnection from culture, as well as trauma, intergenerational trauma, stress, and unresolved grief are significant factors that cause people and communities to sometimes be out of balance and may partially explain a rise in the number of elderly with dementia.

Talking about Dementia

Dementia may or may not be an accepted term for all people. It may be more appropriate to speak of forgetfulness or thoughts being mixed up. There is no word that has been identified to mean dementia in Aboriginal languages in Canada. Instead, First Nations languages have words that describe the symptoms or state of mind. For example, words and phrases such as:

- "forgetful"
- "confused"
- "thoughts mixed up"
- "something wrong with my head"
- "mind changes"
- "going back to childhood"

The words people use to describe the symptoms often indicate the severity or stage of the illness which can be helpful for health care workers, physicians and specialists in their assessments and care planning.

Health care worker interactions with First Nations people concerning dementia should include an early conversation with the patient and family to explore their understandings of the symptoms being experienced and the acceptability of words such as dementia or Alzheimer's disease.

Views held by the family and individual can be respected by adjusting your language use and approach to care.

Citation: Jacklin K, Warry W, Blind M, Webkamigad S (2015) What is Dementia: First Nations Perspectives and Understandings. Developed for First Nation and Inuit Health Home and Community Care Program.

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Appendix E: Signs and Symptoms Fact Sheet

SIGNS AND SYMPTOMS OF DEMENTIA: A FIRST NATIONS GUIDE

SOME FACTS:

Rates of dementia in First Nations people are higher than they are in non-First Nations people in Canada. Research suggests that the number will continue to rise and by 2031 there may be a 4.6 times increase in the number of on-reserve First Nations people living with dementia.ⁱ

Symptoms of dementia may begin in people as young as 45-50 or may begin much later depending on the type of dementia. Recent studies suggest that Alzheimer's disease and dementia may occur as much as **10 years** earlier in First Nations people compared to non-First Nations people in Canada.ⁱⁱ

Research with Indigenous people in Canada suggests that Alzheimer's disease and age-related dementias are not being diagnosed early enough for clients and families to benefit from locally available care and support services.

Some First Nations people may be reluctant to discuss forgetfulness or memory loss with health care providers for many reasons, for example:

- They consider it to be a normal part of aging and not problematic
- They have not had good experiences with health care providers in the past
- They do not think a diagnosis would make any difference
- They are embarrassed and do not want others to know about their symptoms
- They do not want to take the memory tests
- They have difficulty accessing health care services

WHEN IS FORGETFULNESS A PART OF NORMAL AGING VERSUS A SYMPTOM OF ILLNESS?ⁱⁱⁱ

Forgetting can be a normal part of getting older. We may forget to pay a bill, lose things, and find it hard to remember the words we want to use every once and a while. It can be normal for our memories of events to be less detailed than they once were, we may take a little bit longer to remember. Sometimes we may have words on the tips of our tongues that we cannot find in the moment.

When these types of forgetting become worse over time or begin to happen more often, it may be a sign that something is wrong. For example, missing one bill payment once and a while may be normal, but missing many payments and not being able to manage money may not be normal. Losing track of the day may be normal, but losing track of the month or season is not. Difficulty finding the words we want may sometimes be normal, but not being able to carry on a conversation is not.

WHY SHOULD WE SEEK CARE FOR FORGETFULNESS OR MEMORY LOSS?

Forgetfulness caused by dementia progresses from mild to moderate to severe over time. Seeking help for memory loss early is important. If you are worried you should speak to a health care worker or your doctor. An accurate diagnosis can determine if the forgetfulness is related to Alzheimer's, dementia, or other illnesses that can be more easily treated. For example, medication errors, drug interactions, and complications arising from other infections or diseases can also cause forgetfulness and confusion. If memory loss is found to be caused by a dementia illness, an early diagnosis will help to make sure people are receiving the most appropriate treatment and care strategies. An early diagnosis can help ensure the client and their family has access to the support services and information they need.

Citation: Jacklin, K, Warry W, Blind, M, Webkamigad, S (2015) Signs and Symptoms of Dementia: A First Nations Guide. Developed for First Nations and Inuit Health Home and Community Care Program.
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WARNING SIGNS AND SYMPTOMS OF DEMENTIA^{iv}

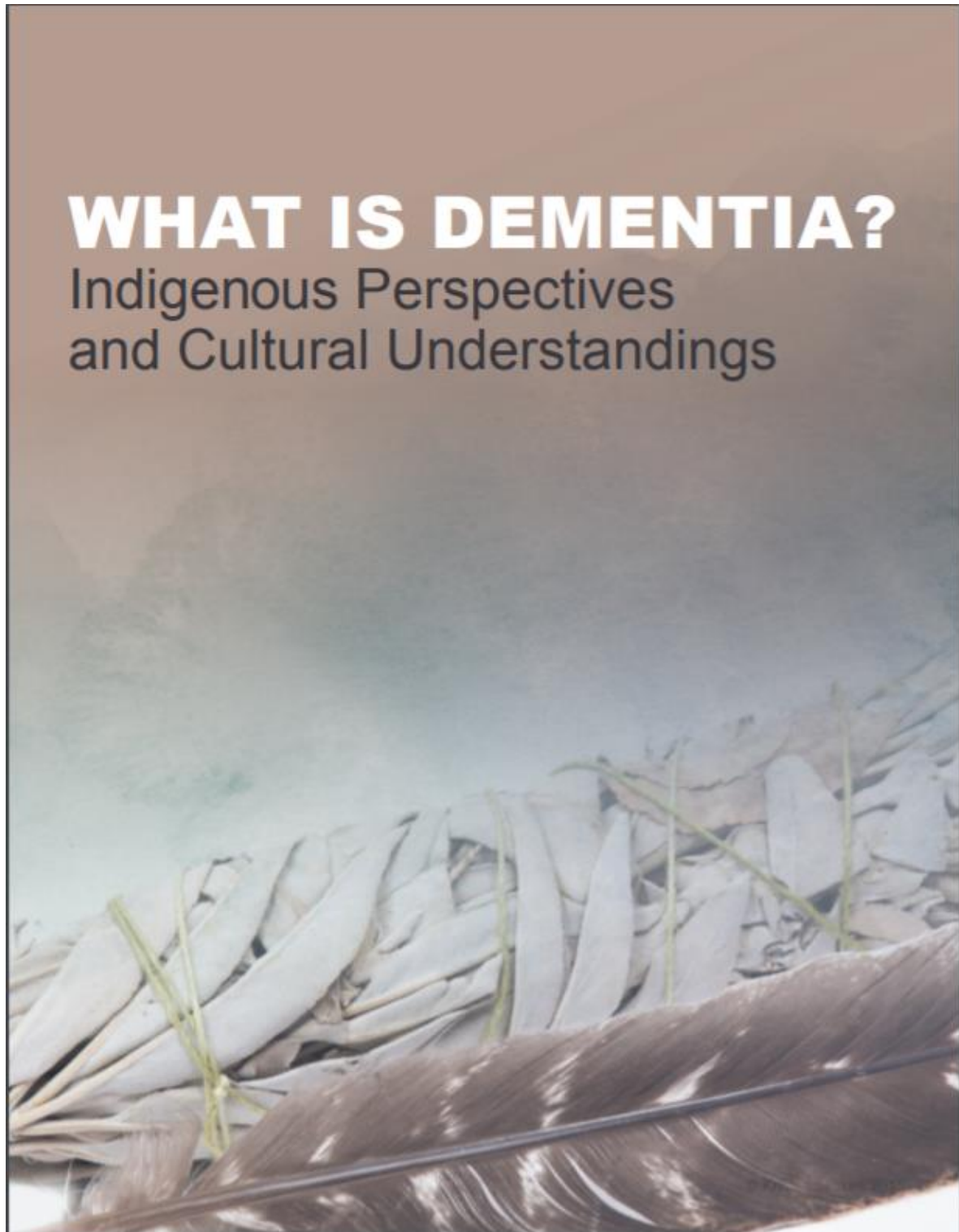
The following are some examples of the signs and symptoms described by First Nations people with dementia and their families. When these signs and symptoms are experienced *more than once in a while* they may indicate the early stages of age-related dementia.

You are encouraged to speak with your health care provider about memory loss when you become worried that it is impacting your day-to-day life. Having a few of these symptoms more than once in a while may be a sign of memory loss caused by dementia or another illness.

1. **Forgetfulness and memory loss that affects day-to-day living**
 - Misplacing things like your keys, purse or wallet
 - Having a hard time remembering the names of people who you know, especially family members
 - Forgetting to turn off the stove, leaving the fridge door open, forgetting to turn off the water
 - Repeating yourself; telling the same story over many times in the same day
 - Needing lots of reminders, missing appointments
 - Walking into a room and forgetting why you went there
 - Forgetting if you took your pills or forgetting to get cleaned up in the morning
 - Forgetting things that happened through the day but remembering things from way back
2. **Difficulty performing familiar tasks**
 - Trouble driving a car or cooking
 - Forgetting how to sew, quilt, knit, crochet, or do crafts
 - Having trouble with daily routines such as getting cleaned up in the morning and getting dressed
3. **Problems with language**
 - Forgetting words
 - Having trouble finding the words you want to use
 - Stopping part way through a sentence because you cannot remember the rest of what you wanted to say
4. **Disorientation in time and space**
 - Forgetting the month or season
 - Forgetting when you last had something to eat
 - Getting lost either on foot or while driving or not remembering where you are going
 - Confusing morning with evening
5. **Impaired judgement**
 - Leaving the house without a coat when it is cold outside
 - Wearing unusual clothing
 - Making questionable purchases
6. **Changes in mood, behaviour, and personality**
 - Feeling frustrated and sometimes angry
 - Hiding things
 - Emotional outbursts
 - Losing interest in things you once enjoyed
 - Not participating in social events
 - Hearing or seeing things that other people cannot^v

Citation: Jacklin, K, Warry W, Blind, M, Webkamigad, S (2015) Signs and Symptoms of Dementia: A First Nations Guide. Developed for First Nations and Inuit Health Home and Community Care Program.
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Appendix F: What is Dementia? Polished Fact Sheet



Health Care Providers Understandings of Dementia

"Dementia is an umbrella term for a variety of brain disorders. Symptoms include loss of memory, judgement and reasoning, and changes in mood and behaviour. Brain function is affected enough to interfere with a person's ability to function at work, in relationships or in everyday activities."

The Alzheimer's Society of Canada.

Indigenous Understandings of Age-Related Dementia

There is some evidence that suggests age-related dementias have only recently become more common in Indigenous populations. As people live longer they are more likely to experience dementia.

Just as Indigenous communities in Canada are different, Indigenous peoples, communities and cultures hold different understandings of dementia, memory loss, forgetfulness and confusion related to aging. These understandings may be very different from those held by doctors, nurses and support workers.

Some descriptions of dementia that are common are that:

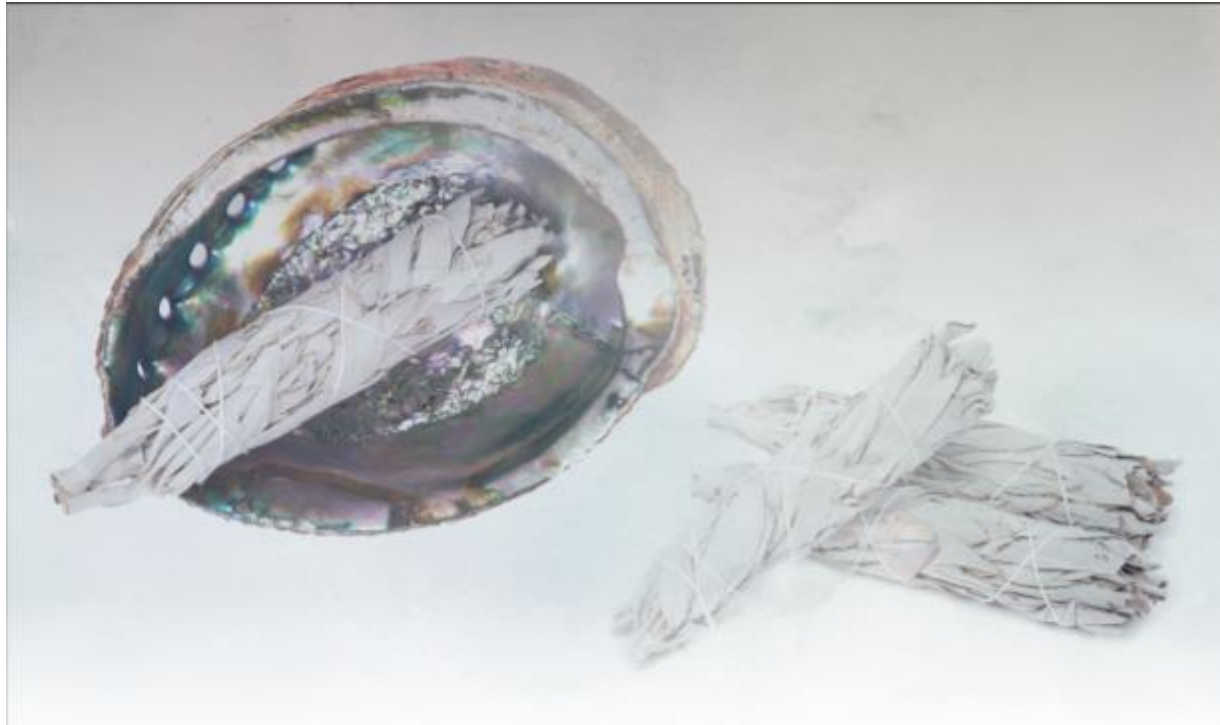
- "It's normal"
- "It's natural"
- "It's part of the circle of life" or "coming full circle"

Dementia may also be described as a "second childhood" and a time when one is "closer to the Creator." A person's spiritual beliefs often influence how dementia is viewed.

Historical changes in diet, changes to the land or environment, disconnection from culture, as well as trauma, intergenerational trauma, stress, and unresolved grief are significant factors that cause people and communities to sometimes be out of balance and may partially explain a rise in the number of elderly with dementia.



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Talking about Dementia

Dementia may or may not be an accepted term for all people. It may be more appropriate to speak of forgetfulness or thoughts being mixed up.

There is no word that has been identified to mean dementia in Aboriginal languages in Canada. Instead, Indigenous languages have words that describe the symptoms or state of mind. For example, words and phrases such as:

- "forgetful"
- "confused"
- "thoughts mixed up"
- "something wrong with my head"
- "mind changes"
- "going back to childhood"

The words people use to describe the symptoms often indicate the severity or stage of the illness which can be helpful for health care workers, physicians and specialists in their assessments and care planning.

Health care worker interactions with Indigenous people concerning dementia should include an early conversation with the patient and family to explore their understandings of the symptoms being experienced and the acceptability of words such as dementia or Alzheimer's disease.

Views held by families and individuals can be respected by adjusting your language use and approach to care.

For more information...

Indigenous Inuit Home and
Community Care

www.hc-sc.gc.ca

Alzheimer's Society of Canada

www.alzheimer.ca

Indigenous Cognition & Aging Awareness
Research Exchange (I-CAARE)

www.i-caare.ca

Government of Canada

www.seniors.gc.ca

End-of-Life Care in Indigenous
Communities

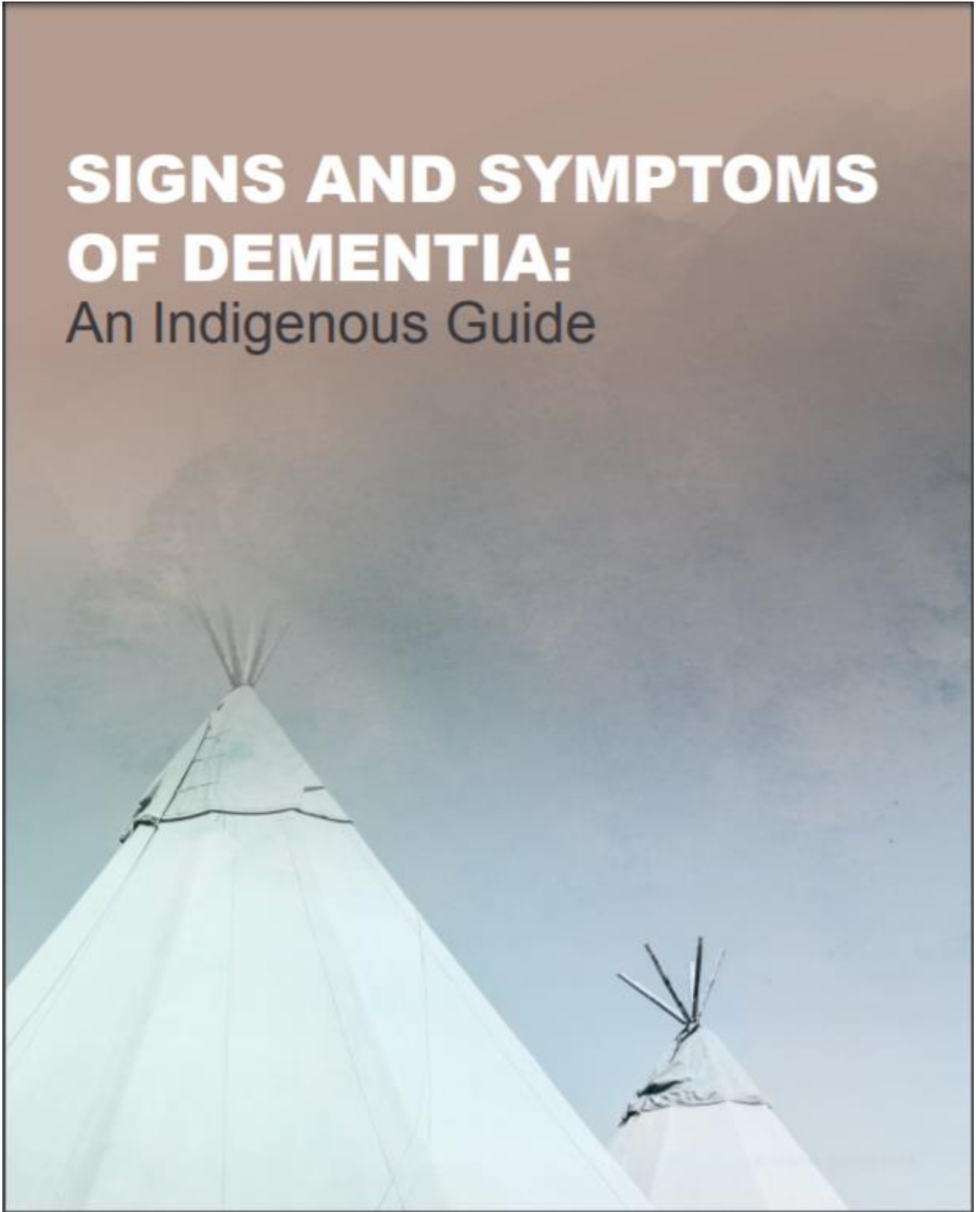
<http://eolfn.lakeheadu.ca/>

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Appendix G: Signs and Symptoms Polished Version

**SIGNS AND SYMPTOMS
OF DEMENTIA:**
An Indigenous Guide



Some Facts:

Rates of dementia in Indigenous people are higher than they are in non-Indigenous people in Canada. Research suggests that the number will continue to rise and by 2031 there may be a 4.6 times increase in the number of on-reserve First Nations people living with dementia.

Symptoms of dementia may begin in people as young as 45-50 or may begin much later depending on the type of dementia. Recent studies suggest that dementia may occur as much as 10 years earlier in Indigenous people compared to non-Indigenous people in Canada.

Research with Indigenous people in Canada suggests that age-related dementias are not being diagnosed early enough for loved ones and families to benefit from local care and supports.

Some Indigenous people may be reluctant to discuss forgetfulness or memory loss with health care providers for many reasons, for example:

- They consider it to be a normal part of aging and not problematic
- They have not had good experiences with health care providers in the past
- They do not think a diagnosis would make any difference
- They are embarrassed and do not want others to know about their symptoms
- They do not want to take the memory tests
- They have difficulty accessing health care services

When is forgetfulness a part of normal aging versus a symptom of illness?

Forgetting can be a normal part of getting older. We may forget to pay a bill, lose things and find it hard to remember the words we want to use every once in a while. It can be normal for our memories of events to be less detailed than they once were, we may take a little bit longer to remember. Sometimes we may have words on the tips of our tongues that we cannot find in the moment.

When these types of forgetting become worse over time or begin to happen more often, it may be a sign that something is wrong. For example, missing one bill payment once in a while may be normal, but missing many payments and not being able to manage money may not be normal. Losing track of the day may be normal, but losing track of the month or season is not. Difficulty finding the words we want may sometimes be normal, but not being able to carry on a conversation is not.



Warning Signs and Symptoms of Dementia

You are encouraged to speak with your health care provider about memory loss when you become worried that it is impacting your day-to-day life. Having a few of these symptoms more than once in a while may be a sign of memory loss caused by dementia or another illness.

The following are some examples of the signs and symptoms described by Indigenous people with dementia and their families. When these signs and symptoms are experienced more than once in a while they may indicate the early stages of age-related dementia.

Forgetfulness and memory loss that affects day-to-day living

- Misplacing things like your keys, purse or wallet
- Having a hard time remembering the names of people who you know, especially family members
- Forgetting to turn off the stove, leaving the fridge door open, forgetting to turn off the water
- Repeating yourself, telling the same story over many times in the same day
- Needing lots of reminders, missing appointments
- Walking into a room and forgetting why you went there
- Forgetting if you took your pills or forgetting to get cleaned up in the morning
- Forgetting things that happened through the day but remembering things from way back

Difficulty performing familiar tasks

- Trouble driving a car or cooking
- Forgetting how to sew, quilt, knit, crochet, or do crafts
- Having trouble with daily routines such as getting cleaned up in the morning and getting dressed

Problems with language

- Forgetting words
- Having trouble finding the words you want to use
- Stopping part way through a sentence because you cannot remember the rest of what you wanted to say

Disorientation in time and space

- Forgetting the month or season
- Forgetting when you last had something to eat
- Getting lost either on foot or while driving or not remembering where you are going
- Confusing morning with evening

Impaired judgement

- Leaving the house without a coat when it is cold outside
- Wearing unusual clothing
- Making questionable purchases

Changes in mood, behaviour, and personality

- Feeling frustrated and sometimes angry
- Hiding things
- Emotional outbursts
- Losing interest in things you once enjoyed
- Not participating in social events
- Hearing or seeing things that other people cannot

Why should we seek care for forgetfulness or memory loss?

Forgetfulness caused by dementia progresses from mild to moderate to severe over time. Seeking help for memory loss early is important. If you are worried you should speak to a health care worker or your doctor. An accurate diagnosis can determine if the forgetfulness is related to dementia, what type of dementia it could be, or other illnesses. For example, medication errors, drug interactions and complications arising from other infections or diseases can also cause forgetfulness and confusion. If memory loss is found to be caused by a dementia illness, an early diagnosis will help to make sure you and your family are receiving the most appropriate treatment, information and supports.

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Appendix H: Conversation Guide

This conversation guide was developed considering the four aspects of the medicine wheel to discuss physical, mental, emotional and spiritual considerations of health information sharing. Questions were adopted from two qualitative studies within Indigenous communities that assessed health resources (Lindeman et al., 2010; Smylie et al., 2009). Further questions have been developed to cover all research questions of my study.

Focus Group and One-on-One Conversation Guide

I will give you some time to review the provided fact sheets.

- What were you thinking when you were reading the materials? (Lindeman et al., 2010) (*emotional*)
- Was the resource useful to you? In what ways? (Lindeman et al., 2010) (*physical*)
- Did you learn anything new about dementia? (Lindeman et al., 2010) (*mental*)
- Is it important to have resources in your local Indigenous language? (*mental, physical*)
 - Will you understand this better if it were available in your language?
 - If so, who would you go to in order to get the best translation of health-related topics so you can understand it better?
- What type of local, culturally appropriate icons and/or symbols are preferred in resources? (examples include a medicine wheel, wampum belt, 4 colors, syllabics, certain animals) (Smylie et al., 2009) (*mental, spiritual*)
- If you wanted to spread a health message in this community, how would you do it? (Smylie et al., 2009) (*physical*)
- How much would you learn if this information was spoken to you? From whom?
- How much would you learn if this information was shown to you? From whom?
- What is your vision of culturally-appropriate health promotion materials? (Examples: a completely translated fact sheet, media, memory stick with the information on it, DVD, tape recorder) (*spiritual*)

Appendix I: Recruitment Advertisement

A recruitment advertisement will be submitted to the N'Swakamok Native Friendship Centre Life Long Care program for admission into the bi-weekly newsletter and will also be displayed throughout the City of Greater Sudbury at Aboriginal organizations and the Société Alzheimer Society Sudbury-Manitoulin.

Are you or do you know anyone who is:

-Aboriginal?

-55 and over?

-From the City of Greater Sudbury?

-Interested in providing input regarding health promotion materials focused on dementia?

Your input will be shared through two focus groups at the N'Swakamok Native Friendship Centre. Each focus group session will be 2 hours long. Light refreshments will be served.

If interested, please contact Sue Roque or Tony Tyson at the Life Long Care program at (705) 674-2128, or Sharlene Webkamigad at (705) 507-9027 for further information.

Are you or do you know anyone who is:

-Aboriginal?

-A caregiver to a family member/friend/or neighbor who has dementia?

-Not a minor?

-From the City of Greater Sudbury?

-Interested in providing input regarding health promotion materials focused on dementia?

Your input will be shared through a one-on-one interview at a location convenient to you at. Each interview session will be 2 hours long and if more time is needed, a second interview will take place.

If interested, please contact Sue Roque or Tony Tyson at the Life Long Care program at (705) 674-2128, or Sharlene Webkamigad at (705) 507-9027 for further information.